





I. R. G. 1

D E L L E
F E B B R I
TEORICA, E PRATICA

SECONDO IL NVOVO SISTEMA,

Ove il tutto si spiega, per quanto è possibile,
ad imitazion de' Geometri.

D I

ALESSANDRO
PASCOLI PERVGINO

*Professore di Medicina, e Lettore nell' Vniversità
di sua Patria.*

Si aggiungono in fine alcuni Discorsi in forma di
Lettere, per chiarezza maggiore di quanto
precedentemente si disse.



IN PERVGIA M. DC. XCIX.

Pe'l Costantini.

CON LICENZA DE' SUPERIORI,

17-2-40

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AM

RIVISTA DELLA SOCIETÀ ITALIANA DI ANTROPOLOGIA MEDICA

Medical Anthropology, Welfare State
and Political Engagement

I. Health, State and Politics

Edited by

SYLVIE FAINZANG - PINO SCHIRRIPIA - JOSEP MARÍA COMELLES - ELS VAN DONGEN

17-18
ottobre 2004



Fondazione Angelo Celli per una Cultura della Salute - Perugia

ARGO



Frontespizio del volume di Alessandro PASCOLI, *Delle febbri. Teorica e pratica secondo il nuovo sistema. Ove il tutto si spiega, per quanto è possibile, ad imitazione de' Geometri, pe'l Costantini, in Perugia, 1699* [riprodotto per gentile concessione della Direzione della Biblioteca comunale Augusta, Perugia].

Alessandro Pascoli (1669-1757), medico e filosofo perugino, fu una figura di spicco nella intellettualità italiana del suo tempo.

La sua formazione complessa e articolata fu il risultato dell'incontro di molteplici correnti filosofiche e scientifiche con una chiara influenza di Galileo Galilei, Francesco Redi e, soprattutto, Cartesio.

Concluso il corso universitario di filosofia e medicina a Perugia, vi iniziò la sua attività di professore e vi insegnò dal 1691 al 1707. Richiesto insistentemente dalle Università di Padova e Roma, probabilmente sensibile alle sollecitazioni di papa Clemente XI, passò ad occupare una cattedra all'Università romana della Sapienza. Anatomista e matematico, abilissimo e ricercatissimo medico di papi e regine, per molti anni ricoprì l'incarico di protomedico generale di Roma e di tutto lo Stato ecclesiastico.

Tra le sue opere principali: *Delle febbri. Teorica, e pratica secondo il nuovo sistema. Ove il tutto si spiega, per quanto è possibile, ad imitazione de' Geometri, pe'l Costantini, in Perugia, 1699* / *Il corpo umano, o breve storia, dove con nuovo metodo si descrivono in compendio tutti gli organi suoi, e i loro principali ufizi, per istruire a bene intendere, secondo il nuovo sistema, la teorica e pratica medicinale, pe'l Costantini, in Perugia, 1700, si vende in Venetia presso Andrea Poletti all'Italia* / *Osservazioni teoriche, e pratiche di medicina inviate per lettera agli eruditissimi signori di sua privata Accademia, per Andrea Poletti, in Venezia, 1702* / *Sofilo senza maschera. All'illustrissimo reverendissimo signore Monsignor Banchieri assessore del S. Offizio, nella Stamperia di Gio. Francesco Buagni, in Roma, 1711* [polemica a favore dell'ipotesi di un'anima sensibile negli animali] / *De vera in literis sapientia physiologiam exposuit pro solemnibus studiorum renovatione in Templo Archigymnasii Romani, typis Joannis Mariae Salvioni in Archigymnasio Sapientiae, Romae, 1715* / *Della natura de i nostri pensieri, e della maniera, con cui si esprimono. Riflessioni metafisiche, presso a Gio. Maria Salvioni nell'Archiginnasio della Sapienza, Roma, 1724* / *Del moto, che ne i mobili si rifonde in virtù di loro elastica possanza, trattato fisico-matematico, presso a Rocco Bernabò, in Roma, 1725* / *De homine, sive de corpore humano vitam habente, ratione tum prosperae, tum afflictiae valetudinis libri tres. In quibus ad mentem tum veterum, tum recentiorum teoria, ac praxis medica nova, clara, ac brevi metodo exponitur, ex typographia Hieronymi Mainardi apud theatrum Capranicense, Romae, 1728* / *Delle risposte ad alcuni consulti su la natura di varie infermità, e la maniera di ben curarle, 2 voll., presso a Rocco Bernabò, in Roma, 1736 e 1738.*

A illustrazione esemplificativa delle posizioni di Alessandro Pascoli riproduciamo qui dal *Nuovo metodo...* (1702):

«Sorge colà in Piccardia quell'acuto Filosofante Renato des Cartes, e con un suo nobile ed ingegnoso Sistema, nuovo se non per le proporzioni, almeno pe'l Metodo con cui fa derivarla, intima a rigore bando universale alle antiche preoccupazioni, e da' fondamenti rovescia il gran Labirinto, dove pe'l corso di molti secoli il discorso degli Uomini in traccia sol di Chimere aggravasi avviluppato e perduto».

E da *Del moto...* (1725)

«Chi in fisica, beffandosi del raziocinio, a tutto confida nei sensi, essere non può, senonche un fisico imperfetto ed un fisico puramente materiale [...] Chi fidando all'incontro alla ragione di tutto, o da sé non osservi o non abbia in conto le altrui sincere osservazioni [...] è un fisico piuttosto metafisico che vero fisico [...] Ond'è, che un fisico puramente speculativo non è meno imperfetto di un fisico puramente pratico [...]».

Per una prima dettagliata bio-bibliografia su Alessandro Pascoli si può vedere la voce a lui intestata alle pp. 170-173 nel volume *Biografia degli scrittori perugini e notizie delle opere loro, ordinate e pubblicate da Gio. Battista VERMIGLIOLI, tomo II, parte II, presso Vincenzo Bartelli e Giovanni Costantini, Perugia, 1829.*

[T.S.]



Il logo della Società italiana di antropologia medica, qui riprodotto, costituisce la elaborazione grafica di un ideogramma cinese molto antico che ha via via assunto il significato di "longevità", risultato di una vita consapevolmente condotta lungo una ininterrotta via di armonia e di equilibrio.

AM

Rivista della Società italiana di antropologia medica



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To our readers

1.

As was the case with the Second Session of *Medical Anthropology at Home*, held in Tarragona, Spain on 19-21 April 2001, for the Third Session, which took place in Perugia, Italy, from 24 through 27 September 2003, The Editor-in-Chief and Editorial Board of *AM* again accepted the proposal of the organizing Committee and the Editors of the *Proceedings* to publish the final text of the presentations made in this magazine.

Medical Anthropology at Home is a mainly European network of medical anthropologists who do much of their research in their own countries. Therefore it is a research activity carried on in the same territorial context in which the researcher lives his “everyday” personal and professional life: thus a condition in which both the researcher and those he studies are rooted in a single, identical social context, together with the problems from which the research arises, the powers promoting it, the concrete effects it has, the expectations it arouses, and a resulting empowerment of the researcher, who day by day stakes his credibility within his own environment. It is a very different condition, we must say, from research practices abroad, i.e. far from the researcher’s everyday life, in which his “return home” marks a more or less final end to every relationship with those who were being studied.

This network was started up in Zeist, Holland, on 16-18 April 1998, during a first session organized by the *Medical Anthropology Unit* of the *Universiteit van Amsterdam*. The proceedings of that session, with its presentations, were not published, but a long account of them by Ivo Quaranta can be read in *AM* magazine, on pages 300-308 of issue n. 5-6 of October 1998.

The Second Session of *Medical Anthropology at Home* took place on 19-21 April 2001 in Tarragona, in Catalogna, Spain, and was organized by the *Departament d’antropologia social i filosofia* of the *Universitat Rovira i Virgili*. As we mentioned at the beginning, we published the *Proceedings* of this Second Session, structured by the Editors around two general topics: *Medical anthropology and Anthropology. Contributions of Medical anthropology to the theory of health studies*, and *Themes in Medical anthropology. Medical anthropology at home contributes to health studies*. These topics formed volumes 11-12 (October 2001) and 13-14 (October 2002) of *AM*, for a total of 431+399=830 pages. And, as planned, both volumes were published and made avail-

able to the participants at the network's Third Session held in Perugia in September 2003.

The decision to hold the Third Session of *Medical Anthropology at Home* in Perugia was reached unanimously at the end of the session in Tarragona, in acknowledgment of the contribution made since the 1950s by Italy, and in particular the "Perugia School", to the modern developments of medical anthropology at home. In fact, unlike other Western countries in which the research which we would call medical anthropology today had an essentially "colonial" beginning, focusing on exotic treatment systems, in Italy medical anthropology studies substantially developed from the 19th century and throughout the entire 20th century within the country: Italian medical anthropology, with its early, complex, and extensive tradition of studies, was always, to a very great extent, a medical anthropology at home. It was, in fact, to a concise "history" of Italian medical anthropology, its beginnings, and a division of its subsequent developments into periods, as well as to an attempt at specifying the characteristic traits of a medical anthropology done at home, that I had devoted my introductory report at the Tarragona Session, published in English in *AM* in the meeting's *Proceedings* (n. 11-12, October 2001, pp. 23-36), and then in Italian in the following n. 15-16, pp. 11-32.

During the network meeting held in Tarragona on the last day of the Session, another decision was also reached. At the unanimous proposal of the Italian delegation, it was decided that from then on the official languages of the network, rather than being solely English, would have become English and Spanish – i.e. one Anglo-Saxon and one Latin language, in order to represent the researchers of "northern" and "southern" Europe in a more balanced manner, since they are all equally involved in the development of medical anthropology at home, and to guarantee a constant dialogue with the "other" continent where medical anthropology "at home" is rapidly growing today: the Americas, from Canada to Argentina. In operational terms, this meant that (a) in our international meetings, the contributions could be made in either of the two languages, (b) in these meetings a mutual simultaneous translation would thus be guaranteed, and (c) in the proceedings of such meetings the contributions could appear in either of the two languages, possibly supplemented with an abstract in the other.

A third decision reached on that occasion was that the following sessions of the network would have been promoted and planned jointly by the local institution to which the session was entrusted, together with the institutions that promoted the previous sessions.

2.

These decisions guided the holding of the Third Session in Perugia, as has already been mentioned, from 24 through 27 September 2003.

The final dates of the conference, the intermediate deadlines, the “call for papers” procedures, and those for the joint evaluation and acceptance of the contribution proposals that would have arrived were decided by common agreement during the meeting of the representatives of the three promoting institutions – the *Medical anthropology Unit of the Universiteit van Amsterdam*, the *Departament d'antropologia, filosofia i treball social of the Universitat Rovira i Virgili (Tarragona)*, and the *Fondazione Angelo Celli per una cultura della salute (Perugia)* – held in Perugia on 30 April 2002. During that meeting the theme of the conference – *Medical Anthropology, welfare state and political engagement* – was also decided, together with the three possible subthemes: the first, which repeated the same theme as the conference in view of its approach in general terms, and the other two (*Patients, health services, power. Human conditions, deliverance of care and patients' strategies in a changing medical context*, and *Spreading men and ideas. Migrations, medical pluralism and creolization of medical cultures*), as bases for contributions to the theme in several specific empirical and operational directions.

The contribution proposals sent following the “call for papers” were thoroughly evaluated by the representatives of the three promoting institutions for the purpose of making up the conference’s *corpus*. All participants thus included in the agenda of the Third Session, as in the subsequent discussions, were guaranteed the possibility to express themselves in English or in Spanish, or even in Italian, since that was the local language, with simultaneous translations provided. And the *Proceedings*, which we are publishing here, also reflect the decision made in Tarragona concerning the languages: English and Spanish. With several specifications that we will make below.

This Third Session of *Medical Anthropology at Home* was organized locally by the *Fondazione Angelo Celli per una cultura della salute*, which also hosted the Secretariat, and by the *Sezione antropologica del Dipartimento Uomo & Territorio della Università degli studi di Perugia*. It was sponsored by the University of Perugia and also by the Province of Perugia and the Region of Umbria. Representatives from fifteen countries took part in its sessions: twelve European (Austria, Denmark, Finland, France, Germany, Great Britain, Holland, Hungary, Italy, Lithuania, Norway, Spain) and three American (Brazil, Chile, United States).

The preparatory work produced a body of 41 accepted contributions: 9 contributions for the first, general theme, 20 contributions for the second, and 12 contributions for the third.

The programme of the conference, from the morning of Wednesday, 24 September to the afternoon of Saturday the 27th, was structured for each of the four days into two (successive) morning sessions and two (successive) afternoon sessions, in order to allow, as in the previous network sessions, sufficient time for an unhurried presentation and discussion of the contents. After the institutional greetings from Cristina Papa on behalf of the University of Perugia and the Anthropology Section of its Man & Territory Department, the first session of the conference, open to the public, was devoted to four opening contributions: a short *Presentation* by Els van Dongen (Holland), an *Introductory Speech* by Tullio Seppilli (Italy), and two general reports: the first by Ronald Frankenberg (UK), *Reclaiming culture as sociopolitical process. Redressing the reified myths of the patient "consumer" facing "tribal" health workers. Medical anthropology understandings of the production of health and sickness*, and the second by Giovanni Berlinguer (Italy), *Ethics and power in Medical anthropology* (*). Moreover, the second afternoon session of Thursday, 25 September, also open to the public, was devoted to *Fifty years of Medical anthropology in Perugia*, in the form of four converging contributions, in a dialogue with Tullio Seppilli, aiming to reconstruct the main work approaches of the "Perugian School" which originated in 1956 (*): popular medicine and the forms of magic-religious protection (Giancarlo Baronti), the strategic and methodological problems of the anthropological contribution to health education (Maria Antonia Modolo), the relationships with psychiatry and the fights against mental hospitals (Ferruccio Giacanelli), strategies and adaptation of the health services in front of new users (immigrants,...), integration of medicines, and international cooperation (Pino Schirripa). Finally, after the contributions given on Saturday 27th September afternoon session, the conference ended with the *Final remarks* by Tullio Seppilli (*) and a document of proposals for the next session of the Network, to be held in Finland, presented by Els van Dongen (*).

This Journal (October 2003, n. 15-16: 549-553) has published a wide review of the whole conference by Giovanni Pizza.

3.

The Editors of the *Proceedings* of this Third Session of Medical Anthropology at Home have organized the contributions presented in Perugia, re-

structuring them all into just two thematic areas: **the first**, *Health, State and politics / Salud, Estado y política / Salute, Stato e politica*, and **the second**, *Care and management of illness and distress / Cuidado y gestión del malestar y de la enfermedad / Cura e gestione del malessere e della malattia*.

This first volume of the Perugia *Proceedings*, after the *Editorial* by the Editors and a *Prologue* consisting of the conference's introductory report by Tullio Seppilli and the general one by Ronald Frankenberg, contains the works attributed by the Editors to the first of the two thematic areas (*Health, State and politics / Salud, Estado y política / Salute, Stato e politica*), in turn broken down into two subareas, **1. People, politics of health and welfare states / Personas, política de la salud y estados del bienestar / Persone, politiche sanitarie e welfare states**, and **2. Health in multicultural settings / La salud en contextos multiculturales / La salute in contesti multiculturali**.

We owe *AM's* regular readers at least two other explanations.

First: In conformity with our magazine's practices, all contributions should appear complete with their abstracts (Italian, French, Spanish, English) and bio-bibliographical notes on the Author. The works given to us by the Editors of the *Proceedings* do not, on the other hand, have these supplements. We preferred not to interfere with this editing criterion.

Second: The conventions for the bibliographical references adopted by the Editors of the *Proceedings* do not envisage certain information we usually request. We did not consider it proper, or even realistic, to intervene in these decisions made by the Editors, either. Nevertheless, beyond the general criteria, the materials that were provided to us for printing presented, to a considerable extent, three other problems: (a) heterogeneity in the order of succession of the various pieces of information making up the bibliographical references of the works mentioned; (b) shortcomings or incongruities of information also with respect to the conventions adopted by the Editors themselves; and, what is worse, (c) bibliographical references in the text that have no corresponding items in the final list of bibliographical references. Faced with these three types of cases, the Editor-in-Chief of *AM* – in agreement with Pino Schirripa, one of the four Editors of the *Proceedings* who is also, at the same time, a member of the Editorial Staff of this magazine – decided to make a series of attempts, with individual Editors or Authors of the contributions, and also sought to work independently, to remedy these shortcomings as much as possible. Much was accomplished in this sense, also thanks to the collaboration of a young anthropology graduate, Laura Giacomello, but it was not possible to fix everything. And for this we apologize to our readers.

Lastly, it must also be said that this publication was made possible by the financial contributions of the organizations that normally support our magazine, the *Società italiana di antropologia medica* and *Fondazione Angelo Celli per una cultura della salute (Perugia)*. And, moreover, those of the *Region of Umbria* and the *Province of Perugia*, which had already sponsored and supported the *Third Session of Medical Anthropology at Home*, whose *Proceedings* are published here. To these institutions, as well as to the Editors and all the Authors who took part in this enterprise, go our heartfelt thanks.

Tullio Seppilli, Editor-in-Chief of *AM*
[translated from the Italian by Derek Boothman]

Note. It was not possible to include the contributions marked by (*) in the two volumes of the *Proceedings (AM, n. 17-18 and n. 19-20)* of this 3rd session of the Network.

A nuestros lectores

1.

Como sucedió para la Segunda sesión de *Medical Anthropology at Home*, que se desarrolló en Tarragona, España, del 19 al 21 de abril de 2001, también para la Tercera sesión, que tuvo lugar en Italia, en Perugia, del 24 al 27 de septiembre de 2003, la Dirección y el Comité de redacción de *AM* han aceptado la propuesta del Comité organizador y de los Compiladores de las *Actas* de publicar en esta revista el texto definitivo de los trabajos que allí se presentaron.

Medical Anthropology at Home es una red, predominantemente europea, de antropólogos médicos que desarrollan gran parte de sus investigaciones en sus propios países. Es decir, una actividad de investigación conducida en el mismo contexto territorial en el que el investigador vive sus “normales” vicisitudes personales y profesionales: una condición, por lo tanto, en la cual tanto el investigador como aquéllos sobre los que indaga están radicados en un único y mismo contexto social, junto a los problemas de los que la investigación nace, a los poderes que la promueven, a las repercusiones concretas que resultan de ella, a las expectativas que la misma suscita y a una consiguiente responsabilización del investigador, que día tras día juega en su mismo ambiente su propia credibilidad. Una condición muy distinta, es necesario decirlo, de las prácticas de investigación *abroad*, es decir lejanas de la vida cotidiana del investigador, en las que su “retorno a casa” rompe más o menos definitivamente cualquier relación con aquéllos a los cuales la investigación ha sido dirigida.

Esta red se puso en marcha en Zeist, en Holanda, durante los días 16 a 18 de abril de 1998, en una primera sesión organizada por la *Medical anthropology Unit* de la *Universiteit van Amsterdam*. De los trabajos entonces presentados no se han publicado las actas pero se puede ver una extensa relación de Ivo Quaranta en esta misma revista *AM*, en las páginas 300-308 del número 5-6, de octubre de 1998.

La Segunda sesión de *Medical Anthropology at Home* tuvo lugar del 19 al 21 de abril de 2001 en Tarragona, en Cataluña, España, organizada por el *Departament d'antropologia social i filosofia* de la *Universitat Rovira i Virgili*. De esta Segunda sesión, como se dijo al inicio, hemos publicado las *Actas*, articuladas por los Compiladores alrededor de dos grandes temáticas

generales: *Medical anthropology and Anthropology. Contributions of Medical anthropology to the theory of health studies e Themes in Medical anthropology. Medical anthropology at home contributes to health studies*, que han constituido respectivamente los volúmenes 11-12 (octubre de 2001) y 13-14 (octubre de 2002) de *AM* por un total de $431 + 399 = 830$ páginas. Y, como estaba previsto, ambos volúmenes han sido publicados y puestos a disposición de los participantes en ocasión de la Tercera sesión de la red, en Perugia, en septiembre de 2003.

La decisión de desarrollar la Tercera sesión de *Medical Anthropology at Home* en Perugia fue tomada unánimemente cuando se concluyó la sesión de Tarragona, como reconocimiento de la contribución que Italia, y en particular la “escuela de Perugia”, han dado desde los años Cincuenta del '900 a la moderna evolución de la antropología médica *at home*. En efecto, a diferencia de otros países occidentales en los cuales las investigaciones que hoy definiríamos de antropología médica han tenido un comienzo esencialmente “colonial”, es decir dirigido a sistemas de atención exóticos, en Italia los estudios de antropología médica sustancialmente se han desarrollado desde el siglo XIX y por todo el '900 en el País: la antropología médica italiana, con su precoz, articulada y amplia tradición de estudios, ha sido siempre, en grandísima medida, una antropología médica *at home*. Justamente a una sintética “historia” de la antropología médica italiana, a sus inicios y a una periodización de sus desarrollos sucesivos, además de a un intento de precisar los rasgos característicos de una antropología médica desarrollada *at home*, había dedicado mi relación introductiva de la Sesión de Tarragona, publicada en *AM* en inglés en las Actas de la reunión (número 11-12, octubre de 2001, páginas 23-36) y luego en italiano (en el sucesivo número 15-16, páginas 11-32).

En la asamblea de la Red realizada en Tarragona el último día de la Sesión se tomó también otra decisión. Según una propuesta unánime de la delegación italiana se decidió que desde ese momento en adelante las lenguas oficiales de la Red, en vez de solamente el inglés, serían el inglés y el español, es decir una lengua anglosajona y una latina, a fin de representar con mayor equilibrio a los investigadores del “norte” y del “sur” de Europa, igualmente empeñados en el desarrollo de la antropología médica *at home*, y de garantizar un diálogo constante con “el otro” continente en el cual hoy la antropología médica *at home* está en pleno incremento: el continente americano, desde Canadá hasta Argentina. En términos operativos, esto significaba que (a) en nuestros encuentros internacionales los trabajos podrían presentarse en una cualquiera de las dos lenguas; (b) en tales encuentros, en consecuencia, se garantizaría la recíproca traducción simultá-

nea; (c) en las actas de tales encuentros los trabajos podrían aparecer en una cualquiera de las dos lenguas, en lo posible integrados por un abstract en el otro idioma.

Una tercera decisión tomada en aquella ocasión fue que las sucesivas sesiones de la Red habrían sido promovidas y proyectadas por las instituciones locales a las cuales la sesión era confiada junto a las instituciones promotoras de las sesiones precedentes.

2.

Estas decisiones han guiado la realización de la Tercera sesión, que tuvo lugar en Perugia, como ya se dijo, del 24 al 27 de septiembre de 2003.

Las fechas definitivas del congreso, los plazos intermedios, las modalidades de difusión del “call for papers” y las de la evaluación colegiada y la admisión de las propuestas de trabajos que llegaran, se decidieron de común acuerdo en la reunión de los representantes de las tres instituciones promotoras – la *Medical anthropology Unit* de la *Universiteit van Amsterdam*, el *Departament d'antropologia, filosofia i treball social* de la *Universitat Rovira i Virgili* (Tarragona) y la *Fondazione Angelo Celli per una cultura della salute* (Perugia) – que se realizó en Perugia el 30 de abril de 2002. En aquella reunión se decidió también el tema del congreso – *Medical anthropology, welfare state and political engagement* – junto a los tres posibles subtemas: el primero, que confirmaba el mismo tema del congreso en vista de un enfoque en términos generales, y los otros dos (*Patients, health services, power. Human conditions, deliverance of care and patients' strategies in a changing medical context* y *Spreading men and ideas. Migrations, medical pluralism and creolization of medical cultures*) como indicaciones orientadoras de aportes al tema en direcciones empíricas y operativas más específicas.

Las propuestas de trabajos enviadas luego del “call for papers” fueron evaluadas completamente por los representantes de las tres instituciones promotoras a fin de constituir el *corpus* del congreso. A todos los participantes así incluidos en la agenda de la Tercera sesión, como en los sucesivos debates, fue garantizada la posibilidad de expresarse en inglés o en español, o también en italiano, como lengua de la sede local, con la respectiva traducción simultánea. Y también las *Actas* que aquí publicamos reflejan, en lo que se refiere a las lenguas – inglés y español – lo que se decidió en Tarragona. Con algunas puntualizaciones de las que hablaremos más adelante.

Esta Tercera sesión de *Medical Anthropology at Home* fue organizada localmente por la *Fondazione Angelo Celli per una cultura della salute*, la que fue también sede de la Secretaría, y por la *Sezione antropologica del Dipartimento Uomo & Territorio della Università degli studi di Perugia*. Fue patrocinada por la misma *Università degli studi di Perugia* y además por la *Provincia di Perugia* y por la *Regione dell'Umbria*. De sus encuentros han participado representantes de quince países: doce países europeos (Alemania, Austria, Dinamarca, España, Finlandia, Francia, Gran Bretaña, Holanda, Hungría, Italia, Lituania, Noruega) y tres americanos (Brasil, Chile, Estados Unidos).

Del trabajo preparatorio resultó un "corpus" de cuarenta y un trabajos aceptados: nueve contribuciones al primer tema, general, veinte contribuciones al segundo tema, doce contribuciones al tercero.

El calendario de los trabajos, desde la mañana del miércoles 24 de septiembre hasta la tarde del sábado 27, fue articulado para cada una de las cuatro jornadas en dos (sucesivas) sesiones matutinas y dos (sucesivas) sesiones vespertinas, en modo de consentir, como en las precedentes sesiones de la Red, el tiempo suficiente para una acabada exposición y discusión de los trabajos. La primera sesión del congreso, abierta al público, fue sin embargo dedicada, después del saludo institucional de Cristina Papa a nombre de la *Università di Perugia* y de la Sección antropológica de su *Dipartimento Uomo & Territorio*, a cuatro trabajos de apertura: una breve *Presentación* de Els van Dongen (Holanda), una *Relación introductiva* de Tullio Seppilli (Italia) y dos relaciones generales: la primera de Ronald Frankenberg (UK), *Reclaiming culture as sociopolitical process. Redressing the reified myths of the patient "consumer" facing "tribal" health workers. Medical anthropology understandings of the production of health and sickness*, y la segunda de Giovanni Berlinguer (Italia), *Ethics and power in medical anthropology* (*). Además, la segunda sesión vespertina del jueves 25 de septiembre, también abierta al público, fue dedicada a *Cinquant'anni di antropologia medica a Perugia*, bajo forma de cuatro trabajos convergentes, en diálogo con Tullio Seppilli, dirigidos a reconstruir las principales corrientes de trabajo de la "Escuela perugina" nacida en 1956 (*): la medicina popular y las formas de protección mágico-religiosas (Giancarlo Baronti), los problemas estratégicos y metodológicos de la contribución antropológica a la educación a la salud (María Antonia Modolo), las relaciones con la psiquiatría y las luchas antimanicomiales (Ferruccio Giacanelli), estrategias y calibración de los servicios sanitarios frente a los nuevos usuarios (inmigrantes, ...), integración de las medicinas, cooperación internacional (Pino Schirripa). Por fin, como se acabaron los trabajos previstos para la sesión de la tarde, el coloquio se clausuró con las *Observaciones finales* por Tullio Seppilli (*) y

con un documento presentado por Els Van Dongen (*) con las propuestas para la siguiente sesión de la Red, a desarrollarse en Finlandia.

Esta revista ha publicado un amplio informe de Giovanni Pizza sobre todo el desarrollo del congreso (AM, n. 15-16, pp. 549-553).

3.

Los **Compiladores de las Actas de esta Tercera sesión de *Medical Anthropology at Home*** han organizado los trabajos presentados en Perugia rearticulándolos globalmente en dos solas áreas temáticas: **la primera**, *Health, State and politics / Salud, Estado y política / Salute, Stato e politica*, e **la segunda**, *Care and management of illness and distress / Cuidado y gestión del malestar y de la enfermedad / Cura e gestione del malessere e della malattia*.

En este primer volumen de las *Actas de Perugia*, después del *Editorial de los Compiladores* y de un *Prólogo* constituido por la relación introductiva al congreso presentada por Tullio Seppilli y por la general, presentada por Ronald Frankenberg, confluyen los trabajos atribuidos por los **Coordinadores a la primera de las dos áreas temáticas** (*Health, State and politics / Salud, Estado y política / Salute, Stato e politica*), articulados a su vez en dos sub-áreas: **1.** *People, politics of health and welfare states / Personas, política de la salud y estados del bienestar / Persone, politiche sanitarie e welfare states*, y **2.** *Health in multicultural settings / La salud en contextos multiculturales / La salute in contesti multiculturali*.

Debemos a los habituales lectores de *AM* al menos otras dos puntualizaciones.

La primera. Conforme a la praxis de nuestra revista, todos los trabajos deberían aparecer provistos de los relativos resúmenes (italiano, francés, español, inglés) y de una "ficha sobre el Autor". Los trabajos entregados por los **Compiladores de las Actas**, en cambio, carecen de estas integraciones. No obstante, hemos considerado que no se podía intervenir en este criterio de trabajo.

La segunda puntualización. Las convenciones para las referencias bibliográficas adoptadas por los **Compiladores de las Actas** no prevén algunas informaciones que nosotros normalmente pedimos. También en el caso de estas decisiones de los **Compiladores** no consideramos correcto, y tampoco realístico, intervenir. Más allá de los criterios generales, los materiales que nos fueron definitivamente entregados para la publicación manifestaron en medida no indiferente tres problemas ulteriores: (a) heterogenei-

dad *en el orden* de sucesión de las varias informaciones constitutivas de las referencias bibliográficas de las obras citadas; (b) *carencias e incongruencias* de informaciones también con respecto a las convenciones adoptadas por los mismos Compiladores; y, lo que es peor (c) citas bibliográficas en el texto *que no encuentran correspondencia en la lista final de las referencias bibliográficas*. Frente a esta triple casuística, la Dirección de AM – de acuerdo con Pino Schirripa, uno de los cuatro Compiladores de las *Actas* que es al mismo tiempo miembro de la Redacción de esta revista – ha pensado en llevar a cabo una serie de intentos, con algunos Compiladores o Autores de los trabajos, y ha tratado también de obrar en propio, para obviar, en la medida de lo posible, estos defectos. Mucho, en este sentido, se hizo también con la colaboración de una joven graduada en antropología, Laura Giacomello, pero no se pudo poner remedio a todo. Y de esto pedimos disculpas a nuestros lectores.

Finalmente, debemos decir que esta publicación fue hecha posible por las contribuciones financieras de los organismos que apoyan normalmente a nuestra revista, la *Società italiana di antropologia medica* y la *Fondazione Angelo Celli per una cultura della salute (Perugia)*. Y además, por aquellos de la *Regione dell'Umbria* y de la *Provincia di Perugia*, que ya habían patrocinado y sostenido la Tercera sesión de *Medical Anthropology at Home*, de la cual se publican aquí las *Actas*. A estas Instituciones, además de a los Compiladores y a todos los Autores que han participado en esta empresa, va nuestro agradecimiento.

Tullio Seppilli, director de AM

[traducido del italiano por Gabriela Peñalva y Lorenzo Mariani]

Nota. Las contribuciones marcadas con asterisco (*) no se han podido incluir en los dos volúmenes de las *Actas* (AM, n. 17-18 y n. 19-20) de esta III sesión de la Red.

Ai nostri lettori

1.

Come avvenuto per la Seconda sessione di *Medical Anthropology at Home*, svoltasi a Tarragona, Spagna, nei giorni 19-21 aprile 2001, anche per la Terza sessione, che ha avuto luogo in Italia, a Perugia, dal 24 al 27 settembre 2003, la Direzione e il Comitato di redazione di *AM* hanno accettato la proposta del Comitato organizzatore e dei Curatori degli *Atti* di pubblicare su questa rivista il testo definitivo dei contributi che vi sono stati presentati.

Medical Anthropology at Home è una rete, prevalentemente europea, di antropologi medici che svolgono larga parte delle loro ricerche nel proprio paese. Una attività di ricerca dunque, condotta nel medesimo contesto territoriale in cui il ricercatore vive la sua “normale” vicenda personale e professionale: una condizione, perciò, in cui sia il ricercatore sia coloro sui quali egli indaga sono radicati in un unico e medesimo contesto sociale, insieme ai problemi da cui la ricerca nasce, ai poteri che la promuovono, alle ricadute concrete che ne risultano, alle attese che essa suscita e a una conseguente responsabilizzazione del ricercatore, che giorno dopo giorno gioca nel suo stesso ambiente la propria credibilità. Una condizione ben diversa, occorre dirlo, dalle pratiche di ricerca *abroad*, lontane cioè dalla vita quotidiana del ricercatore, in cui il suo “ritorno a casa” rompe più o meno definitivamente ogni rapporto con coloro cui l'indagine è stata rivolta.

Questa Rete ha preso avvio a Zeist, in Olanda, nei giorni 16-18 aprile 1998, in una prima sessione organizzata dalla *Medical anthropology Unit* della *Universiteit van Amsterdam*. Dei contributi allora presentati non sono stati pubblicati gli atti ma se ne può vedere un lungo resoconto di Ivo Quaranta su questa stessa rivista *AM*, alle pp. 300-308 del n. 5-6, ottobre 1998.

La Seconda sessione di *Medical Anthropology at Home* ha avuto luogo nei giorni 19-21 aprile 2001 a Tarragona, in Catalogna, Spagna, organizzata dal *Departament d'antropologia social i filosofia* della *Universitat Rovira i Virgili*. Di questa Seconda sessione, come detto all'inizio, abbiamo pubblicato gli *Atti*, articolati dai Curatori intorno a due grandi tematiche generali, *Medical anthropology and Anthropology. Contributions of Medical anthropology to the theory of health studies* e *Themes in Medical anthropology. Medical anthropo-*

logy at home contributes to health studies, che hanno costituito rispettivamente i volumi 11-12 (ottobre 2001) e 13-14 (ottobre 2002) di *AM* per complessive 431+399 = 830 pagine. E come previsto, entrambi i volumi sono stati pubblicati e messi a disposizione dei partecipanti in occasione della Terza sessione della Rete, a Perugia, nel settembre 2003.

La decisione di svolgere la Terza sessione di *Medical Anthropology at Home* a Perugia è stata presa unanimemente al concludersi della sessione di Tarragona, in riconoscimento del contributo che l'Italia, e in particolare la "scuola di Perugia", hanno dato sin dagli anni '50 del '900 ai moderni sviluppi della antropologia medica *at home*. In effetti, a differenza di altri Paesi occidentali nei quali le ricerche che oggi definiremmo di antropologia medica hanno avuto un esordio essenzialmente "coloniale", rivolto dunque a sistemi di cura esotici, in Italia gli studi di antropologia medica si sono sostanzialmente sviluppati sin dal secolo XIX e per tutto il '900 all'interno del Paese: l'antropologia medica italiana, con la sua precoce articolata ed estesa tradizione di studi, è sempre stata, appunto, in larghissima misura una antropologia medica *at home*. Appunto a una sintetica "storia" dell'antropologia medica italiana, ai suoi esordi e a una periodizzazione dei suoi sviluppi successivi, oltreché a un tentativo di precisare i tratti caratteristici di una antropologia medica svolta *at home*, avevo dedicato la mia relazione introduttiva alla Sessione di Tarragona, pubblicata su *AM* in inglese negli *Atti* della riunione (n. 11-12, ottobre 2001, pp. 23-36) e poi in italiano nel successivo n. 15-16, pp. 11-32.

Nella assemblea della Rete tenuta a Tarragona l'ultimo giorno della Sessione venne presa anche un'altra decisione. Su proposta unanime della delegazione italiana fu deciso che d'allora in poi le lingue ufficiali della Rete, anziché il solo inglese sarebbero state l'inglese e lo spagnolo, una lingua anglosassone e una latina, cioè, al fine di rappresentare con maggiore equilibrio i ricercatori del "nord" e del "sud" Europa, ugualmente impegnati nello sviluppo della antropologia medica *at home*, e di garantire un dialogo costante con "l'altro" continente in cui oggi l'antropologia medica *at home* è in pieno incremento, quello americano, dal Canada all'Argentina. In termini operativi, ciò significava che (a) nei nostri incontri internazionali i contributi avrebbero potuto essere presentati in una qualsiasi delle due lingue, (b) in tali incontri sarebbe stata di conseguenza garantita la reciproca traduzione simultanea, (c) negli atti di tali incontri i contributi avrebbero potuto comparire in una qualsiasi delle due lingue, possibilmente integrati da un abstract nell'altra lingua.

Una terza decisione presa in quell'occasione fu che le successive sessioni della Rete sarebbero state collegialmente promosse e progettate dalla istituzione locale a cui la sessione veniva affidata insieme alle istituzioni promotrici delle sessioni precedenti.

2.

Queste decisioni hanno guidato la realizzazione della Terza sessione, tenuta a Perugia, come si è detto, dal 24 al 27 settembre 2003.

Le date definitive del convegno, le scadenze intermedie, le modalità di diffusione del "call for papers" e quelle per la valutazione collegiale e l'ammissione delle proposte di contributi che sarebbero pervenute, sono state decise di comune accordo nella riunione dei rappresentanti delle tre istituzioni promotrici – la *Medical anthropology Unit della Universiteit van Amsterdam*, il *Departament d'antropologia, filosofia i treball social della Universitat Rovira i Virgili (Tarragona)* e la *Fondazione Angelo Celli per una cultura della salute (Perugia)* – tenuta a Perugia il 30 aprile 2002. In quella riunione fu anche deciso il tema del convegno – *Medical anthropology, welfare state and political engagement* – insieme ai tre possibili sottotemi: il primo, che ribadiva lo stesso tema del convegno in vista di un suo approccio in termini generali, e gli altri due (*Patients, health services, power. Human conditions, deliverance of care and patients' strategies in a changing medical context* e *Spreading men and ideas. Migrations, medical pluralism and creolization of medical cultures*) come indicazioni orientative di apporti al tema in più specifiche direzioni empiriche e operative.

Le proposte di contributi inviate in seguito al "call for papers" sono state valutate compiutamente dai rappresentanti delle tre istituzioni promotrici al fine di costituire il *corpus* del convegno. A tutti i partecipanti così inseriti nell'agenda della Terza sessione, come nei successivi dibattiti, è stata garantita la possibilità di esprimersi in inglese o in spagnolo, o anche in italiano in quanto lingua della sede locale, con relativa traduzione simultanea. E anche gli *Atti* che qui pubblichiamo rispecchiano, per quanto riguarda le lingue – inglese e spagnolo – quanto era stato deciso a Tarragona. Con alcune precisazioni di cui diremo in seguito.

Questa Terza sessione di *Medical Anthropology at Home* è stata localmente organizzata dalla *Fondazione Angelo Celli per una cultura della salute*, presso la quale ha anche avuto sede la Segreteria, e dalla *Sezione antropologica del Dipartimento Uomo & Territorio della Università degli studi di Perugia*. È stata patrocinata dalla stessa Università degli studi di Perugia e inoltre dalla Provincia di Perugia e dalla Regione dell'Umbria. Alle sue sedute hanno

partecipato rappresentanti di quindici Paesi: dodici Paesi europei (Austria, Danimarca, Finlandia, Francia, Germania, Gran Bretagna, Italia, Lituania, Norvegia, Olanda, Spagna, Ungheria) e tre americani (Brasile, Cile, Stati Uniti).

Dal lavoro preparatorio è risultato un “corpus” di 41 contributi accettati: 9 contributi al primo tema, generale, 20 contributi al secondo tema, 12 contributi al terzo tema.

Il calendario dei lavori, dalla mattina di mercoledì 24 settembre al pomeriggio di sabato 27, è stato articolato per ciascuna delle quattro giornate in due (successive) sedute antimeridiane e due (successive) sedute pomeridiane, in modo da consentire, come nelle precedenti sessioni della Rete, il tempo sufficiente per una non affrettata esposizione e discussione dei contributi. La prima seduta del convegno, aperta al pubblico, è stata tuttavia dedicata, dopo il saluto istituzionale di Cristina Papa a nome dell'Università di Perugia e della Sezione antropologica del suo Dipartimento Uomo & Territorio, a quattro contributi di apertura: una breve *Presentazione* di Els van Dongen (Olanda), una *Relazione introduttiva* di Tullio Seppilli (Italia) e due relazioni generali, la prima di Ronald Frankenberg (UK), *Reclaiming culture as sociopolitical process. Redressing the reified myths of the patient “consumer” facing “tribal” health workers. Medical anthropology understandings of the production of health and sickness*, e la seconda di Giovanni Berlinguer (Italia), *Ethics and power in medical anthropology* (*). Inoltre, la seconda seduta pomeridiana di giovedì 25 settembre, aperta anch'essa al pubblico, è stata dedicata a *Cinquant'anni di antropologia medica a Perugia* sotto forma di quattro convergenti contributi, in dialogo con Tullio Seppilli, volti a ricostruire i principali filoni di lavoro della “Scuola perugina” nata nel 1956 (*): la medicina popolare e le forme di protezione magico-religiose (Giancarlo Baronti), i problemi strategici e metodologici del contributo antropologico alla educazione alla salute (Maria Antonia Modolo), i rapporti con la psichiatria e le lotte antimanicomiali (Ferruccio Giacanelli), strategie e calibrazione dei servizi sanitari nei confronti delle nuove utenze (immigrati,...), integrazione delle medicine, cooperazione internazionale (Pino Schirripa). Infine, terminati i lavori previsti per la seduta pomeridiana di sabato 27 settembre, il convegno si è chiuso con le *Osservazioni conclusive (Final remarks / Observaciones finales)* di Tullio Seppilli (*) e un documento di proposte per la successiva sessione della Rete, da svolgersi in Finlandia, presentato da Els van Dongen (*).

Dell'intero svolgimento del convegno, questa rivista ha pubblicato un ampio resoconto di Giovanni Pizza alle pp. 549-553 del n. 15-16, ottobre 2003.

3.

I Curatori degli *Atti* di questa Terza sessione di Medical Anthropology at Home hanno organizzato i contributi presentati a Perugia riarticolandoli complessivamente in due sole aree tematiche: **la prima**, *Health, State and politics / Salud, Estado y política / Salute, Stato e politica*, e **la seconda**, *Care and management of illness and distress / Cuidado y gestión del malestar y de la enfermedad / Cura e gestione del malessere e della malattia*.

In questo primo volume degli *Atti* di Perugia, dopo l'*Editoriale* dei Curatori e un *Prologo* costituito dalla relazione introduttiva al convegno tenuta da Tullio Seppilli e da quella, generale, tenuta da Ronald Frankenberg, confluiscono i lavori attribuiti dai Curatori alla prima delle due aree tematiche (*Health, State and politics / Salud, Estado y política / Salute, Stato e politica*), articolata a sua volta in due sottoaree, **1.** *People, politics of health and welfare states / Personas, políticas de salud y estados del bienestar / Persone, politiche sanitarie e welfare states*, e **2.** *Health in multicultural settings / La salud en contextos multiculturales / La salute in contesti multiculturali*.

Dobbiamo infine agli abituali lettori di *AM* almeno due altre precisazioni.

La prima. Conformemente alla prassi della nostra rivista, tutti i contributi dovrebbero apparire corredati dai relativi riassunti (italiano, francese, spagnolo, inglese) e da una "scheda sull'Autore". I lavori consegnati dai Curatori degli *Atti* sono invece privi di queste integrazioni. Non abbiamo tuttavia ritenuto di poter interferire in questo criterio di curatela.

La seconda precisazione. Le convenzioni per i riferimenti bibliografici adottate dai Curatori degli *Atti* non prevedono alcune informazioni da noi normalmente richieste. Anche su queste scelte dei Curatori non abbiamo ritenuto corretto, e nemmeno realistico, intervenire. Al di là dei criteri generali, tuttavia, i materiali che ci sono stati definitivamente consegnati per la stampa hanno manifestato in misura non indifferente tre ulteriori problemi: (a) eterogeneità nell'ordine di successione delle varie informazioni costitutive dei riferimenti bibliografici delle opere citate; (b) carenze o incongruenze di informazioni anche rispetto alle convenzioni adottate dagli stessi Curatori; e quel che è peggio (c) rinvii bibliografici nel testo che non trovano riscontro nell'elenco finale dei riferimenti bibliografici. A fronte di questa triplice casistica, la Direzione di *AM* – in accordo con Pino Schirripa, uno dei quattro Curatori degli *Atti* che è al tempo stesso membro della Redazione di questa rivista – ha ritenuto di esperire una serie di tentativi, con singoli Curatori o Autori dei contributi, e ha anche cercato di operare in proprio, per ovviare nella misura del possibile a queste mende. Parecchio, in questo senso, è stato fatto, anche con la collaborazione di una giovane

laureata in antropologia, Laura Giacomello, ma non a tutto si è potuto rimediare. E di ciò chiediamo venia ai nostri lettori.

È da dire infine che questa pubblicazione è stata resa possibile dai contributi finanziari degli organismi che supportano normalmente la nostra rivista, la *Società italiana di antropologia medica* e la *Fondazione Angelo Celli per una cultura della salute (Perugia)*. E inoltre da quelli della *Regione dell'Umbria* e della *Provincia di Perugia*, che già avevano patrocinato e sostenuto la **Terza sessione di *Medical Anthropology at Home*** di cui qui si pubblicano gli *Atti*. A queste Istituzioni, oltretutto ai Curatori e a tutti gli Autori che hanno partecipato a questa impresa, va il nostro ringraziamento.

Tullio Seppilli, direttore di *AM*

Nota. I contributi contrassegnati con asterisco (*) non si sono potuti inserire nei due volumi degli *Atti (AM n. 17-18 e n. 19-20)* di questa III sessione della Rete.

Editorial

Health, State and Politics

Sylvie Fainzang - Pino Schirripa - Josep M. Comelles -
Els Van Dongen

In the fall of 2003 anthropologists working mainly in Europe assembled in Perugia for the third meeting of the MAAH network (Medical Anthropology at Home, founded in 1998 in The Netherlands). The three-day meeting – organized by the Fondazione Angelo Celli per una cultura della salute, Università degli studi di Perugia, Universitat Rovira i Virgili and the Universiteit van Amsterdam – brought together scholars from many countries working on different themes of health and illness to report on research carried out in their own cultures. The aim of the conference was to foster research in health issues in welfare states. The meeting resulted in two volumes: *Health, State and Politics* and *Care and Management of Illness and Distress*.

This first volume brings together papers of anthropologists currently studying issues of health and illness in European and Latin American countries, grouped within two sub themes: **1.** *Persons, health politics and welfare states* and **2.** *Health in multicultural settings*. Based on research undertaken in Spain, Italy, France, Norway, United Kingdom, The Netherlands, Latvia, Chile, and Brazil, the papers incorporate a critical analysis of the processes that currently take place on the terrain of health and illness. The contributors share an interest in the relationships between individuals who have to deal with illness, the medical domain and the politics of welfare states.

Health, State and Politics is a serious effort to present what is happening in European and Latin American states in the field of health. It is a broad-ranging collection that defines why developments in welfare states are important to anthropologists. The authors explain the major issues that have occurred in the modern arena of health. The papers describe experiences of sufferers and professionals in local worlds. However, the descriptions do more than that. They challenge the taken-for-granted world of everyday

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life by placing health interactions in the broader social and political context. They rethink concepts of power and hegemony and challenge the European idea that citizens are self-determining and autonomous beings who have unlimited access to health care facilities and health knowledge.

On the one hand, it has become commonplace that in multi-cultural setting – such as the all Latin American countries and several European states – health-seeking processes of individual persons are to a large extent the responsibility of those individuals. It has also become commonplace that individuals are capable of determining their health-seeking path based on knowledge they can obtain from modern media. It is assumed that individual patients or clients are in a position to negotiate with professionals about what has to be done.

On the other hand, “culture” has become a well-accepted concept in multi-cultural health care.

Professionals, governments and institutes struggle with the conceptualization of culture in order to develop a democratic and cultural-sensitive health care. At the same time welfare states deteriorate. Services and health care provisions experience the consequences of the decline of welfare and governmental support.

The framework of the Perugia meeting was threefold. It covered *Medical anthropology, welfare state and political engagement / Patients, health services, power. Human conditions, deliverance of care and patients' strategies in a changing medical contexts / Spreading men and ideas. Migrations, medical pluralism and creolization of medical cultures.*

The authors challenge the assumptions and commonplaces that are current in health policies and practices. They critically study patients-professionals interactions and show how medical knowledge is negotiated and contested. They examine power relationships and self-determination. They show how radical political changes, such as those that took place in Latvia, affect individual experience of (mental) illness. And the authors take a critical stance towards multi-culturalism and immigrant health care.

The volume has a prologue of Ronnie Frankenberg, who not only reflects on his theoretical perspectives and former work, but also builds on the work of Marx and Gramsci «to suggest that the method of critical analysis of production can also be usefully applied to the activity of anthropological scholarship in general, and medical anthropology in particular.» (FRANKENBERG R., in this volume, p.10)

The first part of the volume discusses issues of power, resistance, knowledge, self-care and autonomy of patient's *vis-à-vis* medical institutes and professionals. Through their analyses the authors show that the relationship between patients and professionals is not unproblematic and is characterised by a dynamics in which the outcome is not always favourable for the patient. The authors show that power and hegemony are complexes continuously negotiated and contested in daily health practices.

The second part of the volume focuses on multi-cultural societies and in particular health care for immigrants and ethnic minorities. In the contributions, the authors criticise the concept of culture as health professionals and policy makers use it. Themes as acculturation and marginalisation are central. Well-being and health is related to the migrant condition. In-depth research shows that immigrants struggle to find their way in the European health systems, which eventually leads to exclusion of good health care. Concepts of identity, the body and health are discussed. Culture and cultural differences are often used to maintain the status quo in health care. The authors show how daily health practices of immigrants and minorities are shaped by larger health and political structures.

This book, that follows the Proceedings of the previous Meeting held in Tarragona in 2001 (*AM*, n. 11-12 and n. 13-14), shows the commitment of the MAAH network to develop medical anthropology in one's own culture and to establish an open community of scholars, to renew and refine theoretical debates and to contribute to the improvement of health care. It presents substantial ethnographic work and current theoretical orientations among European, African and Latin American medical anthropologists. The network Medical anthropology at home promotes, respect and appreciation of the diversity in people, and develops critique on social and political structures that produce inequality and social exclusion in health care.

Editorial

Salud, estado y política

Sylvie Fainzang - Pino Schirripa - Josep M. Comelles -
Els Van Dongen

En el otoño del 2003 los antropólogos que trabajaban principalmente en Europa se reunieron en Perugia para la tercera reunión de la red de MAAH (Medical anthropology at home, fundado en 1998 en los Países Bajos).

La reunión de tres días – organizada por la Fondazione Angelo Celli per una cultura della salute, Università degli studi di Perugia, Universitat Rovira i Virgili y por la Universiteit van Amsterdam – reunió expertos de muchos países que trabajan en diversos temas de la salud y de enfermedad y que presentaron las investigaciones realizadas en sus propias países. El punto central de la conferencia fue fomentar las investigaciones acerca de los problemas de salud en los estados de bienestar. La reunión dio lugar a dos volúmenes: *Health, State and politics (Salud, Estado y política)*, y *Care and management of illness and distress (Cuidado y gerencia del malestar y de la enfermedad)*.

Este primer volumen reúne los trabajos de los antropólogos que estudian actualmente los problemas de salud y enfermedad en países europeos y en América Latina, agrupadas dentro de dos sub-temas: **1.** *Persons, health politics and welfare states (Personas, política de la salud y estados del bienestar)*, y **2.** *Health in multicultural settings (Salud en contextos multiculturales)*. Las investigaciones emprendidas en España, Italia, Francia, Noruega, Reino Unido, los Países Bajos, Letonia, Chile, y el Brasil, incorporan un análisis crítico de los procesos que ocurren actualmente en el terreno de la salud y de la enfermedad. Los contribuidores comparten un interés por las relaciones con individuos que tratan con la enfermedad, el dominio médico y la política de los estados de bienestar.

Health, State and Politics es un serio esfuerzo de presentar qué está sucediendo en los estados europeos y en América Latina en el campo de la salud. Es una colección de amplio radio que define el motivo por el cual los progresos en los estados de bienestar son importantes para los antropól-

ogos. Los autores explican los principales problemas presentes hoy en la escena de la salud. Los trabajos describen experiencias de enfermos y de profesionales en contextos locales. Sin embargo, las descripciones hacen más que eso. Desafían el mundo pre-establecido de la vida diaria poniendo interacciones de la salud en el más amplio contexto social y político. Redefinen conceptos de poder y de hegemonía y desafían la idea europea de que los ciudadanos son seres autodeterminados y autónomos que tienen acceso ilimitado a las instalaciones del cuidado médico y al conocimiento de la salud.

De una parte, ha llegado a ser corriente que en el ambiente multicultural – tal como en todos los países latino-americanos y en varios estados europeos – la búsqueda de salud por parte de cada individuo depende en gran medida de su propia responsabilidad. También ha llegado a ser lugar común que los individuos son capaces de determinación de sus trayectorias de búsqueda en salud basada en conocimiento que pueden obtener de modernos medios de comunicación. Se asume que los pacientes o los clientes están en una posición a negociar con los profesionales sanitarios sobre qué se tiene que hacer.

Por otra parte, la “cultura” se ha convertido en un concepto bien aceptado en una sanidad multi-cultural.

Los profesionales, los gobiernos y las instituciones hacen referencia al concepto de cultura para desarrollar una sanidad democrática y culturalmente abierta.

Los servicios sanitarios y las provisiones del cuidado médico pagan las consecuencias de la decadencia del bienestar y de la ayuda gubernamental.

El marco de la reunión de Perugia era triple. Cubrió “*Medical anthropology, welfare state and political engagement / Antropología médica, estados del bienestar y compromiso político*”, “*Patients, health services, power: Human conditions, deliverance of care and patients’ strategies in a changing medical contexts / Pacientes, servicios médicos, poder. Condiciones humanas, cuidados y estrategias de los pacientes en contextos médicos que cambian*”, y “*Spreading men and ideas. Migrations, medical pluralism and creolization of medical cultures / Hombres e ideas que se expanden. Migración, pluralismo médico y creolización de las culturas médicas*”.

Los Autores desafían las asunciones y los lugares comunes que existen en las políticas y en las prácticas sanitarias. Estudian críticamente las interacciones entre pacientes y profesionales y demuestran cómo el conocimiento médico es negociado y contextualizado. Examinan relaciones de poder y de autodeterminación. Demuestran cómo los cambios radicales de las políti-

cas, tales como los que ocurrieron en Letonia, afectan experiencias individuales de la enfermedad (mental). Y los autores toman una postura crítica hacia multiculturalismo y cuidado médico del inmigrante.

El volumen tiene un prólogo de Ronnie Frankenberg, que refleja no solamente sus perspectivas teóricas y su trabajo anterior, sino también el trabajo de Marx y de Gramsci «to suggest that the method of critical analysis of production can also be usefully applied to the activity of anthropological scholarship in general, and medical anthropology in particular» (FRANKENBERG R., en este volumen, p.10).

La primera parte del volumen afronta problemas de poder, de resistencia, de conocimiento, de auto-cuidado y de autonomía de los pacientes cara a cara con las instituciones y los profesionales médicos.

Por medio de sus análisis los Autores demuestran que la relación entre los pacientes y los profesionales no es una relación sin problemas y se caracteriza por una dinámica en la cual el resultado no es siempre favorable para el paciente. Los autores demuestran que el poder y la hegemonía son complejos negociados y disputados continuamente en prácticas diarias de la salud.

La segunda parte del volumen se enfoca a sociedades multicultural y en particular al cuidado médico para los inmigrantes y otras minorías étnicas. En sus contribuciones, los Autores critican cómo los profesionales de salud y los hacedores de política utilizan el concepto de la cultura. Los temas como la aculturación y marginalización son centrales.

El bienestar y la salud se relacionan con la condición migratoria. Además, las investigaciones demuestran que los inmigrantes luchan para encontrar su manera en los sistemas europeos de la salud, que en el final conduce a la exclusión de la buena sanidad. Se discuten sobre los conceptos de la identidad, del cuerpo y de la salud. La cultura y las diferencias culturales se utilizan a menudo para mantener el status quo en cuidado médico. Los autores demuestran cómo las prácticas diarias de la salud de inmigrantes y de minorías son formadas por las estructuras sanitarias y políticas.

Este volumen, que sigue las Actas de la precedente Reunión que tuvo lugar en Tarragona en el 2001 (AM, n. 11-12 y n. 13-14), expresa el empeño de la red de MAAH en el desarrollo de una antropología médica en su propia cultura y en la promoción de una comunidad abierta de investigadores, para renovar y profundizar los debates teóricos y para contribuir a la mejora de la atención médica. Presenta un ámbito de actividades sustancialmente etnográfico y las actuales orientaciones teóri-



cas entre los antropólogos médicos europeos, africanos y latinos americanos.

La red *Medical anthropology at home* promueve el respeto por la diversidad de las personas, y desarrolla una crítica de las estructuras sociales y políticas que producen la desigualdad y la exclusión social en la atención médica.



Editoriale

Salute, Stato e politiche

Sylvie Fainzang - Pino Schirripa - Josep M. Comelles -
Els Van Dongen

Nell'autunno del 2003 numerosi antropologi i cui campi di indagine sono principalmente in Europa si sono riuniti a Perugia per il terzo incontro della rete MAaH (*Medical Anthropology at Home*, fondata nel 1998 in Olanda).

L'incontro che è durato tre giorni – e organizzato dalla Fondazione “Angelo Celli” per una cultura della salute, l'Università degli studi di Perugia, l'Universitat Rovira i Virgili di Tarragona e dall'Universiteit van Amsterdam – è stata l'occasione di confronto per studiosi provenienti da differenti paesi che lavorano su diversi temi riguardanti i processi di salute e malattia, ognuno riferendo di ricerche incentrate sul proprio paese. Il punto centrale della conferenza era quello di promuovere e discutere ricerche incentrate su problemi concernenti la salute e il *welfare state*. Il risultato di questo incontro è ora pubblicato in due volumi: *Health, State and Politics* (*Salute, Stato e politiche*) e *Care and Management of Illness and Distress* (*Cura e gestione del malessere e della malattia*).

Il presente volume, che raccoglie i lavori di antropologi che attualmente stanno studiando i processi di salute e malattia in Paesi europei e in America Latina, si struttura in due sezioni: **1.** *Persons, health politics and welfare states* (*Person, politiche sanitarie e welfare states*) e **2.** *Health in multicultural settings* (*La salute in contesti multiculturali*). Basati su ricerche, svolte o in corso, in Spagna, Italia, Francia, Norvegia, Gran Bretagna, Paesi Bassi, Lettonia, Cile e Brasile questi lavori propongono un'analisi critica delle dinamiche in corso nel campo dei processi di salute e malattia. Gli Autori denotano un comune interesse per le relazioni tra individui che devono confrontarsi con la malattia, il settore medico e le politiche del *welfare state*. *Health, State and Politics* è un concreto sforzo di presentare ciò che sta accadendo nei Paesi europei ed in America Latina nel campo della salute. I saggi raccolti, che occupano una vasta gamma di temi, definiscono come le dinamiche concernenti i differenti *welfare states* siano importanti per l'analisi antropologica. Gli Autori si confrontano le principali questioni che oggi interessa-

no le arene della salute, descrivendo – nei vari contesti locali – le esperienze dei malati e degli operatori sanitari; ma si va anche oltre, mettendo in causa, per quel che riguarda i processi di salute e malattia, ciò che viene dato per scontato nelle interazioni quotidiane, ponendolo in un più ampio contesto sociale e politico. In tal modo vengono ripensati i concetti di potere ed egemonia, e viene messa in questione l'idea, dominante negli Stati europei, che i cittadini siano capaci di autodeterminazione ed autonomi e che abbiano un accesso illimitato alle cure sanitarie e anche al sapere medico.

Per molti versi è consolidata l'idea che in un ambiente multiculturale – come quello dei Paesi latino-americani e di alcuni Stati europei – siano i singoli individui a farsi carico, in larga misura, dei processi di ricerca della salute che li riguardano. Allo stesso tempo è dato per scontato che essi siano capaci di determinare il proprio processo di ricerca della salute in base alla conoscenza che possono ottenere dai moderni *media*, e che, come pazienti o utenti, siano in una posizione tale che consenta loro di negoziare con gli operatori sanitari i concreti atti che vanno compiuti.

D'altra parte, "cultura" è diventato un concetto ben accettato in una sanità multi-culturale: operatori sanitari, istituzioni e politici si confrontano con esso per sviluppare una sanità democratica e culturalmente sensibile. Allo stesso tempo però si assiste al tramonto del *welfare state*, e i servizi sanitari, così come i fondi ad essi destinati, pagano le conseguenze del declino del benessere e dell'indebolimento del sostegno governativo.

La struttura della riunione di Perugia era tripla. Ha riguardato: *Medical Anthropology, welfare state and political engagement* (Antropologia medica, welfare state e impegno politico) / *Patients, health services, power. Human conditions, deliverance of care and patients' strategies in a changing medical context* (Pazienti, servizi sanitari, potere. Condizioni umane, pratiche di cura e strategie dei pazienti in un contesto medico in cambiamento) / *Spreading men and ideas. Migrations, medical pluralism and creolization of medical cultures* (Propagarsi di uomini e idee. Migrazioni, pluralismo medico e creolizzazione di culture mediche).

Gli Autori mettono in causa le presupposizioni e i luoghi comuni presenti nelle politiche e nelle pratiche sanitarie, studiando criticamente le interazioni tra pazienti e operatori e dimostrando come la conoscenza medica sia negoziata e contestata. Allo stesso tempo esaminano le relazioni di potere e di auto-determinazione e mostrano in che modo i cambiamenti radicali della politica, come quelli avvenuti in Lituania, producano esperienze specifiche di malessere (mentale). Inoltre gli Autori adottano uno sguardo critico sui temi del multi-culturalismo e della cura della salute degli immigrati.

Il volume ha un prologo di Ronnie Frankenberg che propone una riflessione su alcune sue prospettive teoriche e sul suo lavoro, ma facendo riferimento a Marx e Gramsci «per suggerire che il metodo dell'analisi critica della produzione può essere utilmente applicato anche al sapere antropologico in generale e a quello dell'antropologia medica in particolare». (FRANKENBERG R., in questo volume, p.10)

La prima parte del volume esamina problemi di potere, resistenza, conoscenza, auto-cura e autonomia dei pazienti di fronte alle istituzioni e agli operatori sanitari. Attraverso le loro analisi gli Autori dimostrano che la relazione tra pazienti e operatori è spesso problematica ed è caratterizzata da dinamiche il cui risultato non è positivo per il paziente. Evidenziano inoltre la complessità in questo campo del potere e dell'egemonia e come siano continuamente negoziati e messi in questione nelle pratiche quotidiane concernenti i processi di salute e malattia.

La seconda parte del volume si focalizza sulle società multi-culturali ed in particolare sul rapporto tra servizi sanitari, immigrati e minoranze etniche. Nei contributi, gli Autori criticano il concetto di cultura per come viene usato dai professionisti del settore medico-sanitario e dai politici. Temi come l'acculturazione e la marginalizzazione sono centrali e il benessere e la salute vengono posti in relazione con le condizioni dei migranti. Attraverso ricerche approfondite si mostra come gli immigrati lottino per trovare un modo di confrontarsi con i sistemi sanitari europei e come spesso l'esito sia l'esclusione da servizi sanitari adeguati e di buona qualità. Vengono discussi i concetti di identità, corpo e salute. Inoltre si evidenzia come la cultura e le differenze culturali sono spesso utilizzate per mantenere lo *status quo* nella sanità. Gli Autori dimostrano che le pratiche quotidiane di salute degli immigrati e delle minoranze sono modellate dalle strutture sanitarie e politiche.

Questo volume di *AM* (n. 17-18), così come il prossimo (n. 19-20), si ricollega agli *Atti* della seconda Riunione MAAH tenuta a Tarragona nel 2001, pubblicati anch'essi su questa Rivista (n. 11-12 e n. 13-14). Documenta l'impegno della rete MAAH per sviluppare l'antropologia medica nelle proprie culture e società, e per stabilire una comunità aperta di studiosi, per rinnovare e perfezionare i dibattiti teorici e per contribuire al miglioramento della sanità. Presenta un lavoro sostanzialmente etnografico e gli attuali orientamenti teorici di antropologi medici europei, africani e latino americani.

La rete *Medical Anthropology at Home* promuove il rispetto per la diversità e sviluppa una critica alle strutture sociali e politiche che producono disuguaglianza e esclusione nella sanità.



0.

Prologue / Prólogo / Prologo





*Medical Anthropology, welfare state
and political engagement*

*Introductory Speech at the III Session of the Medical Anthro-
pology at Home Network (Perugia, 24-27 September 2003)*

Tullio Seppilli

President of the Società italiana di antropologia medica and of the Fondazione Angelo Celli per una cultura della salute (Perugia)
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0.

First of all to all the colleagues who have come from many different countries of Europe and America, as well as from other regions in Italy, I would like to extend a warm welcome to Perugia, this ancient city that has been a university site since the fourteenth century. To all of you, to the representatives of the local and regional Authorities, to our guests, and to everyone present, welcome to the III session of the Medical Anthropology at Home Network. And I extend a particularly warm greeting to Els van Dongen and to Josep Maria Comelles, the organisers of the I Session of the Network, at Zeist in the Netherlands in 1998, and of the II, at Tarragona in Catalonia, Spain, in 2001, respectively.

A warm welcome from the Angelo Celli Foundation for a Culture of Health and from the Italian Society for Medical Anthropology, which I represent directly, and also from the Man and Territory Department (Dipartimento Uomo & Territorio) of the University of Perugia, directed by Cristina Papa, which together with us has organized this meeting. And I am also the bearer of special greetings to everyone from Maria Rita Lorenzetti and Maurizio Rosi, President and Executive member for Health of the Region of Umbria, and from Giulio Cozzari, Palmiro Giovagnola and Silvano Ricci, President, Vice-President and Executive member for Culture, respectively, of the Province of Perugia, in the name of the two territorial Authorities under whose auspices and patronage, together with our University, this meeting has been organized.

In opening the conference, I should also say that, among the participants, this inaugural public session sees the presence of forty three colleagues forming part of the Network. They come from fifteen countries, twelve from Europe – Austria, Denmark, Finland, France, Germany, Hungary, Italy, Lithuania, the Netherlands, Norway, Spain and the United Kingdom – and three from America – Brazil, Chile and the United States.

Welcome to all, then, and may we all profit from the work of the conference!

1.

As you know, the general theme of this conference, which on the basis of the contributions that have been sent in to us, subsequently grouped into three subsidiary themes, is *Medical Anthropology, Welfare State and Political Engagement*.

We find ourselves, then, at the centre of the reflection on the deep-lying nexuses and the very meaning of our activity: on its general horizons, on what in specific terms stems from the public nature of the health systems that operate over almost the entire territory of our countries, on the perspectives for social use that we mean to give to our research. We are, thus, *also* dealing with the values and the ethico-political options that in our view must lie at the basis of our work: on what criteria of priorities, on what urgencies, have we, according to the occasion, to found the “objective” choices of our investigations? In other words, in relationship to what problems and with what operational aims? In these choices what is the weight attached to the institutional apparatuses involved and the various social subjects? In what “concrete” logic do we operate? Essentially, what really do we produce, and to whom, and how much, are we of use with the results of our cognitive engagement?

Certainly, we have to start from the assumption of the society-health nexus as the founding node of medical anthropology: that is to say that the historical-social set-ups, and therefore conditions and styles of life, networks of relations, cultural orientations, power structures, all have a determining influence on the welfare and human health, on the typology and seriousness of morbid forms and on the interpretative and operational responses by means of which people attempt to confront diseases.

But in the societies within which we work, this nexus is configured in a complex and quite articulated way, since the strongly heterogeneous nature of the living conditions of the various social strata and their different colloca-

tion with respect to power set-ups and to the related instruments and channels of social control, are translated into meaningful heterogeneities *even* as regards the incidence of what determines health and of the real possibilities of access to available health resources. And these heterogeneities *also* weigh heavily on the cultural subjectivity on whose basis each individual perceives and faces the situations connected with his or her own health.

Stemming from our involvement are implications of notable importance that offer no easy solution. Indeed, in our contexts, just because of the diverse nature of the situations themselves, because of the contrasting interests and the specific objectives of the various social segments, and because of the heterogeneous nature of the means at their disposal, we have to undertake our research activity – meaning the production of new knowledge regarding the relationships between society and health – in a different way for each of these segments.

Thus, the object of our research and the problems that it aims to clarify – the question of what we investigate and what instead we leave unexplored – the areas of knowledge that it produces, the social segments that are really able to use in practice this new knowledge and the knowledge that that will in whatever way be involved, the consequences that stem from it, the power equilibria that in consequence are shifted, these are all things that concern us directly and place us in front of different possible options from the very moment in which we engage in our professional activity. In brief, even in medical anthropology, as in all scientific research, the production of knowledge has a purchase on reality, modifies material and cultural equilibria, and is therefore *not neutral*.

The responsibility coming from this is for us born of two orders of awareness: (a) the ever clearer one (coming from our own work), of the strong and multi-sided impact of the social and power set-ups on the conditions of health of the various strata of the population, and (b) that of the social “disequilibrating” impact that is inevitably produced by our own research or, more exactly, by the social implications of the options that we choose (or undergo) as regards the object of study, the research framework, its results and the operational use they are put to.

2.

Allow me here to emphasize on this subject a number of questions that to my mind seem of relevance as fundamental conditions and subjects in the overall way our work is conducted.

First of all, there is the question of the socio-economic and power disequilibria within the “advanced” societies, those in which we carry out our research, and, even more so, the between these and the rest of the world, with consequent deep-rooted discriminants on the type and the spread of pathologies and of the effective possibilities of access to health resources: on all this, as is well-known, there is a fairly vast epidemiological and socio-anthropological literature. In every one of our countries there still persist serious “health inequalities”. But this is not all: as has been well documented, the general conditions of health in a number of East European countries is regressing because of the collapse of the local public health systems as a consequence of the regime change. And above all there is a widening gap between the so-called North and so-called South of the world within the framework of a generalized phenomenon of globalization which, by the very nature of the economies and powers at work, is producing in the South of the world conditions of ever growing poverty, insecurity, morbidity and mortality. The consequences are very grave inequalities in infant mortality, in “hopes for life” life expectancy and in average life among the various areas of the world.

Secondly, exactly in our “advanced” societies, the real powers are ever more concentrated at the apices of a dynamic social system which, paradoxically, is productive of an enormous quantity of goods and, at the same time, of profound social inequalities and ever more serious and harmful environmental problems. Socio-anthropological research and reflection, though not only this, have clearly shown the mechanisms through which this social system increases situations of individual and collective precariousness and brought about styles of life and priorities of values that have now corroded the primary traditional bonds of support and solidarity and the old collective horizons of ideals, while instead what are asserting themselves are orientations of marked individualism, competitiveness and aggressiveness, a renewed intolerance for those judged to be “different”. We are thus witnessing states of anomie, loneliness, with a worrying rise in states of anxiety and depression, demonstrated throughout the whole of the western countries by an exceptionally steep rise in the consumption of psychopharmaceutical drugs. This is a situation which is bringing more and more into action the mental health services and in general health resources while there is at the same time a progressive reduction of the traditional support constituted by the nuclei of the family and other primary groups which, in their turn, are progressively weaker and ever more scattered and tenuous.

Third, the enormous and growing importance of the big pharmaceutical industry a determinant factor in health strategies in the globalized world.

This has a number of important implications: (a) the essentially therapeutic orientation focussed on single pathologies at the expense of a possible *systemic* approach, mainly oriented instead towards prevention through a change in conditions and styles of living; (b) a massive concentration of investment in research and health information aimed at the definition, production and proposal of ever newer responses to disease centred on drugs; (c) a consequent and strong “medicalization” of strategies for the defence of psychological health and well being; (d) the tendency to concentrate the attention of research and the production of new drugs on the most widespread diseases and on the “market” of the higher income countries.

Fourth, the importance and influence of the means of communication and channels of hegemony of the “strong powers” in our late capitalist societies, and therefore of the breadth of the processes of organization of consent and of the manipulation of subjectivity of a very wide section of the population *even* as regards the attitudes and practices that directly or indirectly involve levels of health. These include conceptions of the body and relative attention, cognition of pathogenic factors, expectations of pharmaceutical drugs and of medicine, eating habits, styles of personal relationships, and priorities in life’s goals and so on. These, moreover, are processes that *even* in this context are widely supported and confirmed by the daily experience itself of individuals and groups within the forms and modes of functioning in which our social system has its substance is substantiated, in other words within the same and very concrete “logic of the existent” which in consequence appears in fact to be “logical” and in any case the only possible logic even where objectively there is serious and widespread harm to psychic/somatic health.

Fifth, the “crisis” of the old doctor-patient relationship and, more generally – especially in those countries that have been able to create a welfare system – the problems connected with the ever more extended relationships, between the complex and articulated health structures and the varied users – users almost everywhere, moreover, of markedly multicultural origins – because of the massive processes of immigration from all the various countries of the world. This is a “crisis” which, as we know, contains many different factors amongst which, in our view, in particular the following ones stand out: (a) changes in the prevalent pathologies produced by the very success that biomedicine has had in respect of numerous infective diseases, now almost completely eradicated, and the consequent emergence of long-term degenerative pathologies, which have frustrated the widespread hopes of a rapid “victory over all diseases”, and which in any case

have no rapid resolution, to the extent that they generally require a notable compliance on the part of the patient, who is involved as a subject in the necessary specific expertise and daily practices that often last the whole of the patient's life; (b) the strong sectoralization of medical professionalities, consequent on a disciplinary specialization that frequently underestimates the *systemic approach* to the patient, his or her personality and experiences, which, instead, appear more and more frequently in every relationship involving diagnosis and treatment; (c) the progressive technization of diagnostic practices, such as more and more incisive and sensitive laboratory and instrumental examinations, to which however there in fact corresponds a contraction of the real clinical examination and the dialogical relation with the patient, so much so that (d) each relationship has become depersonalized and lost its emotional-symbolic depth and significance as "participative support", just at that moment when these appear clearly as an essential professional component of the therapeutic process itself.

Sixth, and in some ways connected with the dynamics we have just described, the recovery of a "demand" and a "supply" of responses to treatment – of western or of "exotic" origin – that in some way appear "non-conventional" compared with the current biomedical paradigm which in our countries, at least up to the Nineteen Fifties seems to have conquered the near-entire medical territory. In view of possible and desirable processes of integration, it is not the case here to go in depth into the problems that have emerged from this, but it is certain that these have come to the fore over many varied areas, areas that largely imply an anthropological type of interpretative and planning dimension. These are epistemological questions, the relations between techniques and the horizons of cultural reference, the professional training curricula of the operators, normative and organizational questions, and a more careful formulation of the concept of "therapeutic effectiveness" itself and of the methods aimed at the measurement of this latter. As we know, in our countries these problems have been faced and in various ways and solved (or not solved) in equally various ways but, come what may, they must in my view be compared, where there are welfare systems in operation, with the general principle that the public sector, financed out of the citizens' pocket, must guarantee them the right to treatment, it must at the same time guarantee that this treatment is put in the hands of operators who in some way must be "recognized" on the basis of precise normative criteria. By this I mean that the presumed "right" to "freely" choose one's healer – whoever he or she may be and through whatever qualification that person may practise – can only have a preci-

se sense where there is a “free market”, one of a direct and private contractual nature between the patient and the operator, in which the quality of the treatment and the possibility itself of being treated depend for each of these subjects on *his or her own* personal availability of funds.

Seventh, the question of the so-called “medicalization of life”, to which I have already referred, on which there is discussion but on whose meaning, in my view, we have however first to agree, since I have the impression that with this label we are from time to time referring to processes of quite a different nature – of varying origin, of different meaning and above all of quite different implications. A *first valence* attached to this label seems in fact to refer to a number of recent widespread campaigns and, in general, to the ensemble of the processes of information that tend to “popularize” what gradually emerges from scientific research as regards the causal connections between a number of very widespread practices and certain possible damage to the health of the single citizens and the collectivity. I am here thinking, for example, of smoking or of certain types of food, and in general of many other practices that we experience as “gratifying” and substantially outside the “health field”, practices which these processes, with the aim of promoting a progressive abandon, then reconnotate by imbuing them with a disquieting significance as regards health. Here, then, “medicalization” consists in the implicit drive to a thematization of health of a large part our daily habits, since in effect many of them have direct or indirect health implications. Certainly, by so doing, serious anxiety-producing stimuli are introduced into our behaviour, space is subtracted from “spontaneity”, customary habits – significant for the equilibrium of our life – become problematic and delegitimated as being “risky”. In whatever way, we find ourselves faced, in this case, initiatives aimed at publicly sharing scientific discoveries, at the promotion, so to speak, of a “mass scientific consciousness”, in point of fact at operations of prevention through “health education”, at a perspective of the broadening of the spaces of awareness and the self-management of the existence of every single one of us. It seems to me that quite different in significance is the *other valence* to which allusion is frequently made by means of the label “medicalization of life”. This, it appears to me, refers to the realization, by a number of the powerful forces and in particular by the big pharmaceutical companies, of grave ideological and market operations aimed at intercepting the needs of an alleviation, that even though short in duration, that emerge from situations of mental suffering, at confining these situations to a strictly private sphere and channelling the responses to these needs in the direction of an exclusively pharmacological and therefore strictly biomedical sphere. Such

operations are very wide-ranging. They have as object *both* the multiform psychic and “psychosomatic” expressions of an extensive and increasing malaise, of what is by now a widespread and deeply-rooted unease inside the logics of the working of our social system, *and* the manifestations of “psychic pain” produced by any one of the numerous “grievous” events that may happen in the course of our personal or collective life, which moreover cannot be assimilated to any type of pathology. Here, “medicalization” is therefore found in this substantial obliteration of the real psychopathogenic factors that are rooted in the very heart of our society, in this passage beyond the boundary of interpretative and operative attention towards psychic suffering to the sole sphere of single individuals and, above all, is in an improper way to be found in this drive to face its manifestations. To explain this, we may say that there is a renunciation of the necessary though slow “elaboration” of one’s own experiences and the critical and active acquisition of consciousness of one’s own context, in order then instead to take the attractive path of an apparent shortcut – in actual fact superficial, not greatly effective and often dangerous – represented by the use (and by the abuse) of psychopharmaceutical drugs and other psychotropic substances. This is a very different valence, substantially opposed to the first sphere of meanings that, above, I sought to trace out.

3.

I have here sought to emphasize, as stated at the start, some of the most important questions that I believe we are faced with, questions which represent great challenges as regards theoretical reflection, empirical investigation and operational involvement.

But within this overall horizon I think that we must in any case agree on one option, on a basic aim, namely that of contributing through our work to the wide-ranging realization of a full right to health, or, more precisely, to the equal right of all citizens to the best conditions for safeguarding health that are possible in our social contexts and, in outlook, in the system of the global society. We are therefore dealing with the right to equity, under the conditions of defence of this right, and in access to available health resources and the consequent construction of an overall strategy of public intervention directed to health as a *collective* and *indivisible* good.

In just such a perspective, and in view of the precise options that necessarily flow from the, we cannot simply limit ourselves to “applying” our anthropological knowledge without clarifying and subjecting

to criticism the priorities of research and its underlying aims, the logic and sense itself of our work, by deluding ourselves that by remaining within the existent schema what we do is “neutral”.

If we do not want to assume an acritical role of simple “technicians of power”, we must not take anything for granted, we must examine real processes in order to know the reference strategies that are used, in order to define their limits and possible alternatives, investigate the existing situation, not so as to take it for granted but so as to go beyond it.

Allow me to draw these introductory reflections of mine to a conclusion by recalling the words of a great poet, an engaged witness of the dramatic events of the century that has just ended:

«Even the slightest detail, however simple
You should look at with suspicion. Ask if it is needed
Especially when it is quite normal.
Please we say to you now, do not accept
Events that happen every day as natural!
For in these times of bloody confusion
Ordered disorder, deliberate violence
Inhuman humanity –
Nothing must be called natural, so that nothing
May be though unchangeable» (*)

Note

(*) Bertolt Brecht, *Die Ausnahme und die Regel* (1930), English edition: *The Exception and the Rule*, trans. by Tom Osborn, in Bertolt Brecht, *The Collected Plays*, edited by John Willett and Ralph Manheim, vol. 3, part 2, Methuen, London, 1997, X+293 pp., cfr. p. 155.

[translated from the Italian by Derek Boothman]



*Antropología médica, Estado del bienestar
y compromiso político*

Relación introductiva a la III Sesión de la Red Medical Anthropology at Home (Perusia, 24-27 de septiembre de 2003)

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0.

A los Colegas llegados de tantos países de Europa y de América y de las otras regiones italianas, bienvenidos a esta antigua ciudad de Perusia, sede universitaria desde el siglo XIV: a ellos, a la representaciones institucionales, a los invitados y a todos los presentes, bienvenidos a la III Sesión de la Red Medical Anthropology at Home. Un grato saludo en particular a Els van Dongen y a Josep María Comelles, organizadores respectivamente de la I Sesión de la Red, en Zeist, Holanda, en 1998 y de la II Sesión en Tarragona, Cataluña, España, en 2001.

Un cálido saludo de la Fondazione Angelo Celli per una cultura della salute y de la Società italiana di antropologia medica, que represento directamente, y del Dipartimento Uomo & Territorio de la Universidad de Perusia, dirigido por Cristina Papa, que organizó este encuentro junto a nosotros. Además he sido encargado de transmitir un especial saludo a todos de parte de Maria Rita Lorenzetti y Maurizio Rosi, respectivamente Presidente y Consejero de salud de la Regione dell'Umbria, y de Giulio Cozzari, Palmiro Giovagnola y Silvano Ricci, respectivamente Presidente, Vice-Presidente y Consejero de cultura de la Provincia di Perugia, en nombre de los dos gobiernos territoriales que junto a nuestra Universidad, han dado a este encuentro patrocinio y sostén.

Debo aún precisar, en la apertura, que entre los participantes a ésta, nuestra sesión pública inaugural se encuentran presentes cuarenta y tres colegas acreditados a la Red, provenientes de quince países: doce países europeos – Alemania, Austria, Dinamarca, España, Finlandia, Francia, Holan-

da, Hungría, Italia, Lituania, Noruega, Reino Unido – y de tres países del continente americano – Brasil, Chile, Estados Unidos –.

Bienvenidos, entonces, y a todos, ¡buen trabajo!

1.

Como sabéis, el tema general de este congreso, que en base a las contribuciones que nos llegaron articulamos luego en tres sub-temas, es *Antropología médica, Estado del bienestar y compromiso político*.

Nos encontramos, entonces, en el centro de la reflexión sobre los nudos profundos y sobre el sentido mismo de nuestra actividad: sobre sus horizontes generales, sobre cuánto de específico nos deriva del carácter público de los sistemas sanitarios que operan en la casi totalidad de nuestros países, sobre las perspectivas de utilización social que queremos dar a nuestros estudios. Y por ende *también* sobre los valores y sobre las opciones ético-políticas que consideramos deben estar en la base de nuestro trabajo: ¿sobre cuáles criterios de prioridad, sobre cuáles urgencias, vamos fundando las elecciones de “objeto” de nuestras investigaciones? Es decir, ¿en relación a cuáles problemas y en vista de cuáles objetivos operativos? ¿Cuánto pesan en estas elecciones los aparatos institucionales de referencia y los diferentes sujetos sociales? ¿Dentro de qué lógica concretamente nos movemos? En sustancia, ¿qué cosa producimos realmente, y a quién beneficiamos y cuánto, con los resultados de nuestro empeño cognoscitivo?

Ciertamente, debemos partir del asumir la relación sociedad-salud como nudo fundacional de la antropología médica: es decir que los ordenamientos histórico-sociales – y por lo tanto las condiciones y los estilos de vida, las redes relacionales, las orientaciones de las culturas, las estructuras del poder – tienen una influencia determinante sobre el bienestar y sobre la salud humana, sobre la tipología y la gravedad de las formas morbosas y sobre las respuestas interpretativas y operativas con las cuales los hombres tratan de afrontar las enfermedades.

Pero en las sociedades en las cuales trabajamos esta relación se configura de manera compleja y muy articulada, ya que la fuerte heterogeneidad de las condiciones de vida de los varios estratos sociales y su diversa colocación con respecto a los ordenamientos de poder y a los relativos instrumentos y canales de control social, se traducen en significativas heterogeneidades *también* en lo que concierne a la incidencia de los determinantes de salud y las posibilidades reales de acceso a los recursos sanitarios dispo-

nibles. Y pesan gravemente *también* sobre la subjetividad cultural en base a la cual cada individuo percibe y afronta las situaciones conectadas con su propia salud.

De esto derivan, para nosotros, implicaciones de notable relevancia y de no fácil solución. En nuestros contextos, de hecho, justamente por la diversidad de las situaciones, por los contrastantes intereses y los objetivos específicos de los varios segmentos sociales y por la heterogeneidad de medios de los que ellos disponen, nuestra actividad de investigación – es decir la producción de nuevos conocimientos alrededor de las relaciones entre sociedad y salud – juega para cada segmento en modo distinto.

Así, el objeto al que se dirige nuestra investigación y los problemas que la misma se propone esclarecer – sobre qué cosa indagamos y qué cosa, en cambio, dejamos en la oscuridad –, las áreas de conciencia que la misma produce, los segmentos sociales realmente capaces de utilizar los nuevos conocimientos en el terreno práctico y aquéllos que se ven de algún modo involucrados en una u otra medida, las consecuencias que de ella derivan, los equilibrios de poder que resultan desplazados, son todas cosas que directamente nos conciernen y nos ponen frente a diferentes opciones posibles desde el momento en que empezamos a empeñarnos en nuestra actividad profesional. Para decirlo en pocas palabras, también en antropología médica, como en toda la investigación científica, la producción de conocimientos incide en la realidad, modifica equilibrios materiales y culturales, por ende, es *no neutral*.

La responsabilidad que deriva de esto, para nosotros, nace entonces de dos órdenes de conciencia: (a) aquélla, cada vez más clara (que nos deriva de nuestro trabajo mismo), del fuerte y multiforme impacto de los ordenamientos sociales y de poder sobre las condiciones de salud de los varios estratos de población, y (b) aquélla del impacto social “desequilibrante” inevitablemente producido por nuestra misma investigación o, más exactamente, aquélla de las implicaciones sociales de las opciones ejecutadas (o sufridas) en orden al objeto de estudio, a la estructura de la investigación, a sus resultados y a su utilización operativa.

2.

Permitidme subrayar al respecto algunas cuestiones que me parecen incidir como condiciones y temas de fondo en la estructuración general de nuestro trabajo.

Antes que nada, justamente, la cuestión de los desequilibrios económico-sociales y de poder internos a las sociedades “avanzadas” – en las cuales nosotros desarrollamos nuestras investigaciones – y, aún más, entre éstas y el resto del mundo, con consecuencias discriminantes profundas sobre la tipología y la difusión de las patologías y sobre las posibilidades efectivas de acceso a los recursos sanitarios: existe en mérito, como es notorio, una vasta literatura epidemiológica y de socio-antropología. En cada uno de nuestros países todavía persisten, efectivamente, graves “desigualdades en salud”. Y no sólo ellas: están retrocediendo, como se ha documentado ampliamente, las condiciones generales de salud en algunos países del este europeo, por el colapso de los sistemas sanitarios públicos locales como consecuencia del cambio de regímenes. Y, sobre todo, se va ampliando la brecha de las condiciones de salud entre el llamado Norte del mundo y el llamado Sur, en el marco de un generalizado fenómeno de globalización que por la naturaleza misma de las economías y de los poderes que allí actúan produce en el Sur del mundo condiciones de aún más creciente pobreza, inseguridad, morbilidad y mortalidad: con consiguientes gravísimas desigualdades en la supervivencia infantil, en las “esperanzas de vida” y en la edad media, entre las distintas áreas del planeta.

En segundo lugar, justo en nuestras sociedades civiles “avanzadas”, los poderes reales se van concentrando siempre más en los vértices de un sistema social dinámico que, paradójicamente, resulta productor de una enorme cantidad de bienes y, al mismo tiempo, de profundas desigualdades sociales y de cada vez más graves y dañinos deterioros ambientales. La investigación y la reflexión socio-antropológica, y no sólo ellas, han llevado claramente a la luz los mecanismos a través de los cuales este sistema social incrementa las situaciones de precariedad individual y colectiva y determina estilos de vida y prioridades de valores que ya han corroído los tradicionales vínculos de sostén y solidaridad y los viejos horizontes ideales colectivos mientras van afirmándose, en cambio, orientaciones de fuerte individualidad, de competitividad y agresividad, de renovada intolerancia por los “distintos”. De este modo, se van ampliando profundamente los estados de anomia, soledad, malestar, con un preocupante aumento de los estados de ansiedad y de depresión, señalado en todos los países occidentales por el rapidísimo aumento del consumo de psicofármacos: una situación, ésta, que empeña por otra parte cada vez con más fuerza los servicios de salud mental y en general los recursos sanitarios mientras progresivamente disminuye, justamente, el sostén constituido tradicionalmente por los núcleos familiares y por los otros grupos primarios, cada vez más inconsistentes, dispersos y debilitados.

En tercer lugar, el enorme y creciente peso de la gran industria farmacéutica como factor determinante de las estrategias sanitarias en el mundo globalizado. Con algunas importantes implicaciones: (a) la orientación esencialmente terapéutica y focalizada en las patologías individuales en detrimento de un posible enfoque *sistémico* y principalmente orientado, en cambio, hacia la prevención a través del cambio de las condiciones y de los estilos de vida; (b) una intensa concentración de las inversiones relativas a la investigación y a la información sanitaria dirigida a la puesta a punto, la producción y la propuesta de siempre nuevas respuestas a la enfermedad centradas en los fármacos; (c) una consiguiente y fuerte “medicalización” de las estrategias de defensa de la salud y del bienestar psíquico; (d) la tendencia a concentrar la atención de la investigación y de la producción de fármacos sobre las enfermedades más difundidas y sobre el “mercado” de los países con más alta renta.

En cuarto lugar, el relieve y la influencia de los instrumentos de comunicación y de los canales de hegemonía de los “poderes fuertes”, en nuestras sociedades tardo-capitalistas, y por lo tanto la amplitud de los procesos de organización del consenso y de manipulación de la subjetividad de una grandísima parte de la población *también* en lo que se refiere a las actitudes y las prácticas que inciden directamente o indirectamente sobre los niveles de salud: concepciones del cuerpo y relativas atenciones, cogniciones sobre los factores patógenos, expectativas frente a los fármacos y a la medicina, costumbres alimentarias, estilos relacionales, prioridades en las metas de vida... Son procesos, por otra parte, que *también* en este ámbito, resultan ampliamente sostenidos y confirmados por la misma experiencia cotidiana de los individuos y de los grupos dentro de las formas y los modos de funcionamiento en los cuales se sustancia nuestro sistema social: en otras palabras dentro de la misma y muy concreta “lógica de lo existente”, que en consecuencia aparece “lógica”, justamente, y de todos modos la única posible también allí donde objetivamente resultan de ello graves y difusos daños a la salud somática/psíquica.

En quinto lugar, la “crisis” de la vieja relación entre el médico y su paciente y, más en general – especialmente en los países que han podido instituir regímenes de bienestar –, los problemas conectados con las cada vez más extensas relaciones entre las complejas y articuladas estructuras sanitarias y su variado caudal de usuarios – casi en todas partes marcadamente multicultural, además, a causa de los intensos procesos de inmigración proveniente de los más diversos países del planeta –. Es una “crisis”, ésta, que, como es notorio, tiene múltiples factores entre los cuales me parece que emergen, en particular: (a) el cambio de las patologías predominantes pro-

ducido por los mismos éxitos de la biomedicina frente a numerosas enfermedades infecciosas, ya casi totalmente erradicadas, y el consiguiente emerger de patologías degenerativas y de larga duración, las cuales han frustrado las difusas esperanzas de una rápida y generalizada “victoria sobre todas las enfermedades” y no tienen de todos modos una resolución rápida, de manera que requieren en general una notable adhesión por parte del paciente, involucrado en la necesidad de específicas competencias y prácticas cotidianas, que a menudo se prolongan por toda la vida; (b) la fuerte sectorialización de las profesionalidades médicas, como consecuencia de una especialización en distintas disciplinas que con frecuencia subestima el *enfoque sistémico* en el paciente, en su personalidad, en sus vicisitudes experienciales que, cada vez más, en cambio, aparecen como fundamentales en cada relación de diagnóstico y atención, y (c) la progresiva tecnificación de las prácticas diagnósticas, como los exámenes de laboratorio y las instrumentales, siempre más incisivas y sensibles, pero a las que de hecho ha correspondido el abreviarse de la verdadera visita clínica y de la relación dialógica con el paciente, de modo que (d) tal relación ha ido despersonalizándose y perdiendo su trascendencia emocional-simbólica y su valor de “sostén partícipe”, justo en el momento en que éstos aparecen ya claramente como un componente profesional esencial del propio proceso terapéutico.

En sexto lugar, y de algún modo ligada con las dinámicas descritas, el repunte de una “oferta” y una “demanda” de respuestas de atención – de origen occidental o “exótica” – que de alguna manera aparecen “no convencionales” con respecto al actual paradigma de la biomedicina, la cual al menos hasta finalizados los años Cincuenta parecía haber conquistado, en nuestros países, un espacio casi total. No es éste el caso de profundizar los problemas que derivan de esto, también en vista de posibles y deseables procesos de integración; pero es cierto que los mismos se están manifestando en una multiplicidad de terrenos, que implican ampliamente una dimensión interpretativa y proyectiva de tipo antropológico: problemas epistemológicos, relaciones entre técnicas y horizontes de referencia cultural, currícula de formación profesional de los operadores, cuestiones organizativas y normativas, y una más atenta formulación del mismo concepto de “eficacia terapéutica” y de los métodos dirigidos a su medición. Como es sabido, estos problemas han sido diversamente afrontados y diversamente resueltos (o no resueltos) en nuestros países pero deben de todos modos confrontarse, creo yo, allí donde rigen regímenes de welfare, con un principio general: que si el sector público, con el dinero de los ciudadanos, debe garantizarles el derecho a la atención, debe al mismo tiempo

garantizar que la misma sea confiada a operadores de alguna manera “reconocidos” en base a precisos criterios normativos. Quiero decir, con esto, que el presunto “derecho” a elegirse el curador “libremente” – quienquiera que sea y a cualquier título ejercite – puede tener un posible sentido sólo donde rijan un régimen liberal – de contractualidad directa y privada, es decir, entre el paciente y el operador – en el cual la calidad de la atención y la posibilidad misma de ser atendido dependen para cada uno de la propia personal disponibilidad financiera.

En séptimo lugar, la cuestión de la llamada “medicalización de la vida”, a la que ya he hecho mención, alrededor de la cual mucho se discute pero sobre cuyo significado creo, sin embargo, que es necesario previamente entenderse, ya que tengo la impresión de que con esta etiqueta nos referimos cada vez a procesos de muy distinta naturaleza: de variadas matrices, de variado signo y sobre todo, de muy diferentes implicaciones. En una *primera valencia* esta etiqueta parece de hecho referirse a algunas grandes y recientes campañas y, en general, al conjunto de los procesos de información tendientes a “divulgar” lo que emerge poco a poco de la investigación científica en mérito a las conexiones causales entre algunas prácticas ampliamente difundidas y algunos posibles daños para la salud de los individuos y de la colectividad. Pienso en el fumar, por ejemplo, o en determinados consumos alimentarios, y en general en tantas otras prácticas que vivimos como “gratificantes” y sustancialmente extrañas al “campo de la salud”: prácticas que estos procesos, con el objetivo de promover su progresivo abandono, re-connotan cargándolas de inquietantes significados sanitarios. La “medicalización” consiste aquí entonces en el implícito empuje a una tematización sanitaria de gran parte de nuestras costumbres cotidianas, ya que en efecto muchas de ellas tienen implicaciones directas o indirectas para la salud. Ciertamente, de este modo se introducen en nuestros comportamientos pesados estímulos ansiógenos, se quita espacio a la “espontaneidad”, se problematizan y se deslegitiman, como “arriesgadas”, costumbres significativas para el equilibrio de nuestra vida. Sin embargo, de todos modos estamos, en este caso, frente a iniciativas dirigidas a compartir públicamente los descubrimientos científicos, a la promoción – por decirlo así – de una “conciencia científica de masa”, en definitiva a operaciones de prevención a través de la “educación a la salud”, a una perspectiva de ampliación de los espacios de conciencia y autogestión de la existencia de cada uno de nosotros. Muy distinto significado me parece que tiene, en cambio, la *otra valencia* a la que frecuentemente se alude con la etiqueta “medicalización de la vida”: que me parece se refiere a la puesta en acto – de parte de algunos poderes fuertes y en particular de la gran

industria farmacéutica – de fuertes operaciones ideológicas y de mercado dirigidas a interceptar las necesidades de un alivio, si bien momentáneo, que emergen en las situaciones de sufrimiento mental, a confinarlas en una esfera estrictamente privada y a canalizar las respuestas a tales necesidades hacia un terreno exclusivamente farmacológico y por lo tanto, estrictamente biomédico. Se trata de operaciones a amplio radio. Son objeto de ellas *tanto* las multiformes expresiones psíquicas y “psicosomáticas” de un creciente y extendido malestar, de un ya difundido descontento profundamente radicado dentro de las lógicas de funcionamiento de nuestro sistema social, *como* las manifestaciones de “dolor psíquico” producidas por uno cualquiera de los tantos acontecimientos “luctuosos” que pueden verificarse en el curso de nuestra vida, personal o colectiva, que no son por otra parte asimilables a ningún tipo de patología. Aquí, la “medicalización” está entonces en esta sustancial obliteración de los reales factores psicopatógenos que se radican en el corazón mismo de nuestra sociedad, en esta violación de fronteras de la atención interpretativa y operativa hacia el sufrimiento psíquico a la singular esfera de cada uno de los individuos y, sobre todo, en este empuje a afrontar las manifestaciones de modo impropio: es decir, renunciando a la necesaria, si bien lenta, “elaboración” de las propias experiencias y a la toma de conciencia crítica y activa frente al propio contexto, para adherir en cambio a las lisonjas de un aparente atajo – de hecho superficial, poco eficaz y a menudo peligroso – representado por el uso (y el abuso) de los psicofármacos y de otras sustancias psicotrópicas. Una valencia, ésta, bien distinta, y sustancialmente opuesta, respecto del primer ámbito de significados que he tratado de delinear más arriba.

3.

He tratado aquí de subrayar, como anticipé, algunas de las más grandes cuestiones que creo están frente a nosotros: grandes desafíos en el terreno de la reflexión teórica, de las investigaciones empíricas y del empeño operativo.

Pero en este complejo horizonte pienso que al menos sobre una opción debemos de todos modos convenir, sobre un objetivo de fondo: aquél de contribuir con nuestro trabajo a la difundida actuación de un pleno *derecho a la salud* o, más precisamente, de un derecho igualitario de todos los ciudadanos a las mejores condiciones de salvaguarda de la salud posibles en nuestros contextos sociales y, en perspectiva, en el sistema de la sociedad

global: y por lo tanto el derecho a la equidad en las condiciones de su defensa y en el acceso a los recursos sanitarios disponibles, y la consiguiente construcción de una estrategia orgánica de intervenciones públicas orientadas a la salud como bien *colectivo e indivisible*.

Justamente en tal perspectiva, y en vista de las precisas opciones que necesariamente de ella derivan, no podemos simplemente limitarnos a “aplicar” nuestro saber antropológico sin aclarar ni poner en discusión las prioridades de investigación y los objetivos que están en la base, la lógica y el sentido mismo de nuestro trabajo, ilusionándonos con que, manteniéndonos dentro de los esquemas de lo existente, todo lo que hacemos resulte “neutral”.

Si no queremos asumir un acrítico rol de simples “técnicos del poder” es necesario no dar nada por descontado, examinar los procesos reales para conocer los diseños entre los cuales se mueven o para individualizar sus límites y las posibles alternativas, indagar sobre lo existente no ya para asumirlo como descontado sino para superarlo.

Permítanme cerrar éstas, mis reflexiones introductorias recordando las palabras de un gran poeta, testigo comprometido de las dramáticas vicisitudes del siglo apenas transcurrido:

«Desconfíen del acto más trivial y en apariencia sencillo,
y examinen, sobre todo, lo que parezca habitual.
Les suplicamos expresamente:
no acepten lo habitual como una cosa natural.
Pues en tiempos de desorden sangriento,
de confusión organizada,
de arbitrariedad consciente,
de humanidad deshumanizada,
nada debe parecer natural,
nada debe parecer imposible de cambiar.»^(*)

Nota

^(*) Bertolt Brecht, *Die Ausnahme und die Regel* (1930), edición en español: *La excepción y la regla*, en Bertolt Brecht, *Teatro Completo II* (*El círculo de tiza caucásico – La excepción y la regla – El proceso de Lucullus*), traducción de Nicolás Costa, Nueva Visión, Buenos Aires, 1984, 176 pp., cfr. p. 115.

[traducido del italiano por Gabriela Peñalva]



*Antropologia medica, welfare state
e impegno politico*

*Relazione introduttiva alla III Sessione della Rete Medical
Anthropology at Home (Perugia, 24-27 settembre 2003)*

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0.

Ai Colleghi giunti da tanti Paesi d'Europa e d'America e dalle altre regioni italiane, benvenuti in questa antica città di Perugia, sede universitaria sin dal XIV secolo: a loro, alle rappresentanze istituzionali, agli invitati e a tutti i presenti, benvenuti alla III Sessione della Rete Medical Anthropology at Home. Un particolare grato saluto a Els van Dongen e a Josep Maria Comelles, rispettivamente organizzatori della I Sessione della Rete, a Zeist in Olanda nel 1998, e della II a Tarragona in Catalogna, Spagna, nel 2001.

Un caloroso saluto dalla Fondazione Angelo Celli per una cultura della salute e dalla Società italiana di antropologia medica, che rappresento direttamente, e dal Dipartimento Uomo & Territorio dell'Università di Perugia, diretto da Cristina Papa, che insieme a noi ha organizzato questo incontro. E di un particolare saluto a tutti sono stato inoltre incaricato da Maria Rita Lorenzetti e Maurizio Rosi, rispettivamente Presidente e Assessore alla sanità della Regione dell'Umbria, e da Giulio Cozzari, Palmiro Giovagnola e Silvano Ricci, rispettivamente Presidente, Vice-Presidente e Assessore alla cultura della Provincia di Perugia, a nome dei due governi territoriali che insieme alla nostra Università, hanno dato a questo incontro patrocinio e sostegno.

Devo ancora precisarvi, in apertura, che tra i partecipanti a questa nostra pubblica seduta inaugurale sono presenti quarantatre colleghi accreditati alla Rete, provenienti da quindici Paesi: dodici Paesi europei – Austria,

Danimarca, Finlandia, Francia, Germania, Italia, Lituania, Norvegia, Olanda, Regno Unito, Spagna, Ungheria – e da tre Paesi del continente americano – Brasile, Cile, Stati Uniti –.

Benvenuti, dunque, e a tutti buon lavoro!

1.

Come sapete, il tema generale di questo convegno, che in base ai contributi pervenuti abbiamo poi articolato in tre sottotemi, è *Antropologia medica, welfare state e impegno politico*.

Siamo dunque al centro della riflessione sui nodi profondi e sul senso stesso della nostra attività: sui suoi orizzonti generali, su quanto di specifico ci deriva dal carattere pubblico dei sistemi sanitari che operano nella quasi totalità dei nostri Paesi, sulle prospettive di utilizzo sociale che intendiamo dare alle nostre ricerche. E quindi *anche* sui valori e sulle opzioni etico-politiche che riteniamo debbano stare alla base del nostro lavoro: su quali criteri di priorità, su quali urgenze, fondiamo via via le scelte di “oggetto” delle nostre indagini? in rapporto cioè a quali problemi e in vista di quali obiettivi operativi? quanto pesano in queste scelte gli apparati istituzionali di riferimento e i differenti soggetti sociali? in quale “logica” concretamente ci muoviamo? in sostanza, cosa realmente produciamo, e a chi gioiamo, e quanto, con i risultati del nostro impegno conoscitivo?

Certo, dobbiamo partire dalla assunzione del rapporto società-salute come nodo fondante della antropologia medica: che cioè gli assetti storico-sociali – e dunque le condizioni e gli stili di vita, le reti relazionali, gli orientamenti delle culture, le strutture del potere – hanno una determinante influenza sul benessere e sulla salute umana, sulla tipologia e la gravità delle forme morbose e sulle risposte interpretative e operative con cui gli uomini tentano di fronteggiare le malattie.

Ma nelle società in cui lavoriamo questo rapporto si configura in maniera complessa e assai articolata, giacché la forte eterogeneità delle condizioni di vita dei vari strati sociali e la loro diversa collocazione rispetto agli assetti di potere e ai relativi strumenti e canali di controllo sociale, si traducono in significative eterogeneità *anche* per quanto concerne la incidenza dei determinanti di salute e le possibilità reali di accesso alle risorse sanitarie disponibili. E pesano gravemente *anche* sulla soggettività culturale in base alla quale ciascun individuo percepisce e affronta le situazioni connesse alla propria salute.

Ne derivano, per noi, implicazioni di notevole rilievo e di non facile soluzione. Nei nostri contesti, infatti, appunto per la diversità delle situazioni, per i contrastanti interessi e gli specifici obiettivi dei vari segmenti sociali e per la eterogeneità di mezzi di cui essi dispongono, la nostra attività di ricerca – cioè la produzione di nuove conoscenze intorno ai rapporti tra società e salute – gioca per ciascun segmento in modo diverso.

Così, l'oggetto cui la nostra ricerca si rivolge e i problemi che essa si propone di chiarire – su cosa indagiamo e cosa invece lasciamo oscuro –, le aree di consapevolezza che essa produce, i segmenti sociali realmente in grado di utilizzare sul terreno pratico le nuove conoscenze e quelli che ne vengono comunque variamente coinvolti, le conseguenze che ne derivano, gli equilibri di potere che ne risultano spostati, sono tutte cose che direttamente ci concernono e ci pongono di fronte a differenti possibili opzioni sin dal momento in cui iniziamo a impegnarci nella nostra attività professionale. Per dirla in poche parole, anche in antropologia medica, come in tutta la ricerca scientifica, la produzione di conoscenze incide sul reale, modifica equilibri materiali e culturali, è dunque *non neutrale*.

La responsabilità che ne deriva, per noi, nasce dunque da due ordini di consapevolezza: (a) quella, sempre più chiara (che ci deriva dal nostro stesso lavoro), del forte e multiforme impatto degli assetti sociali e di potere sulle condizioni di salute dei vari strati di popolazione, e (b) quella dell'impatto sociale "squilibrante" inevitabilmente prodotto dalla nostra stessa ricerca o, più esattamente, quella delle implicazioni sociali delle opzioni da noi compiute (o subite) in ordine all'oggetto di studio, all'impianto della ricerca, ai suoi risultati e al loro utilizzo operativo.

2.

Permettetemi di sottolineare in proposito alcune questioni che mi paiono incidere come condizioni e temi di fondo nella impostazione generale del nostro lavoro.

Anzitutto, appunto, la questione degli squilibri economico-sociali e di potere interni alle società "avanzate" – in cui noi svolgiamo le nostre indagini – e, ancor più, fra queste e il resto del mondo, con conseguenze discriminanti profonde sulla tipologia e la diffusione delle patologie e sulle possibilità effettive di accesso alle risorse sanitarie: esiste in merito, come è noto, una abbastanza vasta letteratura epidemiologica e socio-antropologica. In ciascuno dei nostri Paesi persistono infatti tuttora gravi "disegua-

glianze in salute". Non solo: stanno arretrando, come è largamente documentato, le condizioni generali di salute in alcuni Paesi est-europei, per il collasso dei locali sistemi sanitari pubblici in conseguenza del cambiamento dei regimi. E, soprattutto, si va allargando la forbice delle condizioni di salute tra il cosiddetto Nord del mondo e il cosiddetto Sud, nel quadro di un generalizzato fenomeno di globalizzazione che per la natura stessa delle economie e dei poteri che vi agiscono produce nel Sud del mondo condizioni di ancora crescente povertà, insicurezza, morbilità e mortalità: con conseguenti gravissime diseguaglianze nella sopravvivenza infantile, nelle "speranze di vita" e nell'età media, tra le varie aree del pianeta.

In secondo luogo, proprio nelle nostre società "avanzate", i poteri reali si vanno sempre più concentrando ai vertici di un sistema sociale dinamico che, paradossalmente, risulta produttivo di una enorme quantità di beni e, al tempo stesso, di profonde diseguaglianze sociali e di sempre più gravi e dannosi guasti ambientali. La ricerca e la riflessione socio-antropologica, e non solo, hanno messo chiaramente in luce i meccanismi attraverso i quali questo sistema sociale incrementa le situazioni di precarietà individuale e collettiva e determina stili di vita e priorità di valori che hanno ormai corroso i tradizionali legami primari di sostegno e solidarietà e i vecchi orizzonti ideali collettivi mentre vanno invece affermandosi orientamenti di forte individualismo, di competitività e aggressività, di rinnovata insofferenza per i "diversi". Così, si vanno pesantemente allargando gli stati di anomia, solitudine, disagio, con un preoccupante aumento degli stati d'ansia e di depressione, segnalato in tutti i Paesi occidentali dal rapidissimo aumento del consumo di psicofarmaci: una situazione, questa, che impegna peraltro sempre più fortemente i servizi di salute mentale e in generale le risorse sanitarie mentre viene progressivamente meno, appunto, il sostegno tradizionalmente costituito dai nuclei familiari e dagli altri gruppi primari, sempre più esili, dispersi e indeboliti.

In terzo luogo, l'enorme e crescente peso della grande industria farmaceutica come fattore determinante delle strategie sanitarie nel mondo globalizzato. Con alcune importanti implicazioni: (a) l'orientamento essenzialmente terapeutico e focalizzato sulle singole patologie a discapito di un possibile approccio *sistemico* e principalmente orientato, invece, verso la prevenzione tramite il cambiamento delle condizioni e degli stili di vita; (b) un massiccio concentrarsi degli investimenti relativi alla ricerca e all'informazione sanitaria verso la messa a punto, la produzione e la proposta di sempre nuove risposte alla malattia centrate sui farmaci; (c) una conseguente e forte "medicalizzazione" delle strategie di difesa della salute e del benessere psichico; (d) la tendenza a concentrare l'attenzione della ricerca e della

produzione di farmaci sulle malattie più diffuse e sul “mercato” dei Paesi a più alto reddito.

In quarto luogo, il rilievo e l’influenza degli strumenti di comunicazione e dei canali di egemonia dei “poteri forti”, nelle nostre società tardo-capitalistiche, e dunque l’ampiezza dei processi di organizzazione del consenso e di manipolazione della soggettività di larghissima parte della popolazione *anche* per ciò che riguarda gli atteggiamenti e le pratiche che incidono direttamente o indirettamente sui livelli di salute: concezioni del corpo e relative attenzioni, cognizioni sui fattori patogeni, attese nei confronti dei farmaci e della medicina, abitudini alimentari, stili relazionali, priorità nelle mete di vita, ... Sono processi, peraltro, che *anche* in questo ambito, risultano largamente sostenuti e confermati dalla stessa quotidiana esperienza degli individui e dei gruppi dentro le forme e i modi di funzionamento in cui si sostanzia il nostro sistema sociale: in altre parole dentro la stessa e molto concreta “logica dell’esistente”, che di conseguenza appare “logica”, appunto, e comunque l’unica possibile anche laddove oggettivamente ne risultano gravi e diffusi nocimenti alla salute somatica/psichica.

In quinto luogo, la “crisi” del vecchio rapporto fra il medico e il suo paziente e, più in generale – specie nei Paesi che hanno potuto istituire regimi di welfare –, i problemi connessi con i sempre più estesi rapporti fra le complesse e articolate strutture sanitarie e la loro variegata utenza, quasi ovunque marcatamente multiculturale, peraltro, a causa dei massicci processi di immigrazione dai più diversi Paesi del pianeta. È una “crisi”, questa, che, come è noto, ha molteplici fattori tra i quali mi pare emergano, in particolare: (a) il cambiamento delle patologie prevalenti prodotto dagli stessi successi della biomedicina nei confronti di numerose malattie infettive, ormai quasi del tutto debellate, e il conseguente emergere di patologie degenerative e di lunga durata, le quali hanno frustrato le diffuse speranze in una rapida e generalizzata “vittoria su tutte le malattie” e non hanno comunque una risoluzione rapida, talché esse richiedono in genere una notevole compliance da parte del paziente, coinvolto nella necessità di specifiche competenze e pratiche quotidiane, spesso protratte per tutta la vita; (b) la forte settorializzazione delle professionalità mediche, conseguente a una specializzazione disciplinare che sottovaluta di frequente l’*approccio sistemico* al paziente, alla sua personalità, alle sue vicende esperienziali, che sempre più, invece, appaiono fondamentali in ogni rapporto di diagnosi e cura, e (c) la progressiva tecnicizzazione delle pratiche diagnostiche, come gli esami di laboratorio e quelle strumentali, sempre più incisive e sensibili, cui ha però corrisposto di fatto il contrarsi della vera e propria visita clinica e del rapporto dialogico con il paziente, talché (d)

tale rapporto è andato spersonalizzandosi e perdendo il suo spessore emozionale-simbolico e la sua valenza di “sostegno partecipe”, proprio nel momento in cui questi appaiono ormai chiaramente come una componente professionale essenziale dello stesso processo terapeutico.

In sesto luogo, e in qualche modo connessa con le dinamiche ora descritte, la ripresa di una “offerta” e di una “domanda” di risposte di cura – di origine occidentale o “esotica” – che in qualche modo appaiono “non convenzionali” rispetto all’attuale paradigma della biomedicina, la quale almeno fino a tutti gli anni Cinquanta sembrava aver conquistato, nei nostri Paesi, uno spazio pressoché totale. Non è qui il caso di approfondire i problemi che ne risultano, anche in vista di possibili e auspicabili processi di integrazione: ma è certo che essi si stanno manifestando su una molteplicità di terreni, che implicano largamente una dimensione interpretativa e progettuale di tipo antropologico: problemi epistemologici, rapporti fra tecniche e orizzonti di riferimento culturale, curricula di formazione professionale degli operatori, questioni organizzative e normative, e una più attenta formulazione dello stesso concetto di “efficacia terapeutica” e delle metodiche finalizzate a una sua misurazione. Come è noto, questi problemi sono stati variamente affrontati e variamente risolti (o non risolti) nei nostri Paesi ma essi devono comunque confrontarsi, io credo, laddove vigono regimi di welfare, con un principio generale: che se il settore pubblico, con il denaro dei cittadini, deve garantire loro il diritto alla cura, esso deve al tempo stesso garantire che questa sia affidata a operatori in qualche modo “riconosciuti” in base a precisi criteri normativi. Voglio dire, con questo, che il presunto “diritto” a scegliersi il guaritore “liberamente” – chiunque esso sia e a qualsiasi titolo egli eserciti – può solo avere un possibile senso dove viga un regime liberista – di contrattualità diretta e privata, cioè, tra il paziente e l’operatore – nel quale la qualità della cura e la possibilità stessa di venir curato dipendono per ciascuno dalla *propria* personale disponibilità finanziaria.

In settimo luogo, la questione della cosiddetta “medicalizzazione della vita”, cui ho già fatto cenno, intorno alla quale molto si discute ma sul cui significato credo che occorra tuttavia previamente intendersi, giacché ho l’impressione che con questa etichetta ci si riferisca volta a volta a processi di assai diversa natura: di varia matrice, di diverso segno e soprattutto di assai differenti implicazioni. In una sua *prima valenza* questa etichetta sembra infatti riferirsi ad alcune grandi e recenti campagne e, in generale, all’insieme dei processi di informazione tendenti a “divulgare” quanto emerge via via dalla ricerca scientifica in merito alle connessioni causali fra alcune pratiche largamente diffuse e alcuni possibili danni per la salute

dei singoli e della collettività. Penso al fumo, ad esempio, o a determinati consumi alimentari, e in genere a tante altre pratiche che viviamo come “gratificanti” e sostanzialmente estranee al “campo della salute”: pratiche che questi processi, con l’obbiettivo di promuoverne il progressivo abbandono, riconnotano caricandole di inquietanti significati sanitari. La “medicalizzazione” consiste dunque qui nell’implicita spinta a una tematizzazione sanitaria di gran parte delle nostre abitudini quotidiane, giacché in effetti molte di esse hanno dirette o indirette implicazioni per la salute. Certo, così facendo si introducono nei nostri comportamenti pesanti stimoli ansiogeni, si toglie spazio alla “spontaneità”, si problematizzano e si delegittimano, come “rischiose”, consuetudini significative per l’equilibrio della nostra vita. Tuttavia siamo comunque di fronte, in questo caso, a iniziative finalizzate alla pubblica condivisione delle scoperte scientifiche, alla promozione – per così dire – di una “coscienza scientifica di massa”, in definitiva a operazioni di prevenzione attraverso l’“educazione alla salute”, a una prospettiva di ampliamento degli spazi di consapevolezza e autogestione dell’esistenza di ognuno di noi. Ben altro significato mi sembra abbia invece l’*altra valenza* cui di frequente si allude con l’etichetta “medicalizzazione della vita”: che mi pare si riferisca alla messa in atto – da parte di alcuni poteri forti e in particolare della grande industria farmaceutica – di pesanti operazioni ideologiche e di mercato dirette a intercettare i bisogni di un seppur momentaneo sollievo che emergono nelle situazioni di sofferenza mentale, a confinarle in una sfera strettamente privata e a incanalare le risposte a tali bisogni verso un terreno esclusivamente farmacologico e dunque strettamente biomedico. Si tratta di operazioni a largo raggio. Ne sono oggetto *sia* le multiformi espressioni psichiche e “psicosomatiche” di un crescente esteso malessere, di un ormai diffuso disagio profondamente radicato dentro le logiche di funzionamento del nostro sistema sociale, *sia* le manifestazioni di “dolore psichico” prodotte da uno qualsiasi dei tanti accadimenti “luttuosi” che possono verificarsi nel corso della nostra vita, personale o collettiva, che non sono peraltro assimilabili ad alcun tipo di patologia. Qui, la “medicalizzazione” sta dunque in questa sostanziale oblitterazione dei reali fattori psicopatogeni che si radicano nel cuore stesso della nostra società, in questo sconfinamento dell’attenzione interpretativa e operativa verso la sofferenza psichica alla sola sfera degli individui singoli e, soprattutto, in questa spinta ad affrontarne le manifestazioni in modo improprio: rinunciando cioè alla necessaria pur lenta “elaborazione” delle proprie esperienze e alla presa di coscienza critica e attiva nei confronti del proprio contesto, per aderire invece alle lusinghe di una apparente scorciatoia – di fatto superficiale, poco efficace e sovente

pericolosa – rappresentata dall’uso (e dall’abuso) degli psicofarmaci o di altre sostanze psicotrope. Una valenza, questa, ben diversa, e sostanzialmente opposta, rispetto al primo ambito di significati che ho cercato sopra di delineare.

3.

Ho cercato qui di sottolineare, come anticipato, alcune delle più grosse questioni che credo ci stiano di fronte: grandi sfide sul terreno della riflessione teorica, delle indagini empiriche e dell’impegno operativo.

Ma in questo complesso orizzonte penso che almeno su una opzione dobbiamo comunque convenire, su un obiettivo di fondo: quello di contribuire con il nostro lavoro alla diffusa attuazione di un pieno *diritto alla salute* o, più precisamente, di un diritto egualitario di tutti i cittadini alle migliori condizioni di salvaguardia della salute possibili nei nostri contesti sociali e, in prospettiva, nel sistema della società globale: e dunque il diritto alla equità nelle condizioni della sua difesa e nell’accesso alle risorse sanitarie disponibili, e la conseguente costruzione di una strategia organica di interventi pubblici orientati alla salute come bene *collettivo e indivisibile*.

Appunto in una tale prospettiva, e in vista delle precise opzioni che necessariamente ne conseguono, non possiamo semplicemente limitarci ad “applicare” il nostro sapere antropologico senza chiarire e mettere in discussione le priorità di ricerca e gli obiettivi che vi sottostanno, la logica e il senso stesso del nostro lavoro, illudendoci che rimanendo dentro gli schemi dell’esistente quanto facciamo risulti “neutrale”.

Se non vogliamo assumerci un acritico ruolo di semplici “tecnici del potere” è necessario non dare nulla per scontato, esaminare i processi reali per conoscere i disegni entro cui si muovono e per individuarne i limiti e le possibili alternative, indagare sull’esistente non già per assumerlo come scontato ma per oltrepassarlo.

Permettetemi di chiudere queste mie riflessioni introduttive ricordando le parole di un grande poeta, impegnato testimone delle drammatiche vicende del secolo appena trascorso:

«Anche il minimo gesto, in apparenza semplice,
osservatelo con diffidenza.
Investigate se proprio l’usuale sia necessario.
E – vi preghiamo – quello che succede ogni giorno

non trovatelo naturale.
Di nulla venga detto: è naturale
in questo tempo di anarchia e di sangue,
di ordinato disordine, di meditato arbitrio,
di umanità disumanata,
così che nulla valga
come cosa immutabile.»^(*)

Note

^(*) Bertolt Brecht, *Die Ausnahme und die Regel* (1930), ediz. italiana: *L'eccezione e la regola*, prefaz. di Luciano Codignola, traduz. di Laura Pandolfi, Einaudi, Torino, 1960, 48 pp., cfr. p. 17.



*The ethnographers' shared task with
their informants: the eye witness as we-witness
or the production of cultures by means of cultures*

Ronald Frankenberg

Marx, with and through Gramsci, has provided a critical social science to those who followed him, now as always, not fully aware of what they owe both to him directly and to the irreversible change in European and many other cultures produced by him and other 19th/early 20th century European scholars (DERRIDA J. 1994). He used a powerful, deceptively simple, basic methodology with which to analyse social and cultural activity. This was to begin by asking a set of questions related to production in general but also to the production of commodities in particular. He poses the question; what human agencies, singularly and in co-operation, living and crystallised, brought this about. Marx's great innovation (in *Capital* vol. I) did not set out to understand the distribution of wealth in the Nineteenth Century by ignoring the exchange of commodities. On the contrary he realised that that was why they were produced at all. He wrote that it was nevertheless necessary to go through the door marked "No Admittance except on Business" and to study relations of production in order to understand all the processes that commodities represented in their final appearance. This led him to posing further questions:

Who is producing what; (people in what social positions)?

Using *what* resources; (the necessary raw materials, labour and investment)?

With *whom* do they collaborate?

Under *whose* control and ultimate direction is production carried out?

Using *what* means and ultimately for what ends, visible or hidden, or as Merton put it long ago, latent or manifest?

The primary end was the production of commodities, which are not just simple objects, but crystallised, or perhaps in a modern idiom, deep frozen, labour. Their potential value awaited release in exchange and in use.

The most important political and social ends and products were the classes that produced themselves and each other as by-products. Despite the distortions in sociology textbooks, Marx did not present these social groupings as fixed entities nor even simple processes. They mutually produced and dissolved one another in mortal (yet, at least in the short run, eternal) battles for control. Furthermore, it is not an accident, although it may seem so to an inattentive reader, that Marx's *Capital* is full of detailed examples of cultural change, difference and inequalities, not least in health and welfare. These are also processes produced by and alongside, the conflict between classes.

The Prussian founder of both pathology and public health, Virchow, discovered part of this independently, by asking what produced appalling Cholera epidemics in Upper Silesia and why it affected mostly Poles and miners rather than German-speaking administrators and settlers. The report to his employers, Bismarck and the government of Prussia, ended his professional paid career and political status but ensured his historical fame.

Gramsci, faced the flowering and first crises of a period when, at least in Europe, class struggle seemed to some to have gone completely underground. It had apparently been exported abroad in the form of violent imperialism and/or buried underneath the surface of an apparently attractive populism. He realised that, for the understanding of manifest and hidden political practice, the study of the production of cultural process, whether artistic or scientific, was not a luxury but a necessity. He made one of his central political themes, the battle over hegemonic ideology, which was at least muted if not latent in Marx. This led him to emphasise the centrality, in struggle and in production, of organic working-class intellectuals, as well as those of the professional upper and middle classes. Anthropologist Kate Crehan (CREHAN K. 2000: 100-105) discusses the complexity of this in the context of Zambian development and illustrates it with well-chosen translations from his prison notebooks.

«.....it is not that Gramsci rejected Marx's insistence on basic economic relations as the ultimate dynamic of history, but rather that his intellectual project was focused on the question of how at particular historic moments, within certain broad economic parameters, specific political landscapes, with their specific possibilities for transformation, come into being. It may be true that basic economic relations, whether those of feudalism or capitalism, contain within them contradictions which may tear them apart, but just as it is impossible to know exactly when and where the seismic faults created by colliding tectonic plates will produce earthquakes or volcanic eruptions, so too with the seismic upheavals of human societies. And, moreover, unlike the inanimate world of geophysics, the social world depends on human volition for its earthquakes and volcanoes. Gramsci's concern was with how

the potential energy of the subordinated classes – an energy given by its objective exploitation – could realize itself as a historical force. Holding this force in check, as long as a particular constellation of class forces exists, is the power exercised by the dominant groups. This power however is not simple brute coercion. If it were it would be impossible to understand how small elites are able to dominate large masses; crucial to any long-term domination is gaining the consent of the dominated. One of the most helpful ways of approaching Gramsci's admittedly difficult concept of hegemony is as a way of thinking about the complicated way consent and coercion are entangled with each other, rather than as the delineation of a specific kind of power » (CREHAN K. 2000: 100-101).

In other words, to use the term hegemony is not to offer a descriptive final summation of an object but to pose questions, as other terms in the theory of praxis do, about the continued, but always incomplete, production of reality. Practice is more than merely economic and political, it is also technical and culturally influenced as we shall observe below. It is demonstrated anew, often ingeniously and independently in some sociology, STS and anthropology.

This paper then builds on the work of Marx and Gramsci's followers and others to suggest that the method of critical analysis of production can also be usefully applied to the activity of anthropological scholarship in general, and medical anthropology in particular. As a premedical student, in 1950, sensitised by serendipitous discovery of a then obscure and unknown critical work of Max Gluckman (GLUCKMAN M. 1958 [1942]), as well as by some knowledge of Freud and the formal study of a dialectical Biochemistry, as taught in just pre-DNA Cambridge, I took the step, not unwelcome to my medical teachers, of abandoning them and undertaking postgraduate research with Gluckman in his new Manchester department. In due course, I carried out my own field-work on village life in North and South Wales, in Britain at large, and then into systems of "health care" in Lusaka (Zambia) and in Italy. Thus began, over a period of time (which now exceeds 50 years), the crystallisation of my views that, although we can certainly learn some answers from our forebears, the most important thing, which their writings help to teach us, is what questions to ask and how to ask them.

Gluckman was born in South Africa and did his first research amongst Zulus and others in Zululand, although, by the time I met him he was best known for his later work, even though it was then still largely unpublished at the time, on Law in Barotseland, an area on its conflictual way to becoming the Western Province of Zambia. He was not a Marxist, nor had he studied Marxism in any detail, but the influences upon him included Marx

and Freud, and he fought all his life against racism in his native South Africa and, after he had left it, abroad. We were similar to one another in that neither of us was then a communist but each of us were influenced in various directions by friends who were.

In his study of a bridge-opening ceremony in Zululand he, encouraged by the historian Macmillan and his teacher, Schapera, had courageously attacked the received (non)-wisdom of Malinowskian cultural anthropology and of (Afrikaans) White South Africa that referred to culture as a bounded entity. This would have required him to see the ceremony as culture contact. Instead, he chose to experience it, in its reality, as a process in which people and groups from different cultures were involved with one another, and which produced new forms of interacting cultures for all the participants whether Zulu warriors, Government officials or the anthropologist. He became thereby one of the first social anthropologists, later mightily reinforced by emphatically non-Marxist, mutual contexts. To put it formally, he set the scene whereby an anthropology based on reified essentialism could be replaced, by recognising the characteristics that arise from difference in practice, and by asking the questions that revealed how difference (within similarity) could be produced⁽¹⁾. In order to do this as my title (echoing and adapting Piero Sraffa, one of Gramsci's closest friends) asserts, it has to be the ethnographers' shared task with their informants and their colleagues; the production of cultures by means of cultures. The secret of properly applied ethnographic method is to avoid disguising the subjective as objective by applying to it the falsifying simplifications of questionnaires and the always doubtful, if not overtly, dubious measures of probability theory. The perceptions of the subject are shared, analysed and assimilated. They can and must then be analysed objectively and, if desirable and possible, put to the test of practice.

This task is made the more urgent in that Management Studies applied to health services in the United States and Britain, if not always elsewhere, while it usually ignores the actual findings of anthropologists, medical and general, has practitioners who have appropriated concepts from the field and used them to erect screens not only around the patients' beds but also the doctors' consulting rooms and surgeries.

Vitally important structural analysis is displaced either on to fixed cultural assumptions or on to one-sided individualised vulnerabilities. Situations of inadequate analysis are transformed into ideological cultures of blame that acquire hegemonic but therefore subvertible status. Our task is to question this distortion by means of metaphorical concepts. A first step is to understand how misleading outcomes are produced by their use.

I present here, in brief summary form, three empirical examples of the analysis of such received but unacceptable wisdom:

- a) The case of “vulnerable” children for which their carers were blamed for inadequately coping with the total (essentialised) vulnerability of their charges;
- b) An examination of the usefulness of Cardio-pulmonary resuscitation (CPR); and
- c) The need for “cultural” change in the British NHS arising out of an enquiry into the failure of a particular Children’s hospital which led to institutional reform at a national level.

In each case my focus is on the study and the meta-study and on posing the questions set about production outlined above.

The Vulnerability of Children in London

Starting from ‘received’ wisdom, colleagues and I set out to study the degree to which a group of primary school children in London could be regarded as vulnerable, both inherently as children and by their actions as individual persons, in ways arising from permanent disability, chronic ill health or relatively persistent injury. The participant observing fieldworker, Amber Delahooke (FRANKENBERG R. - ROBINSON I. - DELAHOKE A. 2000) overthrew, on the very first day of her research, our initial assumptions that health would be the major source of such vulnerability. She observed how vulnerability in the classroom was produced, by whom, and in what way. She soon realised that the interplay between children among themselves and between all of them and teachers and other adults set up a productive system that generated vulnerabilities for all the actors. These vulnerabilities were of differing duration, at different times and in different places. The formal attribution of permanent vulnerability by a legal document (a statement of special needs) more often itself generated in response to so-called “personality or behaviour disorders” rather than to specifically health problems, did sometimes reduce relative vulnerability but in unforeseen ways. It often increased, temporarily or permanently, the vulnerability of other players; teachers, and other children by limiting their rights to respond in what otherwise might have seemed to be constructive ways. The researcher, unusually in investigations of this kind, accepted invitations from the students to visit them at their homes and to accompany them to swimming pools, discos and the like. This facilitated

their attendance by supplying the adult chaperone that they needed. At the same time it enabled her to discover that children seen as predominantly vulnerable at school and by the authorities often exercised considerable power in other contexts. This power sometimes arising from precisely those factors like absent or incompetent parents, jailed or mentally ill siblings, which were seen as giving rise to their long-term vulnerability. When the findings were analysed, we concluded that the presence of children added a productive element to many situations that, in fact, made the production of vulnerability at some time, more likely for most of the people involved. In the same way as Crehan is quoted above as arguing for macro-processes, micro-situations «...contain within them contradictions which may tear them apart, but just as it is impossible to know exactly when and where the seismic faults created by colliding tectonic plates will produce earthquakes or volcanic eruptions, so too with the seismic upheavals of human societies [however small they may be, *comment of the Author*]». (CREHAN K. 2000: 100-101).

The recognition of this, a qualitative finding about process, is very much “common sense” in the Gramscian meaning of that term; it is a making apparent of the embodied knowledge of those involved in particular socio-cultural situations. It seems to be natural but is, of course, produced and reproduced within the framework of particular structural practices. Because reformist reformers of public services, like the vulgar political economists rejected by Marx, cannot grasp that quantitative analysis is neither always possible nor ever self sufficient; they continually suggest changes that are ineffective by reason of their failure to recognise the multiplicity of vulnerabilities continually produced and reproduced in dynamic systems. In Plekhanov’s famous analysis; accidents are the result of a chain of inevitabilities.

Applied Social Science: medical sociology and the evaluation of resuscitation

As I argue above from *Capital*, vol. I, Marx certainly centred his analysis of early Nineteenth century European capitalism on the discussion of the process of production of commodities, but he showed himself aware, even in that allegedly most abstractly economic of works, that other things were also being produced, including social groupings, ideologies and ill health. The major cardinal sin, with the possible exceptions of avarice and overweening pride, tempting the medical applied social scientist, is to take for granted that it is possible to accept without question, her/his clients’ view

of what is usefully produced at the end of a procedure being evaluated or audited. This is literally to short change the client. Nor does one have to apply a political economy approach to perceive this. I have already referred to Robert Merton's distinction between the latent and manifest functions of social action.

More closely related to our own field is Anselm Strauss's and his colleagues' analysis (STRAUSS A. *et al.* 1985) of the patient trajectory, in terms of the different kinds of work needed to shape it and how they are combined and directed in the supposedly acute hospital of his day. One thing that his method revealed, of course, was that most of the patients had chronic disorders and had entered the hospital as a result of their disease being in an acute phase. They left not, usually cured, but either dead or, more usually (except in developing countries or in medical TV soaps) returned to chronic near-manageability outside. Although he and his three colleagues wrote of kinds of 'work', he volunteered to me in correspondence, that 'production' might have been more appropriate. In any case, he used work to mean productive practice and examined each of the productive processes that might occur: machine-, safety-, comfort-, sentimental- and articulation-work, and the work of patients (the last, no doubt needing most patience) and the combined synergic outcomes at which they were aimed and often succeeded in producing. It took four years for the field research alone and another to produce the book. Lack of time and resources (and perhaps will and imagination) have deterred others from following them. It is only very recently, that the Dutch scholar, Annemarie Mol (MOL A. 2002) has, in my view, irreversibly transformed hospital ethnography in particular, as well as social science of medicine in general, and thereby the understanding of how medicine works. She simultaneously reports and analyses her many years of work within the hospital. The innovative and imaginative "duplex" structure of her book perhaps, as she suggests more accessible to ordinary readers in the television age than to conventional text-bound scholars, also enables her to contextualise her work in a wide range of literature. Her focus is «on the way medicine enacts the objects of its concern and treatment» (MOL A. 2002: vii). It is to be hoped that she may succeed where others have failed and shame the majority of practitioners (if such they are?) of medical anthropology and sociology away from the simplistic eclecticism in which they often seem semi-consciously to be drifting. One reality that she impresses upon us, as Strauss *et al.* and Gramsci also did, is that we have to identify and constructively examine (ask questions about) all the relevant practices and not just those that appear to be scholastically (intellectually) respectable let alone universal or commonsensical.

It is salutary in this respect to examine a recent juxtaposition of articulated articles in the *Nursing Times* (DINGWALL E. - SHUTTLEWORTH A. 2002, RICHARDSON M. 2002) under the respective titles "C(ardio) P(ulmonary) R(esuscitation): is it cruel or is it kind?" and "It's the difference between life and death".

The first of these begins under a heading «Why do we assume CPR should be attempted» by suggesting, partly in reference to Timmermans's controversial book (TIMMERMANS F. 1999), that CPR is one of the great unquestioned practices of modern medicine, it being implied that those who refrain from questioning are especially ethicists who are only concerned if the procedure is manifestly futile or if it has been rejected, preferably in writing, ahead of the emergency calling it into play. It is argued that these (false and misleading) assumptions are based on three principles; the rule of rescue, duty to love our neighbours as ourselves and beneficence/non-maleficence. These principles, it is averred, exist in health ethical codes to the extent that not to observe them is held, by officially (the courts, regulatory professional bodies) enforced British practice, to be a dereliction of the duty of care. The legal position is then hypothesised that although the law is uncertain, courts are likely to take the view that only a decision against resuscitation taken by the sufferer or by someone medically qualified and actually present at the scene can be regarded as valid. This attitude is described as having been overdetermined by allegations of discrimination by lobby groups of the elderly who have forced the National Health Service to impose audited policies on practitioners in the name of a very loosely defined principle of protection of patients' rights.

The next set of arguments is headed «Perceptions versus reality» and is presented as arising from the cultural representations derived from television medical soap operas like *ER* in the United States and *Casualty* in Britain. It uses statistics derived from a 1996 study of three such series in the United States to show that CPR was mainly applied to trauma in children and young adults and is portrayed over-optimistically with regard both to its immediate success and its lack of long term damage. In real life it is performed on older patients «whose average age seems to be in the sixties» with short life expectancy; studies suggest that «independent circulation is re-established in less than 30% of patients» most of whom will die shortly afterwards or «suffer significant neurological impairment». Cultural theorists might question the reversion to the injection theory of mass media influence and the implied assumption that viewers are necessarily influenced by percentages rather than qualitative emotional impact of particular instances. I do not however dispute these figures or the quantified

statement that «In the community prospects are even worse». Nor do I think the arguments that follow about the considerable cost of CPR, the ethics of taxation, the non/existence of patient's rights or the author's perceived need for «Reversing the default assumption» are necessarily wrong or even merely seriously misguided⁽²⁾. My objection is that readers might be influenced by his title as professor of sociology (and the sophistication he showed, alas without much effect on his listener, in his analysis of culture for the Bristol Enquiry. See below), into believing that he is exercising his sociological skills. My disappointment arises from the fact that he, in fact uses only his (considerable) rhetorical and statistical skills and plays the *advocate* rather than using his (also considerable) sociological and anthropological skills and acting as *analyst*. In order to have done the latter, he would first have had to participate directly or through an assistant in examples of the actual process he set out to study (as Chairman Mao is reported to have put it, perhaps hypocritically, perhaps not, «no investigation, no right to speak»). Second, it was his duty to the administrators and ethicists he sought to serve, to use his grasp of theory to question, if only provisionally, what other products might have been the outcomes of following the procedure, how they were produced, whom by and in whose interests. An example of this is provided in the accompanying article to his, whose writer (RICHARDSON M. 2002) is able to use her embodied knowledge of her own nursing practice to argue that making apparatus and training available to a wider public would not only improve the efficacy of CPR and life-saving measures in general but reduce death from out-of-hospital heart attacks. Some might argue that this was a more effective way of saving money and lives than merely using the method less? Another example of the production of knowledge by studying and asking questions about apparent failing, internally unforeseen, outcomes is found in anthropological studies of hospice pioneers of ultimate non-intervention in the dying process. This eventually produced more comfort for the dying and their relatives, as well as less frustration for nurses and carers unaccustomed to and untrained in active passivity, resulting in premature burnout or breakdown. Once it was noticed that the latter was a bye-product the productive process changes were made in practice. Even at the level of outcome evaluation in all these examples, it is, of course, necessary to ask not only did the patient survive, for how long and at what cost but also at what cost to whom? Dingwall questions rightly, and rightly does not stay for an answer, the cost to taxpayers and those whom postcode rationing or third world status, deprives of CPR, but he does not consider the production of expertise, knowledge about physiological processes, job satisfaction

or the possibility of travelling beyond doing the sick no harm to saving life (if not every life). His advocacy is not only politically ineffective, it is merely (?) common sense, (once again in the Gramscian sense of the hegemonic ideology partially shared with the fortunate nonsubaltern); his analysis of a more totalising, but theoretically informed questioning as a social scientist could have made a difference, although not necessarily in the direction which as a citizen and political animal he might have preferred. At least he would have provided some evidence for the evidence base!

The British National Health Service

My final example leaves the beating hearts of its patients and goes to the abstract, but personalised, heart of the British National Health Service. It considers the questions posed by and answered by a public enquiry into the manifest and literally scandalous failures of a particular children's hospital in South West England (REPORT 2001). The production process of such an enquiry is a complex one. It is obviously significant that it arises out of public clamour about something that has gone manifestly wrong. In this case, there had been a long series over many years of unexpected deaths of small babies undergoing, often unnecessary, cardiac surgery. This, although it was well known first by the Paediatric department and then by all professionals within the hospital, only gradually leaked out to NHS at large. It finally, complicated by the hospital's retention of the children's body parts, led to a call for public enquiry led by affected parents. In the UK, a public enquiry of this kind is called by a Cabinet Minister (Secretary of State), its terms of reference defined (and perhaps debated and/or modified) and the name of its Chairman, usually a senior lawyer, announced in the House of Commons. A selection of what is often "termed the great and the good"; prominent academics and other people well known in public life, are selected to serve. They meet, and guided by the chairman and civil service secretary, decide whom to call to give direct evidence and what submissions to invite from them and others who volunteer. They also issue a general invitation to the public at large to offer to make submissions. After the preliminary phase of taking evidence they then decided to focus on particular issues that they thought should be addressed and invited particular organisations to submit position papers. They then organised subsidiary seminars to discuss these under different headings; the Commission members discussed these and the secretary will have, after preliminary discussion with the chairman, drafted the lines of the report, which

the chairman finalised, polished and presented in his name to the Commission who approved it to pass on to the minister. They produced an interim report on the body parts issue. They then, with official support and encouragement, produced two reports with recommendations not only in order to correct the specific problems of Bristol Royal Infirmary but also to reform the NHS at large. (Learning from Bristol is its title but it is labelled rather grandly as «Presented to Parliament by the Secretary of State for Health by Command of Her Majesty.» It is known informally as the Kennedy Report, one of several as it happens. Officially, it is styled CM5207(1,2). The Government unusually accepted nearly all the recommendations of all three reports except those few that directly challenged the government's existing powers.

Its overall more notable ultimate products were a new national agency to regulate the use of treatments (National Institute of Clinical Excellence - NICE) and a new audit body (Committee for Health Audit and Improvement - CHI) entrusted to the overall direction of the chairman of the enquiry, Sir Ian Kennedy, Barrister at Law and Professor of Medical Ethics, referred to, ironically but virtually officially, as is customary in many public service fields in Britain, as the Tsar of health service reform⁽³⁾. Its most important product was putting the final touches to his emergence as the major figure in the NHS. Its immediate production was 900+ pages of report, minutes of evidence and appendices all made available on the internet and in print. (REPORT July 2001) At first sight rather surprisingly, the initial findings on the actual issue it was investigating were couched, (in partial agreement with, but also despite the professional sociological protests and excellent expositions of the same Professor Dingwall described above) in somewhat dated, predominantly essentialised, reified but not entirely misunderstood social anthropological concepts. Chapter 22: *The Culture of the NHS* explores the necessity for a series of new cultures of openness, accountability, quality and safety, public service and team work; the last eschewing especially the supposed existing tribal cultures of Doctors and Nurses⁽⁴⁾. Its general theoretical product was the canonisation of the honest Thatcherite principle of capitalist populism enthusiastically adopted less openly by New Labour, which can be summarised as «The customer is always right once s/he has been convinced that s/he wants to buy what we want to sell them, defined as the saleable end of what we produce.» Since management's aim in most organisations is to produce a situation in which they organise first commodities and then markets for them, the NHS, it is said, needs reorganisation whose object is providing for the patients who are therefore to be redefined as consumers – it must therefore be a “pa-

tient-centred culture”.⁵ This idea had given rise to an earlier intriguing illustrated cover and subtitle of a special issue of the “British Medical Journal”, *Dancing with Patients*, “BMJ”, 319, 18 September 1999, which led to both serious and spoof disapproving comment.

In practice, the Commission and developments from it, consolidated the consumerist ideology that Meg Stacey criticised long ago (STACEY M. 1988: 6 and *passim*), that patients are always patients and ignores that patients as a class are produced by the health system from the raw material of social persons and actors (self-producers). It incidentally, in its caricature of doctors and nurses as warring caricatures of tribes, ignores all the other hospital workers in the way that Strauss *et al.* (STRAUSS A. *et al.* 1985) creatively avoided doing⁽⁶⁾. In short it does not analyse the situation in terms of production questions but in terms of consumption answers. This results in culture becoming, as audit (SHORE C. - WRIGHT S. 2000) did before it, not so much a boundary concept (BOWKER G. - STARR S. 1999) that is an example of the shared concepts which mark the relationships between shared but not congruent cultural formulations, as a stop word blurring boundaries. Shore and Wright argue that audit both suffered and enjoyed conceptual inflation and became less useful as it became more influential – both a keyword and a meaningless concept. I illustrate the impact on views of culture in table form:

Commission analysis

Unitary
Managers do not just do tasks;
They create/correct culture
Change organisation “is” to organisation
“has”
Work force is passive reactive recipient of
external objective entity, i.e. culture

Production approach

Plural
Do tasks in a natural way
Socially constructed by members
For workers & patients vital productive
resource
Are soft targets, good at absorbing &
diffusing impacts

The view of culture(s) which emerges from looking at its relations of production is that it is not an object but a continuous and changing process; it is virtually (and in reality) always plural, indeed that is what gives it singularity and uniqueness. This is because it is played out and produced in practices of interaction. Descriptions of it are always therefore provisional which is why its protagonists think it is natural (Gramscian commonsense once more!). Cultures always enact differences between their members as well as the shared identities of their participants. *Vive la difference* Derridean! Like identity, except in crystallized, frozen or fossilised forms, it requires hard work to assert that you have only one culture if you should need to. Such fixed forms for

culture are rituals, symbols and artefacts; and for identity, habitus, memories and again artefacts. These observations do not make applying anthropology to health problems impossible but it does mean it requires creative imagination and that modesty, also required by teachers in general, which forbids dictating answers but rather suggests questions. For anthropologists, doing research is an interesting and hopefully useful, to all parties, way of extending the range of cultures in which they, their subjects of study and their attentive readers are all involved.

Notes

⁽¹⁾ This did not happen overnight and it was not until DERRIDA J. (1994), interestingly in a tribute to the murdered Chief of Staff of the South African ANC, Chris Hanu, attempted fully to theorise some of the non-marxist implications of living after Marx. Derrida's non-concept of *differance* is relevant here.

⁽²⁾ I feel bound to declare an interest as one who is himself in his seventies and with cardiac problems, although I do not think that Dingwall would suggest that either of our chronological ages, some twenty years apart, affect our respective judgements any more than the comparative infancy of his medical journalist co-author.

⁽³⁾ He is to New Labour's embattled NHS as the United States' 8th Cavalry was to cowboys and ranchers besieged by Indians in the classic Western American Movies

⁽⁴⁾ Sections 9 & 10 merit quotation:

9. It is important to avoid caricature when referring to "culture" and to be clear what the word is intended to convey. We take it to refer to those attitudes, assumptions and values which condition the way in which individuals and the organisation work. It is also helpful to bear in mind Professor Robert Dingwall's view (footnoted as Seminar 3 Professor Robert Dingwall, Professor of Sociology, University of Nottingham. Points for discussion) that organisational culture is a complex notion and something that is often resilient to change. One reason for this may be that its complexity lies in the co-existence of competing cultures. This is very much the case within the NHS, where the cultures, for example, of nursing, medicine and management are so distinct and internally closely-knit that the words 'tribe' and 'tribalism' were commonly used by contributors to the enquiry Seminars on this subject.

10. The positive aspects of Tribalism are clear. Tribalism engenders a sense of belonging, a set of common goals, a sense of mutual support. Moreover, competition between various tribes may be beneficial if it creates an environment of creative tension within the organisation. The danger of tribalism, of course, is that where there are numerous tribes it can threaten to undermine the capacity of a large organisation to adhere internally to a set of agreed core values and to represent these values to the outside world. Moreover, when the tribal groups fall out, or disagree over territory in an organisation such as the NHS, the safety and quality of the care given to the patient is put at risk. [Compare Lord LUGARD 1922].

⁽⁵⁾ «We recognise that patients are experts in their own right and that includes parents and there must be a culture of listening to them».

⁽⁶⁾ see *inter alia* Liz HART's (1991) analysis of the organisation of cleaners the breakdown of which, and their replacement by outside tendering, may well be responsible for the increase of hospital cross infection.

Bibliography

- BOWKER Geoffrey - LEIGH STARR Susan (1999), *Sorting Things Out: classification and its consequences*, Mass MIT Press, Cambridge.
- CREHAN Kate (2002), *Gramsci, Culture and Anthropology*, Pluto Books, London.
- DERRIDA Jacques (1994 [1993]), *Specters of Marx. The State of the Debt, the Work of Mourning & the New International*, translation by Peggy KAMUF, Routledge, London - New York [orig. ed. *Spectres de Marx. L'état de la dette, le travail du deuil et la nouvelle Internationale*, Galilée, Paris, 1993].
- DINGWALL Robert - SHUTTLEWORTH Ann (2002), *CPR: is it cruel or is it kind?*, "Nursing Times", 98, 25, 18th June 2002, pp. 36-37.
- FRANKENBERG Ronald - ROBINSON Ian - DELAHOKE Amber (2000), *Countering essentialism in behavioural social science: the example of "the vulnerable child" ethnographically examined*, "Sociological Review", 48, 4 November 2000, pp. 586-611.
- GLUCKMAN Max (1958 [1942]), *Analysis of a Social Situation in Modern Zululand*, Rhodes-Livingstone Paper 28, Manchester University Press, Manchester .
- HART Liz (1991), *A Ward of My Own: Social Organization and Identity among Hospital Domestic*, pp. 84-109, in HOLDEN Pat - LITTLEWOOD Jenny (eds.), *Anthropology & Nursing*, Routledge, London.
- LUGARD F. (1922), *The Dual Mandate in British Tropical Africa*, W. Blackwood & Sons, Edinburgh - London.
- MOL Annemarie (2002), *The Body Multiple: Ontology in Medical Practice*, Duke University Press, Durham NC - London.
- REPORT (2001) *of the Public Inquiry into Children's Heart Surgery at the Bristol Royal Infirmary 1984-1995: Learning from Bristol*.
- RICHARDSON Mary (2002), *It's the difference between life and death*, "Nursing Times", 98, 25, 18th June 2002, p. 38.
- SHORE Cris - WRIGHT Susan (2000), *Coercive accountability: the rise of audit culture in higher education*, pp. 57-89, in STRATHERN Marilyn (2000), *Audit Cultures: Anthropological Studies in Accountability, Ethics and the Academy*, Routledge for EASA, London - New York.
- STACEY Margaret (1988), *The Sociology of Health and Healing: A Textbook Unwin*, Hyman, London.
- STRAUSS Anselm - FAGERHOUGH Shizuko - SUCZEK Barbara - WEINER Caroly (1985), *Social Organization of Medical Work*, University of Chicago Press, Chicago.
- TIMMERMANS Francis (1999), *Sudden Death and the Myth of CPR*, Temple University Press, Philadelphia PA.

1.

People, politics of health and welfare states
Personas, políticas de salud y estados del bienestar
Persone, politiche sanitarie e welfare states



1.1 *El renacimiento de lo cultural en el Estado del bienestar*

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La hegemonía de la clínica

La biomedicina – y las metodologías de base clínica – quisieron abandonar la cultura durante el siglo XX. Ambas son hoy uno de los pilares en la práctica política y asistencial del estado del bienestar europeo. Las metodologías clínicas, desarrolladas a remolque del método experimental y de la hegemonía del modelo anatómico-clínico, han sido instrumentos fundamentales en la detección, clasificación y gestión de la mayor parte de problemas sanitarios, psiquiátricos, sociales y criminológicos en las sociedades contemporáneas. Participan en el diagnóstico de enfermedades, en la clasificación de discapacitados, en el establecimiento de perfiles de criminales, en la distribución de subsidios, en el cálculo de indemnizaciones o en catálogos de prestaciones, en el diagnóstico de niveles de pobreza y enfermedad, en la detección de la exclusión social⁽¹⁾. El diagnóstico de esta hegemonía a mediados del siglo por autores como Foucault permitió hablar de “Estado clínico” o de “biopoder”, o de “biopolítica”, pero ocultó en parte que ese estado, poder y política el fruto de la economía política de una metodología de obtención de datos – la clínica –, que se articulaba perfectamente con el individualismo del liberalismo democrático y que permitía obviar, cuando convenía, tanto el contexto social de las personas, como las causas de los problemas.

Ahora, en el siglo XXI cuando la clínica parece haber triunfado tanto en el diagnóstico como en la terapéutica, cuando todo, o casi todo parece estar protocolizado y todas las respuestas, o casi todas, parecen venir de la biología molecular, de la resolución de las cadenas del genoma, o de los mediadores neuronales el gobierno federal norteamericano anuncia que no financiará instituciones hospitalarias que no se acrediten como “culturalmente competentes”. Ahora, en Europa, en donde ha triunfado mayorita-

riamente – salvo en algunos países singulares –, una versión radical del jacobinismo político nada proclive a las desviaciones del estado multicultural –, las migraciones extra-comunitarias y la presencia de la diversidad cultural en el Estado del bienestar plantean contradicciones aparentemente irresolubles en la cartera de servicios de las instituciones y en el despliegue de políticas públicas. Muchos gobiernos europeos debaten sobre la mejor estrategia para asumir la diversidad cultural que responde a las diferencias identitarias y culturales de los ciudadanos, pero todos topan con las mismas cuestiones. ¿Qué significa la diversidad cultural? ¿Dónde están los límites entre diversidad cultural e igualdad? ¿Es la cultura un fenómeno territorializado como la ideología – jacobina – del Estado Nación parece defender? ¿Es posible la homogeneidad cultural de base territorial? A las que se suman cuestiones propias de la especificidad del sector salud (y de servicios sociales) ¿Qué significa hoy el retorno de la “cultura” al sector salud y de qué “cultura” estamos hablando? ¿Se trata de la “cultura” entendida como *taxonomía étnica*, se trata de “culturas” como *significados*, se trata de la medicalización como arena de producción de *significados culturales* en curso de cambio?

Negar la cultura para crear culturas profesionales

El proyecto corporativo de los médicos, desde el s.XIX, se basó en alcanzar la máxima eficiencia diagnóstica, pronóstica y terapéutica, depurando, casi patológicamente, la clínica y el laboratorio de cuantas variables fuesen accesorias a esos tres actos que eran esenciales para el mercado médico pero no los únicos que formaban parte de los recursos intelectuales de los profesionales (ver COMELLES J. 2000). Operaba sobre una transformación de la construcción del conocimiento médico, a partir de la sofisticación de las metodologías clínicas de base empírica desarrolladas por las ideas naturalistas procedentes del hipocratismo clásico. Este proceso de refinamiento metodológico conocido como el “nacimiento de la clínica moderna”, y desarrollado como fruto de las necesidades de educación médica desde finales del XVII, se sobrepone al papel que la medicina adquiere en las discusiones sobre la gubernamentalidad durante el despotismo ilustrado y prosigue su despliegue coetáneo al del Estado liberal⁽²⁾. Desde entonces se desvaneció, paso a paso, el valor del contexto – el significado del medio, la sociedad y la cultura en el enfermo y en la enfermedad – en la práctica clínica, quedando el cuerpo desnudo del paciente en la mesa de exploración o el del cadáver en la de autopsias en busca de la utopía de una práctica técnica que condujese a una toma de decisiones racional en la que el

cadáver a disecar, máxima expresión de la igualdad de los hombres ante la muerte era el objeto del que debía partir el conocimiento.

Lamentablemente para el modelo, no para los ciudadanos, el conocimiento clínico debía construirse también sobre cuerpos vivos, que aparecían en consultas u hospitales vestidos, rodeados de familiares, y que hablaban, se quejaban u ocasionalmente protestaban. A lo largo del siglo anterior la medicina procuró resolver el problema. El paciente ideal viene a ser hoy uno intubado, monitorizado, que recibe alimentación parenteral para que no defeqe, que orina mediante una sonda, y sobre el cual las computadoras alimentan de parámetros objetivos las decisiones que un médico supervisa desde un *dispatching*, desde el cual dicta órdenes al personal técnico que realiza los inevitables cambios de curas o de ropas del paciente hasta que los robots sean capaces de hacerlo⁽³⁾. En esa arena la cultura, según los médicos –, y en todas sus acepciones- habría dejado de existir.

Aunque en casos concretos y circunstancias particulares sea posible acercarse a esa utopía, como sucede en algunos pacientes internados en unidades de cuidados intensivos, en pacientes en coma *dépassé* a los que puede mantenerse en vida largo tiempo “conectados”, o en donantes, legalmente muertos pero biológicamente vivos mientras esperan la llegada del receptor, la anulación completa de la capacidad interactiva y de la ínter subjetividad entre el profesional y el entorno – el paciente, su red social, la propia institución, los otros profesionales –, no se cumplen jamás. Aunque el ideal goffmaniano de institución total se aproxime más a esas Unidades de Cuidados intensivos, que al manicomio custodial o la cárcel⁽⁴⁾, en las más perfectas, donde parecen imposibles las adaptaciones primarias y secundarias de pacientes y del personal, la evidencia etnográfica revela la producción de culturas idiosincrásicas que afectan al personal, a los enfermos, a los familiares y aún al conjunto de la institución⁽⁵⁾. Estas diferencias ponen cierta sordina a los principios reificados de igualdad en que se basaría el sistema.

Con notable timidez, aunque en público suela afirmarse lo contrario, la creencia monolítica en la racionalidad clínica se ve truncado – y así lo denuncia la experiencia y escritura etnográficas – por cambios sutiles en reglamentos y protocolos, por la permanente construcción de prácticas y representaciones que sin ser del todo verbalizadas, ponen de manifiesto grietas y contradicciones que tratan de resolverse mediante estrategias corporativas. Se recubren de rituales, estilos retóricos, silencios, y cuando son irresolubles llevan a vindicar o la “ética”, o la “humanización” de las prácticas, casi nunca fruto del distanciamiento crítico que emerge de la observación etnográfica, sino de la asunción individual – raras veces colec-

tiva –, de “valores” religiosos o cívicos que por su naturaleza quedan por encima de los imperativos de la racionalidad científica⁽⁶⁾. Tanto es así que, incluso los médicos que “no salvan vidas” porque no atienden casos de gravedad mortal pueden pensar que la búsqueda de la máxima frialdad emocional y la mayor distancia en relación al cuerpo de sus pacientes y reducir cuanto haya de subjetivo en la relación con los pacientes y su entorno mejoran los resultados de su tarea⁽⁷⁾. Si cualquier observador desapasionado puede comprender – y aceptar – la lógica de tal proceder en circunstancias extremas, también advierte su imposible aplicación al conjunto de las personas que piden ayuda a profesionales, así como la imposibilidad de que en cada lugar los propios profesionales puedan actuar según esa regla. Pero incluso en las situaciones más extremas y más cercanas al ideal emergen expresiones como “la salvaremos porque es joven y tiene dos hijos, si tuviese más de cincuenta...”. Negar lo “cultural” – y lo “social” – en la medicina no ha sido en definitiva más que una forma de construir un cultura profesional específica que se adaptaba bien a los intereses corporativos y de poder de los médicos y a la retórica de una radical igualdad de los individuos que componen el taxón *Homo sapiens*.

Sin embargo, hasta que Claude Bernard (BERNARD C. 1984), convirtió a la Medicina en experimental, y abrió las puertas a una identidad corporativa e intelectual que la aproximaba a la Física, la Medicina fue una *tekhné*, un *ars* que combinaba una hermenéutica de los escritos de autoridades, con un conocimiento empírico sobre salud y enfermedad fruto de la interacción más o menos sistemática con el medio y con las poblaciones tratadas, procedente de la teoría hipocrática y de la ciencia aristotélica⁽⁸⁾. Esa *tekhné* limitó su aplicación, hasta el siglo XIX, al entorno mediterráneo clásico, islámico o cristiano, a Europa y a las poblaciones criollas de las colonias americanas. Por eso “la medicalización”, un proceso de hegemonía y de hibridación cultural entre el conocimiento académico y los saberes empíricos populares, fue un hecho inicialmente “local” que fue ampliando su hegemonía en la medida que su significado político se trasladaba de la política local al Estado⁽⁹⁾.

Antes de Claude Bernard, la búsqueda de la hegemonía de los médicos, el proceso de medicalización, tuvo efectos modestos, se limitó a conseguir una patente política de monopolio⁽¹⁰⁾, reconociendo que la producción de conocimiento y experiencia clínica era el producto consciente de su interacción con otros especialistas, con los discursos religiosos, y con los saberes compartidos que se engendraban en la cabecera de los enfermos⁽¹¹⁾. Creo que en este contexto puede aplicarse propiamente la idea de una hegemonía de la *co-producción de saberes* que propone Alberto Bialakowski.

La co-producción explica la apropiación por los médicos, albéitares y boticarios de las terapéuticas y de la materia médica popular que se transportó a las farmacopeas. Explica a su vez la asunción de las interpretaciones hipocrático-galénicas sobre la causalidad por parte de los profanos que los folkloristas del siglo XIX definieron como “medicina popular” y caracterizaron erróneamente como supervivencia, al tiempo que tuvieron buen cuidado de discernir entre aquellos saberes empíricos populares que sí podían incorporarse a la biomedicina⁽¹²⁾.

A pesar de los esfuerzos por legitimar el *arte* médico anteriores al siglo XIX, la cultura profesional contemporánea de los médicos nace entre finales del siglo XVIII y 1850⁽¹³⁾. El nuevo proyecto profesional venía del intento de los médicos para ubicarse como los intelectuales orgánicos de un proyecto de ingeniería social asociada al despliegue de la gubernamentalidad en el Estado moderno, más allá de los anteriores límites “municipales” (PETER J.P. 1975, FOUCAULT M. 1979, PESET J. 1993), implicaba desarrollar una forma distinta de producción del conocimiento científico menos dependiente de la experiencia clínica cotidiana y de la co-producción de saberes⁽¹⁴⁾, y pronto cuestionó las teorías de la causalidad ambientalistas propias del neo-hipocratismo así como el valor de la observación etnográfica en la práctica médica⁽¹⁵⁾. Condujo a cambios sustanciales en el mercado médico, en la reproducción de relaciones de poder entre el curador y el profano, en la posición de mediador orgánico de los profesionales en la sociedad actual y en el significado de las instituciones sanitarias en la sociedad actual. Todo ello da lugar a cambios culturales al deshacer la relación anterior – propia del neohipocratismo –, entre medio – y cultura –, y enfermedad, para dejarla en una relación exclusivamente entre naturaleza y enfermedad. Esta transición entre la *tekhné* como práctica local y la biomedicina científica y experimental no es un cambio brutal, sino un proceso largo y complicado que ni sigue la misma pauta en todas partes, ni supone procesos homogéneos o idénticos incluso dentro del territorio de los estados nacionales. Tanto es así que la fase actual del proceso de medicalización, y que ha conducido a la hegemonía de lo que Menéndez (MENENDEZ E. 1978), llamara “modelo médico”, lejos de ser un proceso monolítico, se muestra como el producto de procesos históricos más complejos, puesto que va a girar en torno a tres pilares complementarios: el desarrollo en sí mismo del Estado liberal⁽¹⁶⁾, el camino en los estados europeos desde el Estado Social al Estado providencia; la ruptura que significó en los Estados Unidos el *Flexner Report* en la gestión, administración y organización profesional de los hospitales articulada con la involución del Estado social⁽¹⁷⁾. Esos tres pilares, y el diálogo entre ellos permiten caracte-

rizar las líneas de fuerza fundamentales que han modelado en los distintos países procesos de medicalización *distintos* – diversos – con formas y significados culturales distintos articuladas con procesos históricos idiosincrásicos⁽¹⁸⁾. Estas formas culturales y esos significados se configuran a partir del *embodiment* por la población de su experiencia en relación a los dispositivos desplegados por la concatenación entre políticas públicas y privadas y el Estado.

La diferencia entre el “arte” médico, que antaño caractericé como “modelo clásico”, y la biomedicina moderna es que no significó la suplantación completa del primero por la segunda, sino su subalternidad⁽¹⁹⁾, a pesar que durante el siglo XX se vindique al primero como el *ideal type* de la práctica médica, menos por su eficacia terapéutica, que por su actitud abierta y comprensiva al paciente y a su circunstancia. Su subalternidad y su condición ideal se ponen de relieve porque la retórica actual respecto al médico generalista – el médico de familia en nuestro país – fue también una forma de combatir la socialización y la salarización de los médicos vistos como un atentado a la libertad del mercado médico. También responde, en algunos casos a la sensación de pérdida de identidad – y de poder – que significa un trabajo en hospital o en atención primaria, cada vez más estructurado en forma cooperativa y en la que el diagnóstico, el pronóstico y la terapéutica acaban siendo el producto de un trabajo en equipo. Junto a ello está el debate por la hegemonía de dos formas de racionalidad y de subjetividad. En la *tekhné* el peso de la experiencia – en el sentido aristotélico del término – era el valor fundamental, más allá del propio conocimiento libresco y exigía una estrategia de incorporación de la misma que por definición era intersubjetiva, por muy cínica y venal que pudiera resultar desde el punto de vista de la ubicación profesional del médico. Más aún la *tekhné* combinaba una mirada clínica sobre el paciente, con una mirada etnográfica sobre el contexto del paciente que le permite manejar esa producción de conocimiento intersubjetivo – mediante técnicas etnográficas – y favorecía el despliegue de saberes en el espacio (*locus*) del paciente. En cambio, en el modelo hospitalario, en la biomedicina, la estrategia de conocimiento pasa por eliminar lo ahora accesorio, dejando al cuerpo libre de los accidentes sociales y culturales, eliminando la etnografía y apostando por la sólo clínica. Para ello el enfermo se transporta a un espacio (*locus*) de conocimiento en el cual el cuerpo se individualiza. Nótese que si en el primer caso el médico busca la co-producción de saber, aunque conserve sus parcelas de secreto, en el segundo se trata de excluir de la co-producción de terceros. El papel cultural de los médicos en la *tekhné* era local, en la biomedicina deja de serlo al articularse con una

filosofía política global. Y como excluye la experiencia intersubjetiva, y acentúa la deslocalización del enfermo de su medio, acaba disolviendo la producción individual de conocimiento a favor de un conocimiento compartido⁽²⁰⁾ lo suficientemente inespecífico para ir a una definición de salud global⁽²¹⁾.

Liberalismo y modelo médico

Las relaciones entre el pensamiento liberal, marxista, socialcristiano o socialdemócrata y el pensamiento médico no han dado lugar a excesiva labor hermenéutica, y sí a muchas simplificaciones. Foucault en sus trabajos sobre la “medicalización” y el “biopoder” o Castel (CASTEL R. 1995) sobre la “salarización”, o Menéndez (MENÉNDEZ E. 1978) sobre el “modelo médico” establecen las profundas relaciones entre pensamiento liberal y modelo médico. Me tienta sugerir que entre el modelo médico y el jacobinismo político – la radicalidad liberal – hay algo más que una relación metafórica. Es algo profundamente estructural. Por eso los textos críticos aludidos, escritos con una voluntad explícita de movilizar una toma de conciencia colectiva en contextos históricos bien definidos, deben tomarse con ciertas precauciones. Una lectura poco crítica puede favorecer una imagen monolítica, mecánica y reduccionista – “terminada” – del proceso de medicalización, lo que no es el caso. Yo prefiero tomarlas como hipótesis o puntos de partida para explorar su variabilidad histórica, y su papel en la producción de significados culturales diversos, lo que nos obliga a no poner en el mismo saco, por ejemplo, las relaciones del modelo médico con el pensamiento liberal en Estados Unidos o Canadá y su evolución, y las que se producen en el Estado del bienestar europeo en sus muy diversas manifestaciones⁽²²⁾. Por eso la reincorporación de “lo cultural” al modelo y la práctica médicas actuales, no puede ser contemplado bajo los mismos criterios y parámetros⁽²³⁾. En Europa, los caminos son tan diversos de un extremo a otro del continente, que no solo es imposible pensar en un proceso de medicalización homogéneo, sino que la propia noción de medicalización no tiene el mismo significado en unos lugares que en otros⁽²⁴⁾.

La teoría clásica sobre la medicalización, y el “modelo médico” proceden del análisis de los casos francés, alemán, británico y norteamericano como referentes históricos en la evolución del Estado liberal y de la transición al capitalismo. Enfatizaron el significado de los dispositivos de protección social, y sus implicaciones jurídicas y políticas en el despliegue de dispositivos de protección social, médicos, psiquiátricos y de asistencia a los po-

bres en un grupo limitado países centrales puesto que en ellos se evidencian con mayor claridad los acontecimientos y la articulación entre medicina, capitalismo y Estado liberal⁽²⁵⁾. Ewald (EWALD F. 1996), sobre el caso francés, cree que el nacimiento del Estado social se enraiza en la verificación empírica de los efectos colaterales del liberalismo económico y político, a principios del siglo XIX, y de la discusión sobre la noción de responsabilidad que contribuirá a la configuración de una cultura civil igualitaria. Castel (CASTEL R. 1995) la ha desarrollado para comprender los recientes procesos de desafiliación a esa civilidad, relacionándola con el auge y la decadencia del modelo de salarización de la ciudadanía. La crítica de Castel al dispositivo comunitario de protección social del Antiguo Régimen, debe verse desde su adhesión a la filosofía política republicana francesa y a los ribetes idiosincrásicos de la evolución de la gubernamentalidad en Francia. Para él la comunidad como instancia de solidaridad no tiene hoy lugar, más que como supervivencia arqueológica (tyloriana), y por esa razón la individualización de los actores sociales a que lleva la hegemonía de la salarización, tendría su correspondencia en la individualización de los cuerpos propia de la transición hacia una biomedicina, brazo armado de la política, en la retórica del combate de ésta contra las desigualdades derivadas del hambre, la mortalidad y las epidemias. En su modelo no cabe la diversidad cultural sino como arcaísmo, puesto que la asocia a un criterio taxonómico de lo cultural, pero no en los términos surgidos de los *post-colonial studies* (BAHBA H. K. 2002, APPADURAI A. 2001), o de los teóricos del multiculturalismo (KYMICKA W. 1996).

Es la rigidez republicana y civil de la concepción jacobina que arrastra Castel, la que pone en crisis sus argumentos. Hay en su concepto de desafiliación, una suerte de nihilismo respecto a la posibilidad de una reconstrucción de las relaciones societales y que le conduce a percibir la crisis del Estado del Bienestar en Europa en términos casi apocalípticos. Contrasta su visión negativa con la riqueza de la producción cultural en la sociedad contemporánea, la complejidad de los procesos de hibridación cultural y mestizaje, la diseminación y riqueza en el espacio y el tiempo de los nuevos movimientos sociales y ciudadanos frente a la rigidez estructural de los movimientos sociales del pasado. Las nuevas formas de afiliación, una de ellas los grupos de ayuda mutua, tienen su correlato en formas muy complejas de construcción de sociabilidad – y de construcción cultural en la sociedad moderna⁽²⁶⁾. En ningún caso Castel se planteó que el problema de la crisis del estado del bienestar había dejado de ser un problema de “cantidad” basado en indicadores sanitarios que responden a problemas masivos de la población (la incidencia de epidemias por ejem-

plo), para serlo de “calidad” en la atención a mosaicos de grupos discretos de afectados por enfermedades y problemáticas sanitarias singulares (discapacitados, escleróticos en placas, familiares de enfermos mentales, etc...). En la medida que Castel había profetizado en 1981, la gestión de los riesgos, había concebido estos en un escenario de exclusión, cuando los hechos muestran que precisamente esos nuevos movimientos operan como estrategias de la ciudadanía para asegurar su incorporación a un proyecto de ciudadanía inclusivo pero en el cual la conciencia ya no es exclusivamente la de clase como también la de identidades múltiples.

Cuando Menéndez, formuló en 1978 las características del modelo médico, olvidamos que lo pensó desde su experiencia sobre dos países sin estado del bienestar (México y Argentina), y en un momento en que en otros – la propia España – discutían el despliegue del modelo, cuando en Francia, Alemania, Gran Bretaña y Suecia ya habían alcanzado sus objetivos. Por eso en España, pero también en América Latina antes de la implantación de las políticas de ajuste neoliberales que acabaron con la utopía, el objetivo era avanzar hacia un Estado del bienestar, sin querer advertir, los evidentes signos de crisis perceptibles tras la primera crisis del petróleo, en los países avanzados. En España, la Transición no tenía sentido si el Estado democrático no conducía a los standards de bienestar que nos ofrecía la Europa de entonces.

La implantación del estado del bienestar – modesto – en España significaron, como en el resto de la Europa occidental una transición demográfica y epidemiológica, tras la cual nos habríamos de confrontar con las nuevas necesidades de una sociedad “sana” en un contexto en el que se han producido cambios culturales de muy distinto orden en el modo como los ciudadanos de la mayor parte de países contemplan ahora el proceso salud/enfermedad/atención⁽²⁷⁾.

Quería llegar aquí puesto que el debate sobre la diversidad cultural en el sector salud y sobre el papel de las variables culturales en el proceso salud/enfermedad/ atención y en las respuestas al mismo surge en dos circunstancias históricas distintas. La primera tiene que ver con el despliegue del proceso de medicalización en países no occidentales que no tienen porque compartir los rasgos judeo-cristianos o ilustrados característicos de la articulación entre modelo médico y pensamiento liberal. Aun en mi modesto conocimiento de Japón, es evidente que la medicalización en Oriente tiene características idiosincrásicas que deberían haber puesto en cuestión el etnocentrismo con que los occidentales lo concebimos⁽²⁸⁾. Lo mismo sucede en el despliegue de servicios sanitarios en el llamado Tercer Mundo.

La segunda circunstancia se refiere la transición de la demanda de ayuda sanitaria en los países desarrollados desde las enfermedades agudas a las enfermedades crónicas y degenerativas, y medicalización de malestares y formas de aflicción en toda la población que pone de relieve la necesidad de estrategias terapéuticas y asistenciales que desbordan los límites de las instituciones sanitarias y exigen replanteamientos de las estrategias de seguimiento de los pacientes y de las formas de comunicación y relación entre profesionales y ciudadanos⁽²⁹⁾. En este nuevo contexto, como en el precedente, la incapacidad de gestionar los significados culturales pone de manifiesto los límites del modelo médico hegemónico: por la banda que corresponde, simplificando, a Europa y América del Norte porque no responde adecuadamente a los cambios en las representaciones y las prácticas de la salud y de la enfermedad de la últimas décadas; por la banda baja, porque la sofisticación del dispositivo técnico de la biomedicina, no puede utilizarse por falta de recursos en la mayor parte de países del mundo, y debe volverse a intentar recuperar los saberes populares (GONZÁLEZ CHÉVEZ L. 1998, OSORIO CARRANZA R. 2001) o a “devolver” funciones a los entornos familiares de los enfermos (CANALS SALA J. 2002). La crisis de la biomedicina revela la inadecuación del modelo médico a medida que profundiza en sus rasgos estructurales al mantenimiento de una relación dialéctica con los saberes de los “profanos”, que le permita mejorar la calidad subjetiva de la práctica asistencial, y no solamente dirigirla a la mejora de los protocolos biológicos. El fiasco del modelo médico, deriva de su incapacidad estructural en adaptarse al cambio desde una demanda legitimada por el riesgo de la muerte, a otra que busca la reducción del riesgo al sufrimiento a medio o largo plazo⁽³⁰⁾. Es el fruto de haber abandonado los criterios de co-producción con los profanos que ha llevado al modelo médico a infravalorar su papel y su conocimiento respecto a la salud y a alentar su dependencia de terceros – los propios profesionales de la salud⁽³¹⁾ – especialmente cuando la implantación del derecho universal a la salud ha derribado las barreras de mercado para acceder a ellos. En el tercer mundo y no solo en él, el auge de los movimientos alternativos representa formas de organización y de resistencia que conducen precisamente a reinventar estructuras de producción de conocimiento colectivo que puedan actuar como grupos de presión, o como alternativas a las carencias de los dispositivos⁽³²⁾.

La falta de análisis cualitativos y de evaluación sobre la biomedicina y sobre las representaciones de la salud y el enfermedad en el estado del bienestar europeo⁽³³⁾ nos mantiene prisioneros del esquematismo. En general se suelen justificar los problemas a partir de las reducciones del gasto,

de las insuficiencias jurídicas, o de la ausencia de valores “humanistas” que habría que reintroducir en los profesionales, o de la psicologización, psiquiatrización o psicodinamización de la relación médico-enfermo. Mucho más raramente – y pocas veces aun en Europa – los antropólogos tratan de buscar explicaciones más globales, unas a partir de las aproximaciones fenomenológicas como *embodiment* pero no ha sido abundante la producción de evidencia empírica en contextos europeos⁽³⁴⁾.

Muy poca investigación se construye sobre etnografías de las relaciones entre los ciudadanos, los profesionales y las instituciones, y menos aún se plantea que la diversidad cultural y sobre todo la construcción de significados culturales en un contexto como en el que vivimos no puede hacerse sobre la base de protocolos de “identificación” cultural administrativa, sino comprendiendo la complejidad de las identidades múltiples de los ciudadanos de una sociedad moderna. Es en este escenario basado en el mestizaje cultural y la hibridación donde pueden observarse cambios muy profundos, y diversos, en la percepción de las amenazas de salud en las sociedades desarrolladas, en los patrones de uso de los servicios y en la retórica política que sustituye hoy la idea de *enfermedad* por la de *salud*, menos médica y más política, menos particular y más universal en un contexto en el que se habla, precisamente de reducir el catálogo de prestaciones de enfermedad. Pero en un contexto en el que la diversidad cultural es un problema nuevo, crucial para el sector salud, y para los antropólogos que nos confrontamos con él.

Dispositivos y diversidad cultural

«The following national standards issued by the U.S. Department of Health and Human Services (HHS) Office of Minority Health (OMH) respond to the need to ensure that all people entering the health care system RECEIVE EQUITABLE AND EFFECTIVE TREATMENT IN A CULTURALLY AND LINGUISTICALLY APPROPRIATE MANNER. These standards for culturally and linguistically appropriate services (CLAS) are proposed AS A MEANS TO CORRECT INEQUITIES that currently exist in the provision of health services and to make these services more responsive to the individual needs of all patients/consumers. The standards are intended to be inclusive of all cultures and not limited to any particular population group or sets of groups; however, they are especially designed to address the needs of racial, ethnic, and linguistic population groups that experience unequal access to health services».

Esta es una de las respuestas del Gobierno en Estados Unidos al problema de la atención a la diversidad cultural. Hace referencia a la necesidad de acreditación cultural de los hospitales públicos que deseen recibir subven-

ciones federales. Si hasta ahora la acreditación hacía referencia a la práctica sanitaria, académica u hotelera, ahora se extiende a un escenario de diversidad cultural en pos de mejorar la equidad en la atención. Tras ella se halla el concepto de “competencia cultural” (*cultural competence*), que aparece reiteradamente en la literatura biomédica norteamericana desde hace años, y revela un cambio en la conciencia de los profesionales de los responsables políticos respecto a la diversidad cultural, en la línea de la discusión sobre los derechos de las minorías (KYMICKA W. 1996).

Para un antropólogo europeo puede parecer un avance. Y no dudo que en algún aspecto lo es, especialmente en lo que hace referencia a la necesidad de los hospitales de asegurar una traducción en lenguas diversas a la documentación clínica que firma el enfermo a su ingreso, así como al derecho del enfermo a ser informado adecuadamente – consentimiento informado – de las actuaciones que van a ejercerse sobre él. Esta dimensión cuyos efectos son fundamentalmente jurídicos, no significa demasiado, es una medida que trata de blindar a las administraciones hospitalarias de la malpráctica relacionada con las dificultades de colectivos cada vez más numerosos en Estados Unidos que no entienden el inglés, y mucho menos la redacción leguleya de los documentos de autorización que, por docenas, un paciente firma a su ingreso en el hospital o antes de la intervención. A mi juicio, no este aspecto no responde tanto a una idea amplia de la diversidad cultural, como a una cultura jurídica en la que la jurisprudencia basada en la *common law* debe garantizar la seguridad jurídica del ciudadano. Pienso, como contraste en el caso lamentable de la muerte de un infante magrebí en el servicio de urgencias del Hospital de Melilla hace un par de años, que fue despachado sin más por la ministra de turno, insinuando que la culpa era de la madre que no hablaba español... En este punto lo que se plantea no es un problema de “competencia cultural” – concepto sobre el que volveré algo más tarde – sino algo que podríamos llamar “competencia lingüística”, o “competencia jurídica” y que tiene que ver con el más elemental sentido común en un contexto globalizado en el que el recurso a las instituciones sanitarias, tanto en situaciones de emergencia como en otras, plantea a las instituciones sanitarias públicas el problema de poder “traducir” las demandas de atención. En los países turísticos, como España, este es un fenómeno bien conocido desde los primeros sesenta, pero que durante décadas no planteó problemas pues el turista accidental pagaba su visita y era reembolsado posteriormente por sus cajas de Seguridad Social, y más tarde ese turista llevaba su bloc de convenio o disponía de un seguro de viajes que aseguraba su repatriación o la atención de emergencia. Esta problemática se acentúa con la llegada de inmigrantes extracomunitarios,

por el hecho que el catálogo de lenguas se amplía – solo en Cataluña la Conselleria de Sanitat tiene censadas 37 habituales –, algunas de ellas no eran muy frecuentes en nuestros pagos – urdu, bereber –, y muy a menudo la demanda de atención no es sólo la emergencia, que puede resolverse mediante un sistema de traducción por teléfono, sino la continuidad y el seguimiento de los casos.

Desde el punto de vista de la competencia lingüística, esto no significa pues que se produzca un cambio cultural en el modelo médico. Ni mucho menos: el médico recibe traducción telefónica o usa un vocabulario multi-lingüe para “traducir” los signos y reificar los síntomas, sin que ello suponga ninguna sensibilidad especial a favor de la diversidad cultural del paciente. Finalmente, nos hallamos en un escenario administrativo, en el cual la narrativa del paciente, y el modo cómo expresa su enfermedad, tengan que tener relevancia en el diagnóstico, pronóstico, terapéutica y seguimiento, puesto que una vez “traducido” el síntoma, la racionalidad aplicable es la misma. Es más, el sistema espera que a la vuelta de dos o tres años, la competencia lingüística del inmigrante sea suficiente como para prescindir del mediador en esta etapa.

Es en este punto donde puede comprenderse la falacia de la idea de “competencia cultural”, y la hostilidad de los antropólogos norteamericanos al respecto. Tal y como se formula en América no solo no pone en peligro al modelo médico, sino que protege a los profesionales de las acciones judiciales debidas a mal prácticas derivadas del de la lengua o de la idiosincrasia cultural de los pacientes. Es cierto, que en su modestia, la acreditación cultural tiene la virtud de ampliar el espacio de la acreditación a variables de naturaleza cultural, y significa una primera llamada de atención respecto a los derechos de las minorías, pero su fundamentación en un modelo de taxonomía étnica y cultural muy rígido tiene a mi juicio efectos indeseables importantes. El principal el que no pone en cuestión la racionalidad médica, y por tanto una forma de construcción del pensamiento que excluye el valor de lo cultural y los social en la práctica, pero que permite “añadirlo”, sin más a la lista de ítems que deben registrarse en los protocolos clínicos. Kleinman (comunicación personal) nos comentaba tiempo atrás, riendo, que sus estudiantes acaban escribiendo en las historias: signos, síntomas, exploraciones y... modelo explicativo de la enfermedad, convirtiendo lo cultural en un ítem políticamente correcto, pero sin que contribuya a una producción dialéctica de saberes.

Sin embargo, la presencia cada vez mayor de inmigrantes en los países desarrollados está produciendo un efecto, distinto al anterior, mucho me-

nos reducible a variables discretas, y que sí pone en cuestión la propia racionalidad del modelo médico. Me refiero no a los problemas que plantea la atención de emergencia – que sería el caso clásico –, como los problemas que plantea a los servicios de salud la presencia de una población inmigrante, previamente medicalizada en sus países de origen y a menudo con formación media o superior⁽³⁵⁾, cuya demanda corresponde a atención primaria, en salud mental o que va a precisar seguimiento. Es decir un escenario de práctica en el cual la comunicación intercultural, la intersubjetividad, y la co-producción de saberes van a ocupar la parte principal de la escena⁽³⁶⁾, de un modo idéntico a como se produce con los ciudadanos del país, pero ante una situación en la que entre los nuevos clientes y profesionales, no puede haber, a corto plazo, las mismas complicidades que se han construido durante décadas entre los profesionales de la salud y los ciudadanos, y que dan lugar a la producción de práctica y representaciones con las que nos manejamos en lo cotidiano. El efecto de la inmigración tiene el valor de llamar la atención sobre la necesidad de co-producir y de gestionar las variables culturales, una vez que las culturas en torno a la salud parecían tan compartidas por la ciudadanía que parecía que no debían merecer atención, puesto que nuestra ciudadanía ya había asumido y compartía un estilo de funcionar idiosincrásico y a menudo muy automatizado.

La diversidad cultural asociada a la inmigración, representa elementos de reorganización de la cultura de la salud en el conjunto de la población, tanto porque desafía la organización de los dispositivos o abre espacios imprevistos de uso, porque desafía las culturas organizaciones de los profesionales y de las instituciones exigiendo cambios y nuevas estrategias de formación, y porque supone desde el punto de vista político – y especialmente en Europa –, un reconocimiento de los derechos de las minorías que habitualmente se había escudado en el principio de la homogeneidad cultural “nacional”, para disimular la diversidad cultural.

En la literatura sanitaria europea el concepto de *cultural competence* no ha llegado apenas, puesto que nuestro Estado del Bienestar, basado en el derecho al acceso universal de la salud con independencia de la variabilidad cultural del ciudadano resuelve, al menos sobre el papel, el uso de los servicios, aunque no los efectos de la diversidad cultural sobre un sistema, cuyo proyecto fundacional era y es radicalmente igualitarista. Amparada en este principio, que le permite trazar políticas públicas idiosincrásicas, la filosofía y la práctica política europea, suele ser reacia a introducir lo cultural⁽³⁷⁾, incluso en contextos, como el catalán, que deberían ser más sensibles a la variabilidad cultural. Así, en los “Plans de Salut” (*Health Plans*)

bianuales de la Generalitat de Catalunya, el principio de la “salud igual para todos” parece excluir para siempre cualquier atisbo de discriminación por razones étnicas, culturales o religiosas, lo mismo que la Constitución española ⁽³⁸⁾ y la “Ley General de Sanidad” de 1986, pero la realidad es más tozuda que la escritura leguleya y tanto en *welfare states* como en los que carecen de él, la discriminación y la falta de equidad, y las desigualdades de acceso asociadas a variables culturales, identitarias o lingüísticas son un hecho cotidiano por acción u omisión, puesto que los proveedores de los servicios, las instituciones y los profesionales construyen ellos mismos sus propias culturas institucionales y corporativas en las que se proyectan no sólo los perfiles profesionales sino también las identidades múltiples de sus miembros.

Este es el punto clave. Hasta aquí la medicalización había sido *embodied* en los países desarrollados, como un rasgo más de los instrumentos de homogenización cultural “nacional” y de ciudadanía. Ahora, los inmigrantes ponen de manifiesto que “su diversidad”, no es únicamente “suya”, sino que es compartida también por el conjunto de la ciudadanía, en la medida que la demanda de servicios es ahora matizadísima y diversa, del mismo modo que es diversa la economía post-fordiana. Pero la cultura de la fase presente de la medicalización se construyó en un escenario fordiano: reparación de mano de obra, lucha contra la mortalidad, etc... mientras ahora el conjunto de la población padece menos enfermedades que malestares y esos son mucho más diversos que la diversidades de perfumes que pueden encontrarse en las tiendas de cosméticos de los centros comerciales... Ante estos malestares el peligro está en pensar que los malestares de la ciudadanía no son culturalmente diversos, o pueden reducirse todos o casi todos a “ansiedad” y “depresión” y tratarse dentro del modelo médico fordiano, mientras que son singulares los de los inmigrantes, aun cuando el mayor interés sería verlos reducidos también a “ansiedad” y “depresión”. Pero lo peor es no comprender que en ese modelo de gestión de esos malestares estamos también co-produciendo saberes que conducen a que la demanda en base a malestares crezca indefinida y exponencialmente si nos limitamos a actuar sobre las consecuencias y no sobre las raíces.

El reto de futuro

La superación del concepto de “competencia cultural” debe partir de la revisión de las concepciones taxonómicas de “cultura” – en la cual incluso los politólogos más abiertos como KYMLICKA W. (1996) se sienten más có-

modos – y el acercamiento a las concepciones fluidas de la cultura en la línea de lo señalado desde los *colonial studies* (APPADURAI A. 2001, BAHBA H. K. 2002) o de la literatura sobre el *embodiment* (CSORDAS T. 1994). Por eso más que pensar la acreditación en términos de asegurar el conocimiento de las taxonomías culturales, o de disponer de los recursos de traducción, por otra parte indispensables, el problema remite a cambios sustanciales en las *abilities*, a la de *agency* y a la de “profesionalidad”, necesarias para una concepción de “cultura” flexible y en constante construcción y deconstrucción, capaz de responder a la variabilidad y la complejidad de las “identidades” en un universo esencialmente mestizo⁽³⁹⁾, en donde la producción de *etnoscajes* es un fenómeno constante atrapado en historicidades particulares, y por lo tanto sometido a procesos transaccionales permanentes que a su vez constituyen formas de saber, saberes o formas de *agency*. En este ámbito se trata de plantear *anthropological abilities* en la práctica profesional para acabar ante las situaciones de desconcierto ante la diversidad cultural y mitigar las respuestas situadas en la banda discriminatoria del espectro aludido. En una comunicación reciente destinada a una reunión profesional de médicos de familia, Xavier ALLUÉ lo sintetiza:

«El médico debe tener una percepción de su propia cultura y su status y de las diferencias en control y poder existentes en la relación médico/paciente, y un conocimiento básico de cómo la teoría y la práctica de la Medicina están condicionadas culturalmente, de la existencia de fenómenos de exclusión (racismo), de las diferencias en las estructuras familiares y los diferentes roles asumidos por los miembros de las familias en las diferentes culturas, los factores sociopolíticos que repercuten sobre la existencia de los pacientes y de los síndromes o enfermedades culturalmente contruidos (“*culture-bound syndroms*”). Además debe adquirir habilidades o destrezas que le permitan comprender los modelos explicativos de la enfermedad de los pacientes, ser capaz de modificar sus instrumentos de interacción con el paciente en función de las diferencias culturales y procurar evitar prejuicios o conceptualizaciones preestablecidas. Entre sus cualidades se deben incluir la empatía, el respeto, la capacidad de inspirar confianza, la comprensión y establecer lazos que faciliten la colaboración, que proporcionen esperanza y ánimo y que permitan al paciente asumir el control propio de su proceso (“*empowering*”)» (ALLUÉ X. 2003).

De un médico y destinado a médicos se trata de a partir del fenómeno inmediato, la toma de conciencia de los médicos *a partir de* la novedad de la presencia de extranjeros en las consultas, derivar esa toma de conciencia, inicialmente identificatoria, hacia un modelo mucho más comprensivo del contexto cultural y de la diversidad de todos sus pacientes. Y aunque para muchos antropólogos esta propuesta estaría aún demasiado cerca de un concepto taxonómico de cultura, no debe olvidarse que resulta difícil, desde un punto de vista pedagógico y en este momento histórico,

explicar a profesionales sanitarios con una formación radicalmente neopositivista y taxonómica y en que solo algunos han desarrollado una conciencia de la diversidad cultural, asumir que las nuevas concepciones de lo cultural exigen imperativamente deconstruir sus propias identidades y en algunos sentidos su propia racionalidad.

Notes

⁽¹⁾ Una interesante aportación a los orígenes del trabajo social y a sus influencias metodológicas está en MIRANDA ARANDA M. (2004).

⁽²⁾ Aunque para la transición entre la medicina galénico-hipocrática y la clínica moderna siguen siendo interesantes FOUCAULT M. (1978), y ACKERCKNETCH E. (1986), los trabajos de VON BUELTZINGSLOEWEN I. (1996) y RISSE (1999) permiten matizar mucho más el significado, importante, pero no esencial de la Escuela de París en esa transformación.

⁽³⁾ El desarrollo de la “medicina de la evidencia” es una consecuencia del desarrollo de la epidemiología clínica y apunta hacia ese objetivo. En un monográfico reciente de la revista “Health” (TRAYNOR, 2003), POPE (2003) la presenta como un nuevo movimiento social y no únicamente clínico y analiza las “resistencias” de amplios sectores clínicos a su penetración. CRONJE R.- FULLAN A. (2003) resaltan la utopía de la búsqueda de una nueva “racionalidad” en ese tipo de acercamientos.

⁽⁴⁾ Goffman no pudo conocerlas en los cincuenta, puesto que su diseño se definió apenas hace una década. PALLARÉS A. (2003) hace una interesante revisión de sus fundamentos teóricos

⁽⁵⁾ Hay en castellano algunas etnografías sobre Unidades de cuidados intensivos. Las referencias fundamentales son las de ALLUE M. (1996, 1997, 1999), y PALLARÉS A. (2003). Ver también POUCHELLE M.C. (1995), COMELLES J., (2000) y la autobiografía de TELLECHEA IDIGORAS J. (1991).

⁽⁶⁾ Un reciente libro de BOIXAREU R. (2003) hace una interesante revisión de la literatura al respecto desde la perspectiva de la antropología filosófica y la antropología social.

⁽⁷⁾ En PERDIGUERO E. - COMELLES J. (2000) se discute largamente la cuestión.

⁽⁸⁾ Para una discusión amplia de la cuestión ver COMELLES J. (1993, 1998, 2000).

⁽⁹⁾ La mejor aproximación a los inicios locales de la medicalización están en GARCÍA BALLESTER L. - McVAUGH M. - RUBIO VELA A. (1989) - McVAUGH M. (1993).

⁽¹⁰⁾ Una buena aproximación a la problemática de la legitimación política de la práctica médica está en el dossier de la revista “Dynamis” sobre el Protomedicato en España (LÓPEZ TERRADA M. - MARTINEZ VIDAL A. (eds.), 1996) - McVAUGHN M. (1993).

⁽¹¹⁾ La mejor aproximación en castellano a esta problemática es el excelente dossier de “Dynamis” compilado por BALLESTER R. - LÓPEZ TERRADA M. - MARTINEZ VIDAL A. (2002) especialmente PERDIGUERO E. (2002). También ZARZOSO A. (2001).

⁽¹²⁾ Sobre el papel de los folkloristas médicos y la medicina popular ver COMELLES (1996), y la reciente aportación de BALLESTER R. - PERDIGUERO E. (2003) desde el caso del médico Rubio i Gali.

⁽¹³⁾ Aunque el clásico de FOUCAULT M. (1978) suele ser la referencia, el problema fue estudiado largamente por Rosen desde los años cuarenta (ROSEN G. 1985). Ver también para Alemania VON BUELTZINGSLOEWEN I. (1997).

⁽¹⁴⁾ Y que se acuña en torno al desarrollo del modelo anátomo-clínico, el pastorianismo, las teorías degeneracionistas y la clínica kraepeliniana en Psiquiatría, todos ellos a remolque del experimentalismo

⁽¹⁵⁾ al respecto el esclarecedor libro de LARREA KIRRRINGER C. (1997) sobre el auge y la crisis de la teoría miasmática, y COMELLES J. (2000), sobre la crisis de la etnografía a favor de la clínica

- ⁽¹⁶⁾ Incluidas en él modelos radicales como los fascistas o los comunistas.
- ⁽¹⁷⁾ Esto significó cambios en la gestión y en la administración de los hospitales (VOGEL M. J. 1980), en las estrategias profesionales de los médicos, en el significado de las instituciones en la formación médica y en el proceso salud /enfermedad / atención, y en la creación de un mercado de salud específico muy distinto del que caracterizara la práctica médica desde antes de la Ilustración. ver también el clásico de FREIDSON E. (1963).
- ⁽¹⁸⁾ Para una discusión sobre la diversidad de los procesos de medicalización y la especificidad de los dispositivos ver COMELLES J. (1991).
- ⁽¹⁹⁾ Para una discusión teórica ver COMELLES J. (1993). URIBE OYARBIDE J.(1996) analizó magistralmente la producción cultural de subalternidad desde un centro de atención primaria.
- ⁽²⁰⁾ Aquí no está de más invocar los textos clásicos de FLECK L. (1986) y de LATOUR B. - WOOLGAR S. (1995) sobre la producción del conocimiento experimental
- ⁽²¹⁾ Sobre la ideología de la salud pública en el modelo médico es indispensable el interesantísimo estudio de LUPTON D. (1995).
- ⁽²²⁾ El lector comprenderá que el caso de Japón, y en general la mayoría de los del llamado Tercer Mundo son un universo que no me puedo ni de lejos plantear, pero que exigen estudios idiosincrásicos.
- ⁽²³⁾ El propio FREIDSON E.(1978), aunque destina un capítulo de su libro clásico a los modelos de seguros social europeo no podía tener suficiente perspectiva, ya que cuando prepara su monografía a finales de los sesenta el Estado del bienestar europeo estaba en plena construcción. Únicamente CASTEL R. (1981) apuntó algunas ideas clave sobre su evolución
- ⁽²⁴⁾ Para una discusión sobre este tema ver CASTEL R. (1995), pero también COMELLES J. (1991) sobre las cronologías distintas de la medicalización incluso en el interior de los estados-nación.
- ⁽²⁵⁾ De Francia, Alemania y Gran Bretaña se ocuparon Castel, Foucault y Rosen en obras ya citadas, sobre los Estados Unidos ver ROTHMAN D. (1971) y CASTEL F. - CASTEL R. - LOVELL A. (1980) y más recientemente MIRANDA (2004) entre muchos otros. Ver también el reciente ensayo de CASTEL R. (2003) sobre la inseguridad social...
- ⁽²⁶⁾ Sobre los grupos de ayuda mutua y el debate sobre esta cuestión es indispensable CANALS SALA J. (2002), sobre la problemática de los colectivos diferentes ver sobre todo ALLUÉ M. (2003).
- ⁽²⁷⁾ Esto lo apuntaba en algunos aspectos DE MIGUEL J. (1985). Los distintos informes SESPAS sobre el estado de salud en España que se publican desde 1994, muestran claramente ese proceso.
- ⁽²⁸⁾ Ver ejemplos en el volumen colectivo de OTSUKA Y. - SAKAI S. - KURIYAMA S. (1999).
- ⁽²⁹⁾ Este problema fue detectado en los sesenta y dio lugar a la literatura y los posicionamientos respecto a la idea de participación ciudadana en salud, cuyos límites ha examinado recientemente SERAPIONI M.(2003). La evolución de un modelo de participación más o menos colectivo, a nuevas formas de participación, mucho más cualitativa ha sido examinada por CANALS SALA J. (2002).
- ⁽³⁰⁾ La estrategia de los *hospice* como dispositivos de cuidados paliativos se plantea como una atención a término, siempre en un relativamente corto plazo, pero no sucede lo mismo cuando la experiencia del dolor se prolonga años y años. ver al respecto ALLUÉ M. (1999).
- ⁽³¹⁾ Para una crítica ver sobre todo ALLUÉ M. (2003) y CANALS SALA J. (2002), desde la perspectiva del derecho de los usuarios.
- ⁽³²⁾ Ver por ejemplo las formas de organización de las mujeres en América latina, por ejemplo en MÓDENA M.E. (1990), OSORIO CARRANZA R. (2001) y GONZÁLEZ CHÉVEZ L. (1998).
- ⁽³³⁾ Las revistas "Health" y "Sociology of Health and Illness" vienen publicando artículos sobre esta temática desde hace algunos años.
- ⁽³⁴⁾ Ver a este respecto los dos *readers* de VAN DONGEN E. - COMELLES J. (2001) y COMELLES J. - VAN DONGEN E. (2002), en el que hay bastantes aportaciones sobre casos europeos.
- ⁽³⁵⁾ A veces parece a los profesionales de aquí que los inmigrantes no hayan visto antes un hospital en su vida, ignorando que un 60% de los que están ahora en Cataluña tienen o Bachillerato o grados superiores de educación. La diferencia es que aquí la asistencia es gratuita y en muchos de sus países no necesariamente.

⁽³⁶⁾ Es lo que MENÉNDEZ E. (1990) llama transacciones, y que corresponde a los consensos de que hablara Gramsci.

⁽³⁷⁾ Una comparación entre España y los Estados Unidos en torno a las problemáticas de la diversidad cultural está en GREENHOUSE C. (ed.) (1998) y GREENWOOD D. - GREENHOUSE C. (eds.) (1996).

⁽³⁸⁾ Para el papel de lo cultural en la Constitución española de 1978 ver PRIETO DE PEDRO J. (1992).

⁽³⁹⁾ La distinción entre identidad y identificación se la debemos a Ignasi Terradas. La idea de mestizaje está presente en LAPLANTINE F. (1999), LAPLANTINE F. - LÉVY J. - MARTIN J.B. - NOUSS A. (eds.) (1998), y APPADURAI A. (2001).

Bibliography

ACKERKNECHT Erwin H. (1986 [1967]), *La médecine hospitalière a Paris (1794-1848)*, Payot, Paris [ed. orig.: *Medicine at the Paris hospital (1794-1848)*, The Johns Hopkins Press, Baltimore, 1967].

ALLUÉ Marta (1996), *Perder la piel*, Planeta Seix Barral, Barcelona.

ALLUÉ Marta (1997), *Sobrevivir en la Uci*, "Enfermería Intensiva", n. 8, 1997, pp. 29-34.

ALLUÉ Marta (1999), *La douleur en direct*, "Anthropologie et Sociétés", n. 23, 1999, pp. 117-136.

ALLUÉ Marta (2003), *DisCapacitados. La reivindicación de la igualdad en la diferencia*, Bellaterra, Barcelona.

ALLUÉ Xavier (2003), *La competencia cultural de los médicos de Asistencia Primaria*, ponencia al XV Congreso de la Sociedad Valenciana de Medicina Familiar y Comunitaria, Peñíscola, mimeografiado.

APPADURAI Arjun (2001 [1996]), *Après le colonialisme. Les conséquences culturelles de la globalisation*, Payot, Paris [ed. orig.: *Modernity at Large. Cultural Dimensions of Globalization*, University of Minnesota Press, Minneapolis - London, 1996]

BALLESTER Rosa - LÓPEZ TERRADA María L. - MARTÍNEZ VIDAL Alvar (2002), *La realidad de la práctica médica: el pluralismo asistencial en la Monarquía Hispánica (ss. XVI-XVIII)*, "Dynamis", vol. 22, 2002.

BERNARD Claude (1984 [1865]), *Introduction à l'étude de la médecine expérimentale*, Flammarion, Paris [ed. orig.: Baillière, Paris, 1865]

BHABHA Homi K. (2002 [1994]), *El lugar de la cultura*, Manantial Buenos Aires [ed. orig.: *The Location of Culture*, Routledge, London - New York, 1994].

BOIXAREU Rosa (ed.) (2003), *De l'Antropologia filosòfica a l'Antropologia de la salut*, Fundació Blanquerna, Barcelona.

CANALS SALA Josep (2002), *El regreso de la reciprocidad. Grupos de ayuda mutua y asociaciones de personas afectadas en el estado del bienestar*, tesis de doctorado, Universitat Rovira i Virgili, Tarragona.

CASTEL Françoise - CASTEL Robert - LOVELL Anne (1980 [1979]), *La sociedad psiquiátrica avanzada. El modelo norteamericano*, Anagrama, Barcelona [ed. orig.: *La société psychiatrique avancée. Le modèle américain*, Grasset, Paris, 1979].

CASTEL Robert (1981), *La gestion des risques. De l'anti-psychiatrie à l'après psychanalyse*, Éditions de Minuit, Paris.

CASTEL Robert (1995), *Les métamorphoses de la Question Sociale. Une chronique du salariat*, Fayard, Paris.

CASTEL Robert (2003), *L'insécurité sociale. Qu'est-ce qu'être protégé?*, Seuil, Paris.

COMELLES Josep M. (1991), *Psychiatric care in relation to the development of the contemporary state: The case of Catalonia*, "Culture, Medicine and Psychiatry", 15 (2), 1991, pp. 193-217.

COMELLES Josep M. (1993), *La utopía de la atención integral de salud. Autoatención, práctica médica y asistencia primaria*, "Revisiones en Salud Publica", n. 3, 1993, pp. 169-192.

- COMELLES Josep M. (1996), *Da superstizion a medicina popolare: La transizione da un concetto religioso a un concetto medico*, "AM. Rivista della Società italiana di antropologia medica", n. 1-2, 1996, pp. 57-89.
- COMELLES Josep M. (1998), *Parole de médecin. Le récit sur la pratique dans la médecine contemporaine*, pp. 299-316, en LAPLANTINE François - LÉVY Joseph - MARTIN Jean B. - NOUSS Alexis (eds.), *Récit et connaissance*, Presses Universitaires de Lyon, Lyon.
- COMELLES Josep M. (2000), *The Role of Local Knowledge in Medical Practice: A Trans-Historical Perspective*, "Culture, Medicine and Psychiatry", n. 24, 2000, pp. 41-75.
- COMELLES Josep M. (2000), *Tecnología, cultura y sociabilidad. Los límites culturales del hospital contemporáneo*, pp. 305-351, en PERDIGUERO Enrique - COMELLES Josep M. (eds.), *Medicina y cultura. Estudios entre la antropología y la medicina*, Bellaterra, Barcelona.
- COMELLES Josep M. - VAN DONGEN Els (eds.) (2002), *Themes in Medical Anthropology. Medical Anthropology at Home contributes to health studies*, "AM. Rivista della Società italiana di antropologia medica", n. 13-14, 2002 (dedicado a las Actas de la Reunión de la red Medical Anthropology at Home celebrada en Tarragona, 19-21 abril 2001, vol. II).
- CRONJE Ruth - FULLAN Amanda (2003), *Evidence-based medicine: toward a new definition of "rational" medicine*, "Health", vol. 7, n. 3, 2003, pp. 353-369.
- CSORDAS Thomas J. (ed.) (1994), *Embodiment and Experience. The existential ground of culture and self*, Cambridge University Press, Cambridge.
- DE MIGUEL Jesús (1985), *La salud pública del futuro*, Ariel Sociología, Barcelona.
- DOPSON Sue - LOCOCK Louise - GABBAY John - FERLIE Ewan - FITZGERALD Louise (2003), *Evidence-based medicine and the implementation gap*, "Health", vol. 7, n. 3, 2003, pp. 311-330.
- EWALD François (1996 [1986]), *Histoire de l'État Providence. Les origines de la solidarité*, Le Livre de Poche, Paris [ed. orig.: Grasset, Paris, 1986].
- FLECK Ludwig (1986 [1935]), *La génesis y el desarrollo de un hecho científico*, Alianza Editorial, Madrid [ed. orig.: *Entstehung und Entwicklung einer wissenschaftlichen Tatsache. Einführung in die Lehre vom Denkstil und vom Denkkollektiv*, Suhrkamp, Frankfurt am Main, 1935].
- FOUCAULT Michel (1978 [1963]), *Naissance de la clinique*, Presses Universitaires de France, Paris [ed. orig.: Presses Universitaires de France, Paris, 1963].
- FOUCAULT Michel (1979), *La Politique de la Santé au XVIIIème siècle*, pp. 7-18, en FOUCAULT Michel (ed.), *Les machines à guérir. Aux origines de l'hôpital moderne*, Atelier Pierre Madarga, Bruxelles.
- FREIDSON Eliot (1978 [1970]), *La profesión médica*, Península, Barcelona [ed. orig.: *The profession of medicine: A study in the sociology of applied knowledge*, Harper and Row, New York, 1970].
- GARCÍA BALLESTER Luis - MCVAUGH Michael R. - RUBIO VELA Agustín (1989), *Medical Licensing and Learning in Fourteenth-Century Valencia*, American Philosophical Society, Philadelphia.
- GONZÁLEZ CHEVÉZ Lillian (1998), *El pulso de la sobrevivencia. Estrategias de atención para la salud en un colectivo de mujeres del subproletariado urbano*, tesis de doctorado, Universitat de Barcelona, Barcelona.
- GREENHOUSE Carol J. (ed.) (1998), *Democracy and Ethnography. Constructing identities in multicultural liberal states*, Albany State University of New York Press, New York.
- GREENWOOD Davydd J. - GREENHOUSE Carol J. (eds.) (1998), *Democracia y diferencia. Cultura, poder y representación en los Estados Unidos y en España*, UNED, Madrid.
- KYMLICKA Will (1996 [1995]), *Ciudadanía multicultural. Una teoría liberal de los derechos de las minorías*, Paidós, Barcelona [ed. orig.: *Multicultural citizenship*, Oxford University Press, Oxford, 1995].
- LAPLANTINE François - LÉVY Joseph - MARTIN Jean B. - NOUSS Alexis (eds.) (1998), *Récit et connaissance*, Presses Universitaires de Lyon, Lyon.
- LAPLANTINE François (1999), *Je, nous et les autres. Être humain au-delà des appartenances*, Le Pommier - Fayard, Paris.
- LARREA KILLINGER Cristina (1994), *Los miasmas. Historia antropológica de un concepto médico*, tesis de doctorado, Universitat de Barcelona, Barcelona [publicada en 1997 como *La cultura de los olores*, Abya-Alia, Quito].

- LATOUR Bruno – WOOLGAR Steve (1995 [1979]), *La vida en el laboratorio. La construcción de los hechos científicos*, Alianza Editorial, Madrid [ed. orig.: *Laboratory Life: the Social Construction of Scientific Facts*, Sage, Los Angeles, 1979].
- LÓPEZ TERRADA María L. - MARTÍNEZ VIDAL Alvar (eds.) (1996), *El Tribunal del Real Protomedicato en la Monarquía Hispánica 1593-1808*, "Dynamis", vol. 16, 1996, pp.
- LUPTON Deborah (1995), *The Imperative of Health. Public Health and the regulated Body*, Sage Publications, Londres.
- MCVAUGH Michael R. (1993), *Medicine before the Plague. Practitioners and their patients in the crown of Aragon*, Cambridge University Press, Cambridge.
- MENÉNDEZ Eduardo L. (1978), *El modelo médico y la salud de los trabajadores*, pp. 11-53, en BASAGLIA Franco (ed.), *La salud de los trabajadores*, Nueva Imagen, México DF.
- MENÉNDEZ Eduardo L. (1990), *Antropología Médica. Orientaciones, desigualdades y transacciones*, CIESAS, México DF.
- MIRANDA ARANDA Miguel (2004), *De la caridad a la ciencia. Pragmatismo, interaccionismo simbólico y trabajo social*, Mira Editores, Zaragoza.
- MÓDENA María Eugenia (1990), *Madres, médicos y curanderos: diferencia cultural e identidad ideológica*, La Casa Chata, México DF.
- OSORIO CARRANZA Rosa M. (2001), *Entender y atender la enfermedad. La construcción social materna de los padecimientos infantiles*, INAH, México DF.
- OTSUKA Yasuo - SAKAI Shizu - KURIYAMA Shigehisa (eds.) (1999), *Medicine and the History of The Body. Proceedings of the 20th, 21st and 22nd International Symposium on the Comparative History of Medicine - East and West*, Ishiyaku EuroAmerica Inc. Publishers, Tokyo.
- PALLARÉS Angela (2003), *El mundo de las unidades de cuidados intensivos. La última frontera*, tesis de doctorado, Universitat Rovira i Virgili, Tarragona.
- PERDIGUERO Enrique (2002), «Con medios humanos y divinos»: *la lucha contra la enfermedad y la muerte en el Alicante del siglo XVIII*, "Dynamis", n. 22, 2002, pp. 121-150.
- PERDIGUERO Enrique - BALLESTER Rosa (2003), *Federico Rubio y el Folklore médico*, pp. 475-497, en CARRILLO J.L. (ed.), *Medicina y sociedad en la España de la segunda mitad del siglo XIX: una aproximación a la obra de Federico Rubio y Galí (1827-1902)*, Ayuntamiento de El Puerto de Santa María y Asociación para la Formación, Investigación y Asistencia Médica de Andalucía "Federico Rubio", El Puerto de Santa María.
- PERDIGUERO Enrique - COMELLES Josep M. (eds.) (2000), *Medicina y cultura. Estudios entre la antropología y la medicina*, Bellaterra, Barcelona.
- PESET José L. (1993), *Las heridas de la ciencia*, Junta de Castilla y León, Salamanca.
- PETER Jean-Pierre (1975-1976), *Le grand rêve de l'ordre médical, en 1770 et aujourd'hui*, "Autrement", n. 4, 1975-76, pp. 183-192.
- POPE Catherine (2003), *Resisting evidence: the study of evidence-based medicine as a contemporary social movement*, "Health", vol. 7, n. 3, 2003, pp. 267-281.
- POUCHELLE Marie-Christine (1995), *Transports hospitaliers, extra-vagances de l'âme*, pp. 247 -299, en LAUTMANN Françoise - MAÎTRE Jacques (eds.), *Gestion religieuse de la santé*, L' Harmattan, Paris.
- PRIETO DE PEDRO Jesús (1992), *Cultura, culturas y Constitución*, Congreso de los Diputados - Centro de estudios constitucionales, Madrid.
- ROSEN George (1985), *De la policía médica a la medicina social*, Siglo Veintiuno, México DF.
- ROTHMAN David J. (1971), *The Discovery of Asylum. Social Order and Disorder in the New Republic*, Little Brown, Boston.
- SCHEPER-HUGHES Nancy - LOCK Margaret (1998 [1987]), *The Mindful Body. A Prolegomenon to Future Work in Medical Anthropology*, en VAN DER GEEST Sjaak - RIENKS Ari (eds.), *The Art of Medical Anthropology. Readings*, Universiteit van Amsterdam, Amsterdam [ed.orig.: "Medical Anthropology Quarterly", 1, 1987, pp. 6-41].
- SERAPIONI Mauro (2003), *La participación de los ciudadanos en el ámbito de la salud. Experiencias europeas*, tesis de doctorado, Universitat de Barcelona, Barcelona.

- TELLECHEA IDIGORAS Jose I. (1991), *Tapices de la memoria. Historia clínica 279.952*, Kutxa, San Sebastián - Donosti.
- TRAYNOR Michael (2003), *Understanding the Evidence-based Movements*, "Health", vol. 7, n. 3, 2003.
- TRAYNOR Michael (2003), *Introduction*, "Health", vol. 7, n. 3, 2003, pp. 265-266.
- URIBE OYARBIDE José M. (1996), *Educación y cuidar. El diálogo cultural en atención primaria*, Ministerio de Cultura, Madrid.
- VAN DONGEN Els - COMELLES Josep M. (eds.) (2001), *Medical Anthropology and Anthropology. Contributions of Medical Anthropology at Home to anthropological theories and health debates*, "AM. Rivista de la Società italiana di antropologia medica", vol. 11-12, 2001 (dedicado a las Actas de la Reunión de la red Medical Anthropology at Home celebrada en Tarragona, 19-21 abril 2001, vol. I).
- VOGEL Morris J. (1980), *The invention of modern hospital. Boston 1870-1930*, University of Chicago Press, Chicago.
- VON BUELTZINGSLOEWEN Isabelle (1997), *Machines à instruire, machines à guérir. Les hôpitaux universitaires et la médicalisation de la société allemande 1730-1850*, Presses Universitaires de Lyon, Lyon.
- ZARZOSO Alfonso (2001), *El pluralismo médico a través de la correspondencia privada en la Cataluña del siglo XVIII*, "Dynamis", n. 21, 2001, pp. 141-159.

1.2 *New practices in collective health care*

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This text intends to continue a socio-anthropological discussion initiated with a paper to the 4th Latin-American Congress of Social Sciences and Health (Cocoyoc, 1997), about changes in the health paradigm occurred in the last decades of the 20 century, with the considerable development, and process of inclusion in health care services of the so-called “alternative therapies”, latter designated as “complementary medicines”, their relationship with distinct medical *racionales*, and with bodily health practices in the society. This discussion was deepened in the 4th Brazilian Congress of Collective Health (Salvador, 2000), with an attempt to interpret both phenomena as part of a process of cultural re-signification of social actions, relations and representations related to sickness and health or, in a more general way, *to life* and its extension and conservation in contemporary society.

The core of the proposed interpretation is in the hypothesis that in this cultural re-signification process a set of central values of capitalist society is exacerbated, while others are put aside by a growing part of society, through new health practices and activities that work as forms of sociability recuperation and ethical resistance strategies. These new forms of sociability emerge with the “new practices” in development, in civil society as well as in health care institutions – in the latter in an incipient way. From our point of view, the new collective health practices express the existence of new senses and meanings in culture related to health and life. These new forms of sociability refer to the creation (or “re-creation”) of values indicating the construction of an ethic, different from– and perhaps opposite to, the dominant capitalist ethic, and to the “spirit of capitalism”, in what they have of most harmful to life in common and, in the final reckoning, most contrary to life. The last part of the sentence is difficult to understand. A key point of this work is, therefore, the discussion of cultural values associ-

ated to the present collective health practices, mainly corporeal practices, and the production of new cultural senses and meanings related to these practices.

Theoretical studies and empirical researches: the medical rationales and health practices project

The lines of reflection and argumentation developed in support to our hypotheses in the following pages originate, on one hand, from the results of a set of theoretical studies and empirical researches in the Institute of Social Medicine of the University of Rio de Janeiro, initiated in 1992. The so called "Medical Rationales and Health Practices" project, now in its third phase, began with a comparative theoretical study of complex medical systems (contemporary western medicine, homeopathic medicine, traditional Chinese medicine, Ayurvedic medicine). The central hypothesis of the first phase of the project, concluded in the beginning of 1994, is that there is actually more than one medical *rationale*, contrary to western common sense, which admits only biomedicine (or modern Western medicine) as the bearer of rationality in medicine, that is capable not only of practical efficacy but of verification and confirmation of (theoretical) meaning in experimentation. The Project further aimed to demonstrate that distinct medical rationalities effectively coexist in contemporary culture. The complex medical systems are supposed to have five basic structured dimensions in theoretical or symbolic terms: 1- a human *morphology* (denominated human *anatomy* among us), which defines the structure and the form of organization of the body (or bodies); 2- a human *vital dynamics*; (defined as *physiology* among us), which defines the movement of the vitality, its balance or unbalance in the body (or bodies), its origins or causes; 3- a *medical doctrine*, which is in fact a doctrinal *corpus* defining, what is the health/sickness process, what is a disease or the process of getting ill, in its origins or causes, what is possible to treat or cure, and what does not belong to the medical corpus as a morbid process or capable of cure, among us is simply defined as what does or does not belong to the clinic; 4- a *diagnosis system*, through which it is determined if there is or if there is not a morbid process, its nature, phase and probable evolution, origin or cause; 5- a *therapeutic system*, through which are determined the forms of intervention adequate to each morbid process (or sickness) identified by the *diagnosis* dimension. For the Project, from this point of view, only a specific complex medical system structured according to these five dimensions, elaborated to a greater or lesser degree in practical/theoretical terms, can

be denominated a *medical rationality*. For these reasons, only the four mentioned systems were object of study in the first phase.

At the end of the first phase we also concluded that all complex medical system has as a structuring root a *cosmology*, which provides with a theoretical and symbolic basis the other dimensions. They are also more or less institutionalized systems, be it in the western culture, be it in its original culture (China and India, in the cases studied), sometimes in both, and taught in legitimated institutions for transmission of its formal contents as well as of the attitudes that conform its *habitus*. Complex systems more based in a symbolic universe than in rational propositions, such as the traditional Amerindian medicines, or other systems, which are, such as anthroposophical medicine, centered in metaphysics or in some form of religion, were not studied. However, the study concluded, in its first phase, for the perception of the *limits of rationality* in the systems, since: 1- all medical rationality has in its basis a *cosmology*, proper to the culture where it is established, rooted in a symbolic universe of senses that include images, metaphors, representations, and even conceptions, irreducible to the plane of theoretical or empirical propositions demonstrable by scientific procedures; 2- inside each medical rationale coexist in fact two different forms of apprehension/interpretation, two “paradigms”, linked to the *theoretical* (knowledge accumulated from the health-disease process) and *practical* (intervention in the bodies of sick people through the diagnostic and therapeutic procedures) dimensions. The practical knowledge “uses” the theoretical knowledge as a function of the efficacy to be obtained in its intervention, so being an “active” knowledge. In other words, the modern western duality *science X art* is present in a greater or lesser degree in the practice of the agents of these medicines, being clearly exacerbated in biomedicine.

In the second phase of the Project we could follow to what measure these dualities manifested *in the practice* of the public health professionals of three medical rationalities: biomedicine, homeopathy and traditional Chinese medicine. We also tried to analyze representations and meanings attributed to disease, health, treatment, cure, body, body/mind relation, among others, considered basic to apprehend paradigms in health and medicine in physicians (or therapists) and patients in the distinct rationalities in study, as well as the way the professionals and the clients shared or did not share these representations. Our nuclear hypothesis was that the patients and professionals of a certain medical system tend to share paradigms and representations of its own rationality, and this cultural “sharing” tends to facilitate the physician/patient or therapist/patient relationships, making

easier the therapeutic process. This hypothesis was in great part confirmed, for the three systems, by the interviews and ethnographic material and participant observation obtained during two years in health services in Rio de Janeiro, even considering the differences between systems. For instance, differently from the case of homeopathic medicine, where the link is established through patient's *discourse*, in acupuncture the therapeutic process is essentially *silent* and "physical" (introduction and manipulation of the needles).

Images and representations of illness

In all cases, however, it is necessary to stress that all patients, when they look for a certain medicine for diagnosis or therapeutic end, or both things, carry with them a set of images and representations about their illness, its origins or causes, and about the possibilities of health recovery, which partially coincides with the set of conceptions and representations of the chosen medical system. In many occasions, the images, conceptions and representations are "translated" for the cultural universe of the patients through metaphors and images, or even through other senses and meanings attributed to the expressions employed by doctors, what happens in biomedicine as well as in homeopathy. This is very clear in the case of public health care patients, where the social classes and cultures are different for doctors and patients, what does not happens in the case of private consultations, where the social and cultural universe is basically the same, or at least more homogeneous.

A relevant fact for the analysis is that in all medical systems, however, independently from the institutional environment where the consultation takes place, the representations are not "pure" from the point of view of the attributed senses and meanings, that is, they are not restricted to the *rationale* of a sole medical system. There is much "hybridism" and "eclecticism", or even "syncretism" in the contemporary symbology concerning body, health, disease, treatment, cure, etc. Mechanistic corporeal representations (the "machine" body) can coexist with "bioenergetic" representations (the body seen as a more-or-less balanced organization of energy levels in circulation) in the same subject, not only in patients, but also in therapists. The interpretation presented, in this case, is that the diversity of coexisting cultural patterns in the cultural complexity denominated by some authors *post-modernity*, together with its fragmentary character, induce the subjects to the practice of a constant symbolical "bricolage", al-

though in a dynamic and semi-open universe of senses and meanings, organizing veritable “kaleidoscopes” of meanings, mutable according to the occasions, interests, or social limitations. The diversity of meanings present in present culture in relation to health care, its continuous recomposition and rearrangement in a dynamic whole so that they may be harmonized (“to make sense”) in the same time with the aspirations of the subjects and the social impositions, made us propose the kaleidoscope metaphor. It can be ascertained that there is not, consequently, “fidelity” to a single medical *rationale* in neither side of the relationship, since the patients can go from one to another according to the variation of their disease, and the senses they are attributing to it, and the doctors can also “conciliate” or “conjugate” therapeutic or diagnostic procedures from more than one rationality in their daily routine. There is, consequently, this further limit to medical rationality, as the *logos* of health, clearly observable *in the practice* of both patients and doctors.

Between medical rationalities and therapeutic practices

The third phase of the project had as its starting point (1997) the perception of this duality persisting between medical rationalities and therapeutic practices. The therapeutic practices, even though they may be *elements* in a specific dimension of a specific medical rationale, are frequently used in an isolated form, dislocated from a context of meanings to another, in theoretical/practical “collages” or *bricolages*, as already mentioned, obeying more an *empirical efficacy logic* than a theoretical coherence (or rationality) of the systems. This way, they propitiated the eclecticism, or even the syncretism of two distinct paradigms: an “indication” paradigm, based in the accumulation of single observations obtained from empirical experience of the agents, which is related to *intervention* (diagnosis and, *above all*, therapeutics), and an analytic paradigm, based in the accumulation of the conceptions and propositions of the medical systems, which provides the basis of the *theoretical* knowledge for the medicines. We could perceive, during the process of investigation, that great part of the success of the so-called “alternative therapeutics” or “complementary medicines”, which in fact refer to other rationality in health, is inseparable from the way that the therapist/patient relationship is conducted, the quest of the patient when he or she goes to a doctor or health care service, and the effective interaction between *therapist* and his patient. This interaction tends to develop a link in a shorter or longer period, originating a process that could be denominated, according to clinical tradition, *treatment*. In the development

of the process so established, elements generally disregarded by biomedical rationality as being linked to the subjectivity of the patients, such as feelings in relation to their sickness, isolation, pain, “irrelevant” symptoms since they do not find translation in “objective” records, or sensations of worsening or innocuousness of the procedures, are given great consideration for the ratification or correction of the ongoing treatment. Such procedure is now practically inexistent in biomedicine, at least in public health services (but also in the “standard” private health plans, totally submitted to market rules in Brazil), due to the role occupied by diagnosis and specialization in this rationality. It is necessary to stress that the epistemological centering of biomedicine rationale in the diagnosis of pathologies since the 18th century had as its fruit, in the end of the 20th century, the almost inviability of therapeutics. The procedures in this dimension of biomedicine are basically of two kinds: the **medicaments**, in great part symptomatic, often bearing adverse collateral effects, and **surgery**, which rose from an auxiliary *art* of medical *science* in the 18th and 19th centuries, to the hard core of therapeutics in the contemporaneity. So, it is not surprising that individual patients as well as the service user groups are more and more interested in other forms of addressing and conducting their illness processes. In Brazil these forms of therapeutic practices, called “alternative” or “complementary”, are getting more reachable for the service users, due to the *Sistema Único de Saúde* (Unified Health System).

Up to this moment we analyzed the question of the complex medical systems (“medical rationalities”) and alternative therapeutics, or complementary medicines, in the health field. Its coexistence, undeniable in contemporary culture, is linked to the “practical” recognition of the professionals (medical and not medical) of the therapeutic insufficiency of biomedicine, as well as the search for care and attention to its frail health by a growing part of the population. Both phenomena are inserted, in our opinion, in a specific, albeit wide, socio-cultural picture, which may be recognized as *pertaining to the medical order*, or to the socially legitimized institutions, knowledges and practices for dealing with the questions referring to diseases and sickness. In other words, it is a historical situation strictly related with the functions and roles of medicine in the contemporary society, and its transformations, proceeding from macro-structural factors (socio-economic and cultural), as well as the accelerated development of the structural characteristics (specialization, technologisation) of modern scientific medicine.

Going beyond the medical order

However, although the importance of these factors is undeniable, we must go beyond the examination of macro-structural questions of *medical order* to analyze the new therapeutic practices, as well as the “physical health care” activities, in development in the civil society, which do not have a referential directly linked to the classic health/sickness paradigm, but are associated to a “vitality” paradigm, now associated to *well-being*, now to youth and beauty, taken as values, a paradigm which becomes more distinct when we approach these practices and their practitioners. Our interest, from now on, is to examine how these practices are oriented by certain values, what are these values, and if these values are or not important for the transformation of the senses and meanings now attributed to health and life, for the relationship of the subject with his own being, corporeal and spiritual, and with other beings, as well as the transformation of dominant values in the society as a whole. Again, we must stress the recent (last two decades) proliferation of collective practices and of diversification of senses in health. The cultural complexity supposed by this configuration prevents us from reducing the meanings of the health activities to a single model (the *fitness* model, or the *wellness* model, for example) or to a single paradigm (health/sickness, or *youth/beauty*). To understand the diversity of senses and the plurality of models present in the contemporary practices is the first step to capture and interpret the presence of differentiated values informing these practices. As social scientists, we must avoid to judge such practices as excesses perpetrated by individuals, groups or collectivities, or condemning them as values of the capitalistic society. We believe that it is our part, in this context, to understand and interpret the place and “social functions” of such practices, considering the distinct values they embody, and the symbolic role they play in contemporary culture, *in its diversity and polyphony*, without restricting then to a single set of senses and values, or to a single paradigm.

Coherently we want to point to the difference between “therapeutics practices” and “collective health practices”. The first set of practices maintains their link to the health/sickness/disease paradigm, which approximates them to the medical institutions and knowledge, independently from their rationality. The “therapeutic practices” have a history, and frequently a *tradition* that may have centuries or even millennia of age. Even the “new age” therapies, bearers, in the last three decades of the 20th century, of the *counterculture* ideas, “translators” of ancient practices to the modern imagination, basically refer to the intervention in the processes of sickness/illness in individuals. They oppose to specific aspects of the biomedical *diagnosis* or *therapeutics*, playing an important role in the reconfiguration of what

may be designated as the “cure market”, partly occupying the social place left vacant by the biomedicine therapeutics, creating new actors, discursive practices, professional formations, disputations of discursive hegemony and *status*, always in *the health care field*. The proliferation of these practices and their variety, whose qualitative and quantitative evaluation are still indefinite, is an unequivocal fact of the last twenty years, as is its search of legitimacy by medical institutions. Our interpretation is that his proliferation comes from the search for *care and attention* in growing parcels of the population, considering not only the growth of “objective” diseases (presence of pathologies identifiable by biomedicine), but also such situations as *stress*, psychic isolation and suffering which put people in a situation of great vulnerability, even of *helplessness*, caused not only by the objective conditions of their existence but also by the *cultural values* of contemporary society. According to our point of view, these practices in great part *attend* to this subjective demand for care and attention, mainly in the middle layers of the population, since both therapists and patients are generally from the urban middle classes. These therapies attend individuals or groups, leaning to the model of medicines centered in the *subject* (as homeopathy, Chinese medicine, or Ayurveda), which aim at the recuperation of the identities of the people, their autonomy in face of the disease and medical procedures considered limiting or adverse (medicaments, orthopedics, alimentary restrictions and others.) and their social or familiar insertion. Some of them use the *arts* as a constitutive part of their procedures (music, theater, plastic arts, and dance) and only very recently began to take part in the institutional programs in health services, in urban Brazil. The senses and values generally conveyed by these practices, in their action and results, differ not only from those characteristics of the biomedicine model of diseases and their control, but also from health culture in general. Generally they aim to offer, as mentioned above, not only autonomy for thick people, as they try to reconstruct as much as possible their identity, hit by vital perturbation processes, as well as reiterate values of a life “in harmony with the whole”, that is: balanced mentally and physically, sympathetic in the familiar and social plane, not competitive or aggressive, relaxed, without cares, and, if not happy, at least humorous. The values of control, containment, *moderation*, a symbolic element important in the medical paradigm of pathologies, as we affirmed in a previous work, do not take part in this universe of senses and meanings. The so-called holistic therapeutic model has a *soft* paradigm, in the sense that it does not require from the subjects sacrifices for some “liberation” from their diseases. That does not mean that it does not require changes in conduct, values, and *life*.

Situating the sickness as a dynamic process of unbalance in the development of a *life*, the holistic therapeutic practices attribute the disease to the conjunct of behaviors, habits and values of the subjects, in all planes of life. As in biomedicine, the subject is “responsible” for his health state, although he is not considered guilty of his diseases. But the therapists of these practices often complain that the patients want “fast results” without any effort to change habits, attitudes or behaviors that cause diseases, reaffirming the moral imagination characteristic of the health/sickness field. In short, the new therapeutic practices occupy an important social role in contemporary civil society, filling the blanks of the biomedical system in the relation to the health/sickness process, and introducing senses, meanings, and values before suffering, sickness and the treatment and cure of diseases, distinct from the dominants.

Another plural universe of senses and meanings refers to the new so-called physical health practices in civil society, which are oriented by a paradigm that we denominated as the *vitality* paradigm, associated to the beauty/vigor/youth triad, that uses as the reference of health *fitness*, identified with the “beauty of the forms”, or *wellness*, generally seem as being balanced, or harmonized, or “being well with oneself”.

There is nowadays a trend to identify the practices and the practitioners of physical health activities with total adherence to fitness culture and to the dominant values of the capitalist culture, in the *media* as well as in the theoreticians in the health field. However, we could verify in the development of the Project, in its third phase, that fitness culture is only one universe of meanings among many, adopted by the practitioners, certainly oriented by the central values of contemporary individualism: the use of the body as a form of obtaining social status, consumerism as a prestige value and social differentiation and success as ‘the’ *value* for life. The activities practiced by the adherents of this universe of meanings and values are *specific*, and occur in social spaces which are also specifics, with specific practice “rituals”, where the rhythm, sound, body movements, expected results of the practice, age and social group of the participants are relatively restrict. They generally are students and/or beginners in competitive professional careers, almost always typical of recent capitalist activities, individuals of both genders between 15 and 35 years, that is, basically *middle class youths from the metropolis*. The “gym” academies are the privileged space for these group practices, and the activities involve many modalities of physical exercise, such as bodybuilding, the different forms of aerobics (nowadays diversified according to the objectives and rhythms), *spinning*, and “martial arts” or fights, such as judo, karate, etc.

Other practices equally turned to physical cultivation include sports, above all the risky and adventurous ones, and refer to the same values, that is, vigor, beauty and youth as synonyms of vitality, and consequently health, to be obtained by “winners”. However, it is necessary to understand that the cultivation of these values and the attribution of senses and meanings to the activities exerted by the practitioners are related with *what they do in the society* and, above all, with the *symbolic place* that they occupy in the contemporary culture. In other words: the contemporary social order *designates* this imaginary place to the middle class youth through its dominant values. For the middle-class youth, following these values and exalting them is to be *socially victorious* in contemporary culture. After the defeated revolutionary youths of the Sixties society, the last fighting losers of the Seventies, and the yuppies of the Eighties, came the *fitness cultists* of the Nineties. Universes of cultural senses and values succeeded with the passage of recent history, and some were lost, in the new capitalist culture, with the succeeding generations of young people.

Modern fitness culture has recent roots, in the Seventies, with the international campaign originated in the United States to prevent coronary diseases, through “go exercise”, or “get moving”, to prevent the aging of veins and arteries. Among us, the “get moving” started these values, rooted in the soil of the medical order through Doctor Cooper. Later, in the Eighties, the *fitness* enters in Brazil also through America, as a way of fighting obesity, already considered epidemic in America. The famous videotapes of Jane Fonda, then a very popular actress, encouraged “fitness” as the conservation of beauty and youth, synonym of health maintenance.

Consequently, it is not possible to separate the appeal of *fitness culture* among the youth from the emerging individualism with the yuppies in the stock market in the Eighties, uncompromised with values wider than their own success and accomplishment, and with the neoliberals of the Nineties, willing to open way at any price in the stock market of the so-called “new economy”. From this point of view, it is not possible to separate the cult of the “Biomechanic Apollo” from the triumph of the capitalism values among the youth. The youth is Narcissus’ mirror, where a rigid and aged society needs to see itself. We still believe, as we did a decade ago, that there are « in industrial societies, including the present Brazilian society, a continuous symbolical construction of the “youth” as a model of aspirations and conduct [...] basically aimed to assimilate him to the order, without integrating him, except in an imaginary place» (LUZ M. T.). Even with the continuously renewed invitation (above all from the media apparatus) to society to dive

in the mirage of this Narcissus mirror, not all health activities, even the *hardest* physical ones, are oriented by values of attaining bodily beauty and keeping the conservation of youth.

Final remarks: other universes of senses

The diversity of sectors of the society that look for them with specific objectives, proper to their insertion in society, their life phase and the recurrent vital and sociability need (contact with persons in the same age group or health condition) prevent us from making generalizations distanced from the survey. Nowadays, most of the practitioners of the so-called physical activities aged above forty starts the most diverse modalities, from bodybuilding to ballroom dance, from aerobics to tai chi chuan, through *medical indication*. Be it for organic diseases (diabetes, arthritis, osteoporosis, hypertension, obesity, etc), be it for “mental” problems (mainly depression, but also loss of self-esteem and isolation motivated by losses or separations), what we have heard in participant observation and in interviews is that almost always, behind a practice there is a medical advice. This indicates the existence of another universe of senses, linked to *prevention*, or to *health promotion*. Indeed, from the age of forty onwards, the almost totality of the practitioners wants to *preserve* or *recover* health. This is not necessarily separated from values of youth and beauty conservation, or from the senses of pursuit of wellness and happiness. These senses are not separated among the practitioners, nor among the physicians or therapists; what varies is the pattern of social relations established between the practitioners and their instructors, that may be compulsively individualistic and competitive, or a relationship of empathy, collaboration and, if not friendship, at least cordiality, establishing “focal solidarities” among the groups taking the activities as a starting point. This variation may also be observed according to the *kinds of activities* and their practitioners. Certain activities are more propitious to individualism or the quest for beauty and youth than others, which favor *solidarity and friendship* as consequent values. This diversity indicates, in our opinion, that among the practitioners there is the tendency to form “meaning or senses corridors” linked to the physical collective health practices of civil society. However, these meaningful corridors are not impermeable, and there can be, as in the case of health representation and practices, a certain eclecticism or cohabitation of senses and values. So, *health* can be seen as the *result* of the practices, but also youth, happiness, sociability, in short, *vitality*. The interviewed individuals, practitioners of different activities, use to say that they feel “much better”, that

they recover “the joy of living”, or that they feel “well disposed” (for work, for facing difficulties, for family life) after some time practicing this or that activity. This way, not only the fitness culture values, or even those related to the health/sickness paradigm (symptomatic improvement or normalization, regression of pathological states or pathologies) are present in the so-called physical activities. Values linked to personal wellness, to common living in family or at the work, to the transformation of life situations considered stressing, are linked to these activities. Often, those modifications are associated, in persons over forty, to changes of previous values: individualism, competition, consumerism, and obsession with success. It is possible to argue, with some reason, that those modifications are possible due to the age group of the practitioners. However, this only confirms what we have been trying to establish since the beginning of this paper: that there is a great *diversity* of senses, meanings and values associated to the multiplicity of the present practices and practitioners in collective health care. Some of these values are distinctly associated to the hegemonic culture and their values, as the individualistic cult of body beauty, the consumption of material goods as a way of social differentiation, the competition as a way of life and a way to reach *success*, considered as a value. Others associate to new forms of sociability and to new manners of being with themselves and others: if not sympathetic, at least cordial and friendly. In this sense, to identify the “physical” activities with the *fitness culture* is to impoverish the diversity of meanings continuously created in culture, and the *polyphony* of senses present in health culture.

Bibliography

- ANDRIEU Gilbert (1992), *Force et beauté. Histoire de l'esthétique en éducation physique aux XIX et XX siècles*, Presses Universitaires de Bordeaux, Bordeaux.
- ARNAUD Pierre (1991), *Le militaire, l'écolier, le gymnaste. Naissance de l'Éducation Physique en France (1869-1889)*, Presses Universitaires de Lyon, Lyon.
- BIRMAN Joel (1999), *Mal estar na atualidade. A psicanálise e as novas formas de subjetivação*, Civilização Brasileira, Rio de Janeiro.
- BOLTANSKI L. (1984), *As classes sociais e o corpo*, Graal, Rio de Janeiro.
- BOURDIEU Pierre (1989), *O poder simbólico*, Difel, Lisboa - Bertrand Brasil, Rio de Janeiro.
- CAMARGO Jr. K. R. (1997), *Representações de doença, saúde e seu cuidado na clientela de serviços ambulatoriais da rede pública do Rio de Janeiro*, “Série Estudos em Saúde Coletiva”, n. 149, 1997, pp. 5-13.
- CAMARGO Jr. K. R (2003), *Biomedicina, Saber e Ciência. Uma abordagem crítica*, HUCITEC, São Paulo.
- CAMARGO Jr. K. R - SABINO C. - CONTE F. T. - MARTINEZ D. S. - LUZ M. T. (1998), *Representações de doença, saúde e seu cuidado na clientela de serviços ambulatoriais na rede pública do Rio de Janeiro*, “Série Estudos em Saúde Coletiva”, n. 168, 1998, pp. 13-26.

- CANEVACCI M. (1993 [1990]), *A Cidade Polifônica*, trad. Cecília Prada, Studio Nobel, São Paulo [orig. ed.: *La città polifonica*, SEAM, Roma, 1990].
- CANEVACCI M. (1996 [1995]), *Sincretismos. Uma exploração das hibridações culturais*, trad. Roberta Barni, Studio Nobel, São Paulo [orig. ed.: *Sincretismi. Esplorazioni diasporiche sulle ibridazioni culturali*, Costa & Nolan, Genova, 1995].
- GINZBURG C. (1989), *Mitos, Emblemas, Sinais*, Companhia das Letras, São Paulo.
- GOLDENBERG Mirian (ed.) (2002), *Nu e Vestido. Dez antropólogos revelam a cultura do corpo carioca*, RECORD, São Paulo.
- LUZ H. S. - CAMPELLO M. F. (1997), *Homeopatia*, pp. 5-35, in LUZ M. T. (ed.), *VI Seminário do Projeto Racionalidades Médicas*, "Série Estudos em Saúde Coletiva", n. 151.
- LUZ Madel T. (1993), *Relações entre o adolescente e a sociedade atual: instituição, violência e disciplina*, "Série Estudos em Saúde Coletiva", n. 48, 1993, pp. 1-16.
- LUZ Madel T. (1995), *Racionalidades médicas e terapêuticas alternativas*, "Cadernos de Sociologia", vol. 7, dezembro 1995, pp.108-128.
- LUZ Madel T. (1996) *A Arte de curar x a Ciência das doenças. História social da homeopatia no Brasil*, Ed. Dynamis, São Paulo.
- LUZ Madel T. (1997), *Cultura contemporânea e medicina alternativas: novos paradigmas em saúde no fim do século XX*, "Physis", vol. VII, n. 1, 1997, pp. 13-43.
- LUZ Madel T. (2000 a), *La Salud en forma y las formas de la Salud: superando paradigmas y racionalidades*, in BRICEÑO Leon - MINAYO M. C. - COIMBRA Jr. (eds.), *Salud y equidad: una mirada desde las ciencias sociales*, Fiocruz - Laco, Rio de Janeiro.
- LUZ Madel T. (2000 b), *Medicina e racionalidades médicas: estudo comparativo da medicina ocidental contemporânea, homeopática, tradicional chinesa e ayurvédica*, in CANESQUI A. M. (ed.), *Dilemas e desafios das ciências sociais na saúde coletiva*, HUCITEC, São Paulo.
- LUZ Madel T. (2001), *Políticas de descentralização e cidadania: novas práticas em saúde no Brasil atual*, in PINHEIRO R. - MATTOS R. A. (eds.), *Os sentidos da integralidade na atenção e no cuidado à saúde*, IMS/UERJ - ABRASCO, Rio de Janeiro.
- LUZ Madel T. (2003), *Novos saberes e práticas em saúde coletiva: estudos sobre práticas corporais e saúde*, HUCITEC, São Paulo.



1.3 *Patients, doctors, information and the power of decision*

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Introduction

A central question, which is raised in the debates on the position of the patients in the health system and in doctor-patient relationships, relates to information about the illness and the treatments patients receive. The objective of providing such information would ostensibly be to give the patient some power vis-à-vis the doctor (LETOURMY A. - NAIDITCH M. 2000).

The contemporary Western patient is usually described as a person who is able to choose, to negotiate with the medical profession, to act as an informed patient, and to adopt the most reasonable health behaviours (MOUMJID-FERDJAOUI M. - CARRÈRE N.O. 2000; KHODOSS H. 2000). One speaks of the rise of an era of patients' autonomy. The studies on this topic make this claim based on the many texts promoting the right of the patient to information and the concept of informed consent. Such statements underlie the present concept of a "health democracy". This concept implies the redistribution of power in the field of health from professionals to nonprofessionals, and more particularly users of health care (RABEHARISOA V. - CALLON M. 1999, DODIER N. 2002, BARBOT J. 2002).

In the social sciences, the emergence and promotion of the concept of health democracy is explained by the disenchantment of many with the medical field (cf. AIACH P. - FASSIN D. 1994⁽¹⁾), and was brought to the forefront by the French conference – the "États Généraux de la Santé" in 1998 – where patient organisations reaffirmed their wish to receive complete and accurate information.

During this conference, the Prime Minister presented a declaration to take measures that would allow direct access of patients to their medical files. There were also many publications that asserted that the position of the

patient has known a true revolution in doctor-patient relationships. For example, Gillot writes that today «being sick doesn't mean any longer to give up its rights and its prerogatives, it is on the contrary to affirm its quality of user of the system of health and to take advantage of the rights which are related to it», and considers that «it is an important change in the social relations» (GILLOT D. 2000: 5) [my translation]⁽²⁾. According to Brocas & Coz, «the paternalism characterizing a certain form of relationship between doctor and patient is called into question by patients who are more highly educated, better informed and less submissive» (BROCAS A. - M. - COZ G. 2000: 10) [my translation]⁽³⁾. Today, public institutions and many observers in the field of health praise themselves for the situation of the contemporary patient, saying that he/she has now more power and that he/she can take his/her health in hand, because he/she is educated and informed.

However, we may wonder to what extent this change can be observed. Can we consider that the contemporary patient is truly given this decision-making power, which some authors credit him with? These questions are at the core of my paper because I will put some interrogation marks behind the concept of patient power. My first question is: Is information really shared within the doctor-patient relationship? This question undoubtedly has a Foucauldian accent because the power of medical doctors tries to affirm itself and to fight nozzles and nails against the supposed growing power of patients. Yet, I will show that the responsibility for this unequal sharing of power is not always due to the doctors alone and that it is, in reality, well shared. My second related question is if patients really claim their power in this relation. The analysis will lead us to conclude that doctors and patients have practices enmeshed in strong compelling cultural patterns, and lead us also to call in question the quasi consensual postulate in social sciences of the patient as an actor.

The texts and the law

The principle of information availability is posed in many legislative texts and many charters, such as the Code of public health, the medical Code of ethics, and the recommendations of the ANAES. For example, the L.1111-2 article of the Code of public health of March 2002 lays out that each person has the right to be informed on his/her health. In fact, it was not necessary to wait until the holding of the Etats Généraux de la Santé to find legislative texts that guarantee the patient's rights and in particular their

right to information: there are many texts and professional codes on the rights of patients, whether on the national level (Law Huriet 88, bioethic laws 94, the New medical code of ethics 95, the charter of the in-patient renovated 95) or on the international level (declaration on the patient's rights in Europe of WHO, etc.) (cf. KHODOSS H. 2000).

Article 35 of the medical code of ethics (of September 6, 1995) states that: «the medical doctor owes to the person whom he examines, whom he cares or whom he advises, honest, clear and adapted information on his state, and on the investigations and the cares he proposes to him» [my translation]⁽⁴⁾. Yet, if this text guarantees information, it allows for one exception; it stipulates indeed that: «However, in the interest of the patient and for legitimate reasons that the expert appreciates in conscience, a patient can be held in the ignorance of a serious diagnosis or prognosis (except whenever his illness exposes others to a risk of contamination)»⁽⁵⁾. The principle of information suffers then some transgressions, provided by the law itself.

Information is of increasing concern in our societies nowadays. The whole of the European health systems tends toward an increased respect of the individual patient's rights. It is well known that this situation was instigated by the questioning of the medical profession consecutive to the occurrence of medical scandals, which largely eroded the confidence patients placed in doctors and contributed to 'the crisis of legitimacy of medicine'.

The studies on doctor-patient relationships generally agree to recognize a radical change in the paradigm of this relation. Charles & al. (CHARLES C. - GAFNI A. - WHELAN T. 1999) identified three predominant models: paternalistic, shared and informed. The paternalist approach (that the author locates before the Eighties in the US) implies that the doctors assume the dominating role; the approach rests on the idea that they know what is best for their patients. This legitimation of medical control was buttressed by ethical codes, which urged medical doctors to act in the best interests of patients. In turn, this allowed both doctors and patients to expect that doctors (and not patients) should play the dominant role in the decision-making process. During the Eighties and afterwards, the credibility of this assertion was called into question. The informed model and the shared model of treatment decision-making were both developed in reaction to the paternalistic model. However, although Charles & al. (CHARLES C. - GAFNI A. - WHELAN T. 1999) assume that these two models (informed and shared) are distinct, they describe both of these new models of decision-making as resulting from the search for alternatives to the traditional paternalistic approach.

In a review of the scientific literature (mainly Anglo-Saxon) on the recent transformation of doctor-patient relationships made by Moumjid-Ferdjaoui and Carrère (MOUMJID-FERDJAOUI M. - CARRÈRE N.O. 2000), the authors present evidence for the transformation of this relationship in France through the use of legal and administrative texts, justifying this by the fact that scientific literature is not very developed on the subject. But can one adequately support such an argument using only legal texts? If these texts bear witness to an interesting change in the society, their use as an exclusive source to evaluate the reality of this transformation is not enough, though it is in itself an eloquent source. On close examination of the reality of the situation, one fails to establish such a modification in the doctor-patient relationship and above all to affirm that the patient is really informed.

This is the case within hospital-based medicine. The declarations on the necessary provision of information to the patient may rest on an ethical and political presupposition that information is an essential condition to the efficiency of a democracy. It indicates respect of the patient's autonomy and dignity. These declarations may also rest on a pragmatic point of view, since the provision of information to the patient contributes to the improvement of the quality of care (GHABI V. 2001). However, Ghabi notes that in a great number of cases, the written documents that the patient must sign aim more at protecting the doctor from the legal consequences of possible risks of treatment, than to inform the patient adequately. If the law relating to the hospital reform envisages the communication of all information contained within the medical file, there is no question in this law of actually giving the file to the patient. Rather it is the presentation of information by the practitioner, which is sought out (PONCHON F. 1998), based on the idea that the patient is unable to understand the contents of the file. If the claim of patient associations to view medical files without an intermediary led the minister to promise in 1998 a patient's direct access to his file, this is far from being realized. The provision of information to patients recommended by the texts is not so much an answer to ethical or therapeutic concerns as to a legal concern. It is very often because of the fear of prosecution that doctors inform their patients. If the goal of the legislative texts is to "cool down" associations of patients and their claims, they do not express a real will by the medical profession to make available, for the patients, information concerning their illness and their body, even though some of them agree it is better to pass information for therapeutic reasons. The model of shared decision itself seems to have been forged on the fear of lawsuits, more than based on the conviction of the doctors⁽⁶⁾. It

appears as if only legal reasons are at stake. The investigations on this topic show that doctors are often, insofar as it is not strictly required by the law, extremely reticent to give patients information on the state of their bodies and their care. If the declaration on the promotion of the patient's rights in Europe of 1994 would refer to the patient's right to be fully informed, on his health and on the risks and advantages that the medical acts entail (cf. PONCHON F. 1998), the communication of the patient's medical file is always done by the practitioner. My investigations reveal that many patients do not know their illness and their treatment, its risks and its consequences. In a way, the recommendations made by Hippocrates to hide things from the patient⁽⁷⁾ seem to be still used. Broclain notes the absence of search for consent in the routine examinations in a service of cardiology, and considers that a long way remains to be made for the autonomist paradigm⁽⁸⁾ to take shape in the practices of care (BROCLAIN D. 2001).

The issue of provision of information to the patient doesn't only amount to the issue of consent. It includes all that relates to the body and the health of the patient, the diagnosis and treatments, benefits and risks, and the action of prescribed medicines on their illness and their body. The gap between the texts of law and the reality of practices can be checked on various levels. For example, although the Code of Public health states that «any person has access to the whole of the information concerning his/her health held by professionals and establishments of health», information continues to be withheld from the patient. In the case of breast cancer screening as it is practised in screening centres the patient is forced to give the name of a doctor to whom the result will be communicated. The result of the screening is not communicated to the patient directly. This suggests that the patient is unable to deal with his life, his body, his health, and is incompetent to take the necessary measures. The refusal to recognize this capacity of the patient remains the strong marker of the paternalist model. It is a refusal orchestrated by the entire system of health and relayed or reinforced by health professionals.

Doctors and patients

The deficiency of information can also be observed within the framework of private consultation. In this respect, it is necessary to consider the real practices of the protagonists of this doctor-patient relationship. For example, a good part of what is called the misuses of pharmaceuticals is con-

nected to ignorance of the patients, an ignorance that is maintained by the French system of health and, more broadly, by its social and cultural context: there is a tendency, on the part of doctors, not to inform the patient and even to lie to him about the illness, treatment, its reasons and its risks. These considerations are based on the observation that the practice of lying is a recurring practice in the behaviours of the medical profession with regard to the patients, as for example the fact of lying on the possible side effects of the drugs to incite the patients to comply with the prescription (FAINZANG S. 2002).

Many physicians to whom a general practitioner has sent a patient, rather than inform the patient of their impressions during the consultation, merely address a mail to their colleague without informing the patient about the diagnosis, or they will refuse to answer the patient's questions. Consequently, how can doctors claim that they guarantee the patient's autonomy when they refuse to disclose information relating to his own body and to his therapy? Therefore, if some social classes are denied the material conditions of the access to care, they are also denied a possibility of being in charge of their own health.

The fact that information is differently dealt with and communicated to patients (for ex., see GORDON D. 1991, for a comparison between Italy and the US) shows the social and cultural (and of course always historical) nature of information and of the reasons which underlie diffusion or retention. Today, in France, sharing of information continues to be perceived as of little importance considering the competence of the practitioner and the incompetence of the patient.

I do not mean that doctors and patients are necessarily antagonists, that is to say that they would be in a relationship where the first ones would always seek to keep information for themselves, and where the second ones would always seek to acquire it. Diverse studies on associations of ill persons have concluded that the patient is active, an actor dealing with his health problems and his therapy (LASCOURMES P. 1998, RABEHARISOA V. - CALON M. 1999). However, this is not the most common behaviour in patients. This perception of the "contemporary patient" is extrapolated from the existence of relatively marginal associations. Of course, the associations bear witness to this will to react against this paternalist model. The federation of these associations into a "Collectif inter-associatif sur la santé" (which gathers associations of families, consumers, ill or handicapped persons) reveals their will to establish a counter-power vis-à-vis the medical power, by giving an institutional role, namely a direct participation, to the user. However, few people are in such associations. Thus, one can say that

the associations are not representative for the majority of patients. Besides, the fact of belonging to an association of which the national office or the head department expresses some claims doesn't imply necessarily that the patient has, personally, the same attitudes. Though the associations of users clearly defend the right of patients to information (LASCOURMES P. 1998) and convey a model of a patient-actor (KHODOSS H. 2000) who benefits from his right to decision, the question is to know to what extent the majority of the patients really wish to exercise this right. (DEGNER L. F. - SLOAN J. A. 1992). This question leads us to wonder whether the patient is really an actor, as is asserted by Rabeharisoa & Callon (RABEHARISOA V. - CALLON M. 1999) and Barbot (BARBOT J. 2002). To be an actor is to be active. It is interesting to note that according to Blanchard & al., though 92% of the patients admitted to hospital with cancer would prefer that all the information is given to them, whether it is good or bad, their wish to have every piece of information doesn't necessarily result in active behaviour of seeking information when they meet the doctor (BLANCHARD C. G. - LABRECQUE M. S. - RUCKDESCHEL J. C. 1990) (cf. also BEISECKER A. E. - BEISECKER T. D. 1990). According to these authors, this discrepancy is related to the patients' vulnerable situation or fear that their request for information would be interpreted by the doctor as a lack of trust.

It is naïve to speak of the "contemporary patient", without taking into account his social and cultural characteristics. It is clear that information is mainly given to the persons who are socially in the position not only to understand it, but also to ask for it, and who are the most inclined to confront the doctor and the authority he embodies. A recent study on the behaviours of patients towards their medicines, their prescriptions and their doctors, shows that even people from the same social milieu have different ways of behaving, which are related to their culture, namely religious family belonging or origin, and that these underlying influences are articulated in a certain relationship to power and authority (FAINZANG S. 2001). More concretely, it seems that many patients put themselves completely in the hands of their doctors and tend to deprive themselves of control over their body. This happens more in the milieus of catholic origin than of protestant origin, as members of the first do not grant the same value to autonomy and to dealing with their body and their illness. On the whole, and probably because the French population is much more marked by catholic culture than by protestant culture, a great number of patients do not read the leaflet of the medicines they take, do not draw their doctor's attention to their possible allergies if the latter doesn't ask, and, thinking that it is the role of the doctor to know what he has to do, delegate a great

part of their possibilities of choice and decision to medical authority⁹. Therefore, one must not put all responsibility on the medical system nor on the medical professionals; the patients do play a part in this situation. There are contrasted observations on the percentages of patients who declare they want to participate in decisions or that they prefer leaving this responsibility to the doctor (ENDE J. 1989, BEISECKER A. E. - BEISECKER T. D. 1990). For Ende (1989) the seriousness of the illness, the age, the genre and education have a strong predictive value regarding the seeking for information; for Beisecker & Beisecker (1990), the socio-demographic characteristics and the state of health do not explain the differences among the patients. Other factors exist: Baider & al. insists on the ethical and cultural characteristics of the patients, especially as demonstrated by a study on the attitudes of Israeli versus Russian patients in cancerology (BAIDER L. - EVER HADANI P. - DE NOUR K. 1995)

If the paternalist model has not disappeared, it is also because patients have been taught, especially in the context of catholic culture, to conform to an authority, and namely to have a certain passivity and a certain submissiveness towards medical authority. It is interesting to note that many of those who resort to the Internet, do so because they do not dare to ask their doctor for the explanations they'd like to have. Many authors think that the Internet contributes to the emergence of a new patient role. Some go as far as speaking of an "expert-patient" (HARDEY M. 2004), insofar as, the patients use the Internet to gather information. To Hardey, this approach of the expert knowledge of citizens is inscribed in the vast movement of democratisation of science, connected to the loss of trust in the power of science and in the capacity of experts to save lives and bodies. Of course, a growing number of persons use the Internet as a source of information on health, expressing a real will to gather information, but this information is not often acquired in the framework of the relationship with the doctor. Patients confess that they often do not dare to ask for it. The Internet continues to be perceived in an ambivalent way by people who resort to it: some view it as a source of authority competing with that of their doctor in the same way as television (some spectators not knowing to distinguish what is information and what is advertisement), while others say that they consult the Internet out of curiosity but that they only believe what their doctor tells them⁽¹⁰⁾. Here, the doctor remains the expert likely to confirm or to invalidate the information obtained elsewhere, as he sometimes does, with the content of the leaflets (FAINZANG S. 2002). Another issue is that of the reservations or even the reticence of some doctors towards the recourse and the use of the Internet by their patients. One may

ask whether this reservation or reticence is due to the fear that this recourse makes the consultation less necessary because patients are able to obtain medicines without prescriptions. Or does the reluctance stem from a real concern of wrongly understood information: “*It's terrible! We have to repair the damages afterwards !*”, some doctors lamented during my investigations.

The issue of information availability extends beyond the sole framework of the doctor-patient relationship. The problem of the access to information, a necessary condition of access to care and health, can be studied on other levels. For example, there is no other pharmaceutical information than that given by laboratories. The pharmaceutical industry is the main actor in the production and diffusion of medical information, and only some data resulting from clinical trials (achieved in order to obtain the authorization of commercialisation) are used in the commercial promotion of these products to doctors and patients (cf. MINTZES B. 2001, LEJEUNE S. 2002, COLLIER J. - IHEANACHO I. 2002). An important part of the responsibility for this belongs to the State, which doesn't provide any neutral and independent information on pharmaceuticals ¹¹. The medical doctor is also, in part, a victim of this bad information (“Revue Prescrire”, 1999). In this respect, the situation today is not exclusively that of an omnipotent doctor in front of a powerless patient, who would be a victim according to the “paternalist” model. It is rather that doctors and patients together are victims of pharmaceutical industry. Some doctors are aware of this power, as a recent Website called <Healthy Skepticism> proves. Doctors no longer have complete power, even though some fight to regain it, through adapted information (see <http://www.healthyskepticism.org/index.htm>). The desperate struggle for information is nowadays one of the major issues of our healthcare system.

Conclusion

It is obvious that information is an issue where shared power is at stake (DELCEY M. 2001). This issue is differently dealt with depending on the pragmatic (that is therapeutic) or on the ethical (that is political) level. However, if its legitimacy and usefulness is now recognised by the law, the reality of the doctor-patient relationship shows it is not recognised on a practical level. It is illusory to believe that contemporary patients enjoy all the conditions which would allow them to make choices, since, against current ideas of “enlightened patients”, society doesn't give them the information that is the prerequisite.

The difficulties are many. For Lahoute, «If the rights of the users of the health system are well framed by legislation, the main problem is that of the application of these rules» (LAHOUTE C. 2000: 17) [my translation]⁽¹²⁾. The author seems to see only a difficulty of application of the legislation in the civil society. Yet, the obstacles are not only in the juridical difficulties or delays. They are also cultural. There seems to be, among healthcare professionals, more professions of faith and declarations of intention on the necessity to inform patients than effective behaviours attesting this will to inform them. In spite of these declarations, one notices strong resistance from doctors as well as from patients, calling into question the postulate of a structural evolution in the doctor-patient relationship. Beyond the progress made possible by the action of patients' associations, the new practices of some medical professionals and the law on the necessity of information disclosure, it appears that doctors and patients have behaviours deeply rooted in strongly marked cultural patterns, and rest on values which are conflicting with the democratic carrying-out of information provision or seeking. There are social and cultural obstacles to health democracy.

I wish also to call into question the so-called "working-out" of the logics which prevailed in the previous model of this relationship; not in order to argue that things have not changed, but to acknowledge that this model, resting on claims and rights to which the behaviours and practices do not echo; is desperately gasping for a new type of relationship. The issue of medical power must be raised in new terms⁽¹³⁾. The point is to stress the new configuration in the doctor-patient relationship. If it is true that power is no longer exclusively in the hands of doctors and that it has become an object of covetousness between doctors and patients, it is also obvious that this power is unequally used, held or even claimed by patients. In this respect, the notion of "citizen" attached to that of "health democracy" is reducing insofar as it obliterates the social and cultural diversities on this matter, presenting patients as having a homogeneous statute in front of doctors.

These reflections lead me to question the conclusions of some studies in social sciences, which sometimes seem to convey more the phantasms of their authors than the description of reality. Declarations such as of Giddens' (GIDDENS A. 1994) on information, negotiation and decision seem to place us in front of the vision of a coming golden age for the patient, a patient who would be informed and reflexive. Is the patient really this active individual, knowing how to choose and negotiate? Observation of real situations reveals that information on health often remains in the hands of doctors. If the role of anthropology is to dismantle myths and to ques-

tion “evidences”, one should wonder if the idea of a “changing medical context” is not partly a myth⁽¹⁴⁾, and ask more shrewdly what is really “changing”. Maybe the nature of the change is not so much in the statute of patients as the discrepancy between the values conveyed by the notion of “health democracy” and the values that underlie the concrete behaviours of the protagonists in doctor-patient relationships.

Notes

⁽¹⁾ These authors evoke the shift of confidence to suspicion and doubt, and the crisis of legitimacy, which medicine has undergone

⁽²⁾ «Etre malade, ce n'est plus abandonner ses droits et ses prérogatives dans l'urgence et la résignation; c'est au contraire affirmer sa qualité d'usager du système de santé et faire valoir les droits qui lui sont afférents. Il s'agit là d'une mutation importante des relations sociales».

⁽³⁾ «Le paternalisme caractérisant une certaine forme de relation entre médecin et malade est remis en cause par les attentes de patients plus instruits, mieux informés et moins soumis».

⁽⁴⁾ «Le médecin doit à la personne qu'il examine, qu'il soigne ou qu'il conseille, une information loyale, claire et appropriée sur son état, les investigations et les soins qu'il lui propose».

⁽⁵⁾ «Toutefois, dans l'intérêt du malade et pour des raisons légitimes que le praticien apprécie en conscience, un malade peut être tenu dans l'ignorance d'un diagnostic ou d'un pronostic grave (sauf dans les cas où l'affection dont il est atteint expose les tiers à un risque de contamination)».

⁽⁶⁾ It will be noted that concerning the “informed consent”, the medical doctor must prove he gave to his patient a honest information, clear and adapted on the risks of investigation or the cares that he proposes to him, in order to enable him to give an informed consent or refusal to them (judgment of the supreme court of appeal of October 14, 1997).

⁽⁷⁾ «We will make any thing with calm, address, hiding to the patient, while we act, the majority of things, giving him with gaiety and serenity the encouragements which are appropriate [...], not letting him foresee anything of what will happen nor of what threatens it: because more than one patient was put at any end by this cause, i.e. by a prognosis where he was told what was to happen or what was threatening» [my translation] («On fera toute chose avec calme, avec adresse, cachant au malade, pendant qu'on agit, la plupart des choses; lui donnant avec gaieté et sérénité les encouragements qui conviennent [...], ne lui laissant rien apercevoir de ce qui arrivera ni de ce qui le menace: car plus d'un malade a été mis à toute extrémité par cette cause, c'est-à-dire par un pronostic où on lui annonçait ce qui devait arriver ou ce qui menaçait») (HIPPOCRATES 2001).

⁽⁸⁾ The autonomist model is supposed to have replaced the paternalist model; it is the model according to which the patient is in right, as an adult citizen, free and responsible, to refuse the decisions of his doctor and to assume, provided that he has an appropriate information, the role of final decision-maker of the cares which regard his case (BROCLAIN D. 2001).

⁽⁹⁾ The use of the term “culture” doesn't imply that we must occult the social, economic and political realities which underlie the behaviours of patients towards their doctors. There are of course other determinants, such as gender, age, class, education, etc. which make the issue of agency a very complex one. But the issue of culture sometimes tends to be neglected on the motive that anthropological research has suffered from the fashion of culturalism and from its tendency to essentialise the realities that are observed. A right criticism has opposed omission to culturalism , on the grounds that it neglects the social realities and namely the social disparities and the historical context. However, rather than submit to this tendency to essentialize social phenomena and to consider them as founded on a reality given for ever, we can have a dynamic conception of culture and see the cultural context in which health behaviours develop as being in perpetual

construction, articulated to other dimensions no less dynamic such as the relationship to the body, to the Other, to knowledge or to power.

⁽¹⁰⁾ Would the Internet be as the horoscope is for some people? Something they regularly consult while saying they don't believe what it says?

⁽¹¹⁾ Many works – for ex. VIAL A. 1999 – show that medical and pharmaceutical information is completely submitted to the requirements of marketing, a situation all the more harmful as they are substances, which are not deprived of iatrogenic risks.

⁽¹²⁾ «Si les droits des usagers du système de santé sont bien encadrés par la législation, le problème essentiel est celui de l'application de cette réglementation».

⁽¹³⁾ Things are complex: how to understand for example the discrepancy between the discourses of some patients (such as: "Doctors do not want to inform us"), and, as a counter-balance, the discourses of the doctors ("patients don't want to know"). In this respect, the position of the anthropologist is to take both discourses as valid and both parties as right. He must merely try to understand what is going on in this discrepancy and how concretely achieved are the use, the seeking for, the divulgation or retention of information. In this respect, social sciences and particularly anthropology should investigate the concrete context in which such notions as the "education of the patient" are used, when the social and cultural environment reveals that, in a complicity between professionals and patients, information and decision remain in the hands of the ones and are withdrawn from the others.

⁽¹⁴⁾ In this respect, we can but agree with Christine Hogg when she stresses the myth of the patient as partner and as consumer: « There is a new myth, that patients can be partners with government, professionals and pharmaceutical companies» (HOGG C. 1999: 171).

Bibliography

AIACH P. - FASSIN D. (1994), *Les métiers de la santé. Enjeux de pouvoir et quête de légitimité*, Anthropos, Paris.

BAIDER L. - EVER HADANI P. - DE NOUR K. (1995), *The impact of culture on perceptions of patient-physician satisfaction*, "Israeli Journal of Medical Science", n. 31, 1995, pp. 179-185.

BARBOT J. (2002), *Les malades en mouvements. La médecine et la science à l'épreuve du sida*, Balland, Paris.

BEISECKER A. E. - BEISECKER T. D. (1990), *Patient information-seeking behaviors when communicating with doctors*, "Medical Care", n. 28, 1990, pp. 19-28.

BLANCHARD C. G. - LABRECQUE M. S. - RUCKDESCHEL J. C. (1990), *Information and decision-making preferences of hospitalized adult cancer patients*, "Medical Care", n. 28, 1990, pp. 58-78.

BROCAS A. M. - LE COZ G. (2000), *Présentation du numéro*, "Revue Française des Affaires Sociales", n. 2, 2000 (numéro spécial: *La démocratie sanitaire*), pp. 9-14.

BROCLAIN D. (2001), *La place de la personne hospitalisée dans la décision en cardiologie*, "Rapport pour la Fondation de l'Avenir", Paris.

CHARLES C. - GAFNI A. - WHELAN T. (1999), *Decision-making in the physician-patient encounter : revisiting the shared treatment decision-making model*, "Social Science & Medicine", n. 49, 1999, pp. 651-661.

COLLIER J. - IHEANACHO I. (2002), *The pharmaceutical industry as an informant*, "The Lancet", vol. 360, n. 9343, 2002, pp. 1405-09.

DEGNER L. F. - SLOAN J.A. (1992), *Decision-making during serious illness : what role do patients really want to play?*, "Journal of Clinical Epidemiology", vol. 45, n. 9, 1992, pp. 941-950.

DELCEY M. (2001), *Quelle information pour permettre un exercice effectif des droits des malades?*, "Actualité et Dossier en Santé Publique" (dossier: *Droit des malades, information et responsabilité*), n. 36, 2001, pp. 56-57.

- DODIER N. (2002), *Recomposition de la médecine dans ses rapports avec la science*, "Santé Publique et Sciences Sociales", n. 8-9, 2002, pp. 37-52.
- ENDE J. (1989), *Measuring patients desire for autonomy. Decision making and information seeking preferences among medical patients*, "Journal of General Internal Medicine", n. 4, 1989, pp. 23-30.
- FAINZANG S. (2001), *Médicaments et Sociétés. Le patient, le médecin et l'ordonnance*, Presses Universitaires de France, Paris.
- FAINZANG S. (2002), *Lying, secrecy and power within the doctor-patient relationship*, "Anthropology & Medicine", vol. 9, n. 2, 2002 (special issue: VAN DONGEN E. - FAINZANG S., *Towards a Medical Anthropology of Lying*), pp. 117-133.
- GHABI V. (2001), *Information des usagers*, "Actualité et Dossier en Santé Publique" (dossier: *Droit des malades, information et responsabilité*), n. 36, 2001, pp. 36-43.
- GIDDENS A. (1994), *The Constitution of Society*, Polity Press, Oxford.
- GILLOT D. (2000), *Sur la démocratie sanitaire*, "Revue Française des Affaires sociales", n. 2 (*La démocratie sanitaire*), 2000, pp. 5-7.
- GORDON D.R. (1991), "Culture, Cancer & Communication in Italy", pp. 137-156, in PFLEIDERER B. - BIBEAU G. (eds.), *Anthropologies of Medicine*, "Curare", n. 7, 1991.
- HARDEY M. (2004), *Internet et société : reconfigurations du patient et de la médecine?*, "Sciences Sociales et Santé", vol. 22, n. 1, 2004, pp. 21-43.
- HIPPOCRATE (2001 [1999]), *L'art de la médecine (De la Bienséance, 16)*, Flammarion, Paris.
- HOGG C. (1999), *Patients, Power and Politics. From patients to Citizens*, Sage Publications, London - New Delhi.
- KHODOSS H. (2000), *Démocratie sanitaire et droit des usagers*, "Revue Française des Affaires Sociales", n. 2, 2000 (*La démocratie sanitaire*), pp. 111- 122.
- LAHOUTE C. (2000), *Droit des usagers du système de santé. De la réglementation à la pratique*, pp. 17-24, in CRESSON G. - SCHWEYER F. X. (eds.), *Les usagers du système de soins*, Editions de l'École Nationale de Santé Publique, Rennes.
- LASCOUMES P. (1998), *Le malade au centre... et les professionnels au milieu*, "Politique Santé", n. 4, 1998, p. 25.
- LEJEUNE S. (2002), *Information médicale: l'inquiétante mainmise de l'industrie*, "Medhermes", novembre 2002 [www.medhermes.com].
- LETOURMY A. - NAIDITCH M. (2000), *L'information des usagers sur le système de soins: rhétorique et enjeux*, "Revue Française des Affaires sociales", n. 2, 2000 (*La démocratie sanitaire*), pp. 45-60.
- MINTZES B. (2001), *Doctor, about that medicine I saw advertised...*, [http://www.inmotionmagazine.com/hcare/mintzes.html].
- MOUMJID FERDJAOUI N. - CARRÈRE M.O. (2000), *La relation médecin-patient, l'information et la participation des patients à la décision médicale: les enseignements de la littérature internationale*, "Revue Française des Affaires Sociales", n. 2, 2000 (*La démocratie sanitaire*), pp. 73-88.
- PONCHON F. (1998), *Le secret professionnel à l'hôpital et l'information du malade*, Berger- Levrault, Paris.
- RABEHARISOA V. - CALLON M. (1999), *Le pouvoir des malades. L'association française contre les myopathies et la recherche*, Presses de l'École des Mines, Paris.
- REVUE PRESCRIRE (1999), *Visite médicale: le bilan accablant du Réseau d'observation de la revue Prescrire*, "Revue Prescrire", vol. 19, n. 193, 1999, pp. 226-231.
- VIAL A. (1999), *Information e(s)t promotion*, "Actualité et Document en santé publique", n. 27, 1999, pp. 65-67.



1.4 *Los derechos del "otro"*

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Desde que trabajo como etnógrafa sobre aspectos relacionados con la enfermedad y la discapacidad me he visto confrontada a menudo con cuestiones derivadas de los derechos de las personas cuando se encuentran enfermas o de las personas con discapacidad. He revisado las declaraciones de derechos que los Estados e instituciones proclaman, las reivindicaciones que los grupos concernidos defienden para ampliar o especificar esos derechos y he visto cómo el resultado de sus reclamaciones ha tenido alguna repercusión en las sucesivas reformas legislativas. Sin embargo, *grosso modo*, me voy dando cuenta, a través de la observación etnográfica de que en el momento en que alguien se ocupa de otra persona (de un igual) aquél usurpa, ignora y hasta viola esos derechos tan primorosamente descritos en las formulaciones. Describiré algunas de esas situaciones y contextos que surgen de la práctica etnográfica para ilustrar la idea para luego tratar de responder a los porqués.

No soy jurista y conozco poco las leyes, sus mecanismos y el grado de cumplimiento que se les debe según su rango. Se esgrimen ante situaciones de injusticia o se enarbolan como amenaza contra quien las viola. En cualquier caso, también se, como ciudadana, que muchas de ellas, sobre todo las que rigen aspectos menores (por ejemplo el código de circulación) son violadas con mucha frecuencia aunque menos veces son sorprendidos y castigados los infractores. Sin embargo el infractor de tráfico sabe perfectamente cuándo está vulnerando una norma y procura evitar que le vean haciéndolo; si le sorprenden en flagrante delito acepta – no sin quejarse – la sanción y, si es económica, le duele. No obstante en otros ámbitos de la vida, a su vez regidos por códigos y normas, los infractores no se sienten tales, desconocen la existencia de la regla y, en muchas otras ocasiones, lejos de sentirse culpables, acusan a la víctima de provocar el incidente.

Mientras escribo, pienso que el lector evocará, por ejemplo, a las mujeres víctimas de violencia doméstica: el maltratador no se considera como tal

(sólo le dice a la mujer qué debe hacer y no hace); no sabe (o dice no saber) que a él no le corresponde ni juzgar ni castigar a un ser (presuntamente) querido y manifiesta abiertamente que es la mujer quien provoca la situaciones, o le enardece hasta el punto de hacerle montar en cólera. Ese es el ejemplo extremo. Pero hay otros ejemplos donde la violencia no suele mediar en el trato, donde el daño es menos perceptible, pero donde su recurrencia me sigue sorprendiendo. Y preocupándome.

En el terreno de la enfermedad y de la discapacidad me encuentro, con demasiada frecuencia, con esas violaciones de la norma que en escasas ocasiones son denunciadas. Cuando una persona no puede ocuparse de sí misma y cede parte de su autonomía a terceros por edad, por enfermedad o por discapacidad, los 'otros' se sienten absolutamente dispuestos a incrementar su vulnerabilidad usurpándole sus derechos. Aparentemente funcionaría como un procedimiento compensatorio: "si yo me ocupo de ti, a cambio y para compensar mi esfuerzo, no menciones cuáles son tus derechos: a mis efectos los acabas de perder".

Tiempo atrás ilustré algún artículo con ejemplos relacionados con esos derechos extraídos de mi experiencia de campo en las salas de hospitalización¹. Los enfermos, en los hospitales del Estado Español, pueden regirse, en primer lugar por los derechos que ampara la Constitución (1978) y de forma específica por los que describe la Ley General de Sanidad (1986) así como por las derivadas de los convenios europeos. Ahora bien, determinadas Comunidades Autónomas del Estado, entre otras Catalunya, disponen de leyes de aplicación territorial sobre el derecho a la información, a la autonomía del paciente y al acceso a la documentación clínica². En el nivel inferior de la pirámide se encuentran las cartas de los derechos de los enfermos de los hospitales. La información no falta: los pacientes disponen de ella porque a su ingreso se les facilita en un tríptico; los profesionales de la salud están obligados a conocerla y, por supuesto, a respetarla. ¿Qué ocurre? ¿Cuáles son los derechos vulnerados? ¿Hasta qué punto se respetan las normas? ¿Los enfermos se quejan si se vulnera su libertad? ¿Si la queja prospera (lo que no suele ocurrir para temas menores), tiene alguna repercusión?

¿Cuáles son los derechos vulnerados?

Uno de ellos es el *derecho al respeto de la personalidad, de la dignidad y de la intimidad sin ningún tipo de discriminación*. En el proceso que sigue a un ingreso hospitalario la despersonalización suele instaurarse a poco de

entrar, cuando el enfermo deja de ser un individuo para convertirse en un número: el de su historia clínica o el de su habitación. Toda institucionalización forzosa implica cierta pérdida de identidad sin embargo cuando el enfermo es diagnosticado además de perder el nombre se convierte en una patología o, en el mejor de los casos, su individualidad queda reducida a una parte de su anatomía. Susan Di Giacomo cuenta que un amigo suyo, a su vez antropólogo, cree que tener un cáncer es como ser negro: «una única característica te define al completo» (DI GIACOMO S. 1987: 319). Di Giacomo argumenta que la estandarización y la despersonalización del paciente se racionaliza, entre el personal sanitario, como necesaria para el funcionamiento eficiente de las instituciones y en beneficio de los pacientes (DI GIACOMO S. 1987: 322). De este modo, en las Unidades de Cuidados Intensivos (UCI) o en las de aislamiento la despersonalización es extrema agravándose con la privación del contacto físico, la ausencia de efectos personales y la incapacidad de ser comprendido, lo que supone asumir el "no ser" y contentarse con el "estar" .

El derecho a la intimidad prácticamente no existe en el ámbito hospitalario a no ser que el propio paciente o su red social organicen adaptaciones secundarias para evitar el exhibicionismo forzoso. Todo enfermo debe asumir que si permanece encamado, todas y cada una de sus intimidades físicas y psicológicas serán automáticamente convertidas en actos públicos. Sus miedos y sus angustias tendrá que compartirlos con desconocidos. Deberá a su vez desnudarse física y moralmente ante extraños en cualquier momento del día, porque tiene el estatus de enfermo y por tanto se verá obligado a olvidar el pudor. La ausencia de intimidad produce mayor sensación de vulnerabilidad en el enfermo.

Los usuarios de la sanidad pública también tenemos *derecho a conocer a los profesionales del equipo de salud y a reconocer la forma de identificar al personal sanitario*. Todos podemos y debemos saber qué cirujano fue el que nos operó. No obstante, el personal sanitario olvida que es un deber para ellos darse a conocer antes de iniciar la relación con el enfermo. Sólo una bata blanca o pijama verde acredita al portador como 'sanador', porque en los hospitales públicos españoles casi nadie lleva placa de identificación cuando sería prudente hacerlo por una cuestión de seguridad interna. En ningún otro tipo de relación profesional sería aceptable un trato íntimo sin que las partes se den a conocer porque en el hospital únicamente el enfermo debe estar identificado en todo momento. Desconocer a quien nos atiende también genera vulnerabilidad y dependencia.

En los países de Europa del Sur no existe una tradición de reclamación así que se ejerce poco y mal el *derecho a utilizar la vías establecidas para*

presentar sugerencias, quejas y reclamaciones. A los enfermos agudos les da miedo la lucha reivindicativa en ese terreno: muchos desconocen sus derechos y/o aceptan la sumisión absoluta por temor a ser tratados peor e incluso separados del sistema⁽³⁾. En cierto sentido, como país con una demasiado reciente (unos quince años) política de “salud para todos”, algunos ciudadanos creen estar recibiendo unos servicios que – entre comillas – “merecen pero no pagan” por lo que no suelen quejarse formalmente. Al desconocimiento y a la falta de costumbre hay que sumar la ignorancia de muchos y bajo nivel de instrucción de otros así como la pasividad, culturalmente aceptada, que se espera del enfermo. En los hospitales nos dicen: “tu descansa, que nosotros nos ocupamos de todo”. Pero en el terreno de la salud “desocuparse” de lo que nos ocurre tiene sus riesgos. Ahora bien, otra de las razones por las que los ciudadanos evitan la queja es porque aun formulándola, en muy escasas ocasiones, ésta tiene efecto.

El paciente tiene *derecho a recibir información relacionada con su proceso* de forma completa, continuada, verbal y escrita en un lenguaje comprensible. Es un derecho que se recoge ampliamente sin embargo es uno de los que más se vulnera. Los médicos suelen inquietarse cuando el enfermo realiza preguntas porque interpretan que se está cuestionando su profesionalidad cuando el enfermo se limita a tomar precauciones⁽⁴⁾. En la consulta de su oncólogo, Susan Di Giacomo (DI GIACOMO S. 1987: 321) estuvo cerca de veinte minutos argumentando datos relativos a supervivencia y estrategias de tratamiento en el cáncer linfático. Llegado un punto del monólogo el médico la interrumpió sentenciando que tal vez «ser un experto en su propia patología podría llegar a ser psicológicamente perjudicial para el enfermo». El enfermo no ‘debe’ saber.

A veces el problema no es la concreción de las respuestas sino la forma cómo se anuncian las malas noticias. Otras, se plantean los diagnósticos como indiscutibles omitiendo al enfermo su derecho a una segunda opinión. Algunos enfermos ‘esconden’ sus visitas a otros especialistas para consultar un primer diagnóstico como si hacerlo fuera poco menos que un delito. Y no ha sido hasta el verano de 2003 que, en Catalunya, se ha aprobado una normativa que permite la libre elección de médico. La legislación actual sobre derecho a la información mejora las normas anteriores de carácter estatal porque, por ejemplo, permite que el paciente pase a ser el titular de pleno derecho a la información, a diferencia de las anteriores leyes sanitarias que otorgaban tal derecho en plano de igualdades a familiares y allegados. Ahora bien, la ley reconoce también el derecho a no ser informado (Vv. AA. 2001: 3).

Las historias clínicas pueden (por ley) y deben (por rigor) incluir un "documento de voluntades anticipadas" ⁽⁵⁾. Este tipo de documentos favorecen la participación del enfermo en la toma de decisiones ampliando *el derecho a la autonomía del paciente* así como allanando el camino del *derecho a morir con dignidad*. En esa línea, el paciente también tiene *derecho a dar su consentimiento* ante cualquier tipo de intervención siempre y cuando haya sido debidamente *informado*. El consentimiento informado garantiza la autonomía del individuo porque subraya las decisiones sobre su propio cuerpo ⁽⁶⁾. Si bien este último documento se utiliza sin reticencias porque su inexistencia en caso de negligencia sería prueba irrefutable, aún es poco conocido el derecho a incluir en la historia clínica el documento de voluntades anticipadas. No es extraño que quien lo solicita sea tildado de excéntrico (por lo infrecuente), y de desconfiado (de la eficacia del sistema de salud) porque *espanta* (por su asociación con la muerte) a quien actúa de testigo o a quien debe incluirlo en la historia.

En otro ámbito muy distinto, el de la vida laboral de las personas con discapacidad, concurren situaciones estructuralmente parecidas. Entre las personas con discapacidad que trabajan o desean hacerlo, el ejercicio de un derecho común a todos se hace más difícil por el resultado de la interacción social que como consecuencia de las deficiencias. La desigualdad de derechos frente al trabajo así como la ausencia de flexibilidad a la hora de compartir empleos con personas válidas y la renuncia a la vida activa laboral serán los aspectos que cerrarán esta reflexión.

Conseguir trabajo para después lograr llegar hasta él constituye quizás un esfuerzo mayor que la realización de la tarea en sí misma. De hecho, las únicas personas con discapacidad que pueden trabajar son aquellas que tienen resuelto el problema de accesibilidad a sus viviendas y a sus puestos de trabajo, y que a su vez están rodeadas de otros trabajadores que entienden y asumen las adaptaciones secundarias de las personas con discapacidad.

Los Estados del Bienestar han entendido a partir de la segunda mitad del siglo XX que las personas con discapacidad tienen trastornos (deficiencias físicas, psíquicas y sensoriales) con consecuencias sociales (exclusión, aislamiento, discriminación) para lo que se arbitraron respuestas públicas en forma de leyes que garantizarían: la prevención, la atención médica y psicológica, la rehabilitación; la educación, la orientación y integración laboral; y los derechos económicos, jurídicos y sociales. Derechos, todos ellos, que ya tenemos como ciudadanos pero que se reconocen a las personas

con discapacidad dada nuestra *condición*, tal vez *diferente*⁽⁷⁾. Es decir, que se trata de unos derechos que garantizan la no exclusión y que favorecerían la integración.

En 1982 el Estado Español promulgó la Ley de Integración Social de los Minusválidos (LISMI, Ley 13/1982). De acuerdo con esa ley las competencias en ese ámbito en Catalunya, por ejemplo, favorecen el desarrollo de un Plan interdepartamental de integración al trabajo para las personas discapacitadas que se aprueba en 1990. Así el trabajo, como vía de integración y a su vez derecho inalienable constituye una de las responsabilidades de los órganos de gobierno.

Hasta el momento, las instituciones se han limitado a elaborar esos planes de integración que tienen por objetivo básico promover y motivar entre los empresarios la contratación laboral de personas con discapacidad. Pero, de nuevo, la práctica etnográfica demuestra que esos planes no se cumplen. Veil opina que

«...algunas tendencias de las disposiciones legales y de sus aplicaciones son tremendamente ambiguas (especialmente la asignación de rentas o la reserva de empleos), ya que bajo el pretexto de una justa compensación corren el constante riesgo de precipitar al minusválido en la trampa de la segregación injusta. La ambigüedad tiene sus raíces en las actitudes frente a la minusvalía» (VEIL C. 1978: 79).

La etnografía demostrará esa trampa frecuente y esa presencia sutil de la ambigüedad frente a las personas con discapacidad cuya eficiencia, en ocasiones, será puesta en tela de juicio cuando el handicap sea lo que defina, según los otros, al individuo.

La provisión de empleo para las personas con discapacidad se sigue entendiendo entre los *válidos*⁽⁸⁾ como un acto de caridad cristiana, no como derecho inalienable para todos los ciudadanos. Tal vez la excesiva normalización conmina, como dice Veil, a la segregación injusta porque – como ocurrirá en otros ámbitos – se entiende la ley como privilegio y no como fórmula compensadora del desequilibrio de oportunidades. En la función pública se utiliza precisamente la ausencia de normativas laborales específicas para personas con discapacidad para justificar la dificultad de establecer adaptaciones secundarias cuando un trabajador tiene determinados problemas para el ejercicio laboral.

A los *válidos* (*able-bodied*) les resulta mucho más práctico evitar la presencia de personas con discapacidad en sus trabajos. Pero si son inevitables, les cuesta mucho preguntar sobre la necesidad de algún tipo de adaptación para el desarrollo de su trabajo. De la misma manera, a los profesionales de la salud les resulta mucho más rentable para el ejercicio de su profesión

(que no para el gasto generado) la sumisión, el silencio y la pasividad del cliente.

En este estado de cosas pocas personas con discapacidad acceden a un lugar de trabajo aunque por derecho puedan hacerlo y renuncian a ello para seguir adelante sólo con la ayuda de las pensiones del Estado. Paralelamente quien sigue en su puesto laboral acepta de forma sumisa cualquier imposición autoritaria, el *mobbing* e incluso el despido improcedente sin denunciarlo: "no sea que no me vuelvan a contratar en otro lugar"⁽⁹⁾.

En el terreno de la discapacidad, la presencia de personas con limitaciones físicas o intelectuales en los ámbitos laborales pone en tela de juicio: la eficacia de las empresas, las deficiencias infraestructurales para el acceso, la ejecución de las tareas encomendada o el rendimiento laboral de quien no padece una discapacidad, así como los tabúes que se siguen sosteniendo frente a la diferencia. La existencia de una ley y de programas de integración responde obviamente a cuestiones relacionadas con la corrección política por lo que el cumplimiento de aquellas no es en absoluto inspeccionado. La consecuencia inmediata de este tipo de respuestas por parte de la sociedad a una situación de este tipo es – de nuevo – un problema de costes: si no trabajamos debemos sostenernos gracias a una pensión estatal con frecuencia no contributiva con lo que se incrementa el porcentaje de personas dependientes de las arcas del Estado. ¿Será posible sostener el gasto en el futuro?

Reclamar derechos mínimos en una relación de prestación de servicios relacionados con el cuerpo o en el trabajo siendo portador de una deficiencia es, en nuestra sociedad, una cuestión todavía poco frecuente. Dicho de esta manera, no debería preocuparnos: si nadie reclama derechos es que no le son vulnerados. Sin embargo no es así. La práctica etnográfica, o el trabajo cualitativo al que todavía siguen sin acostumbrarse los sistemas nacionales de salud o los servicios sociales de nuestro país, demuestra las repercusiones negativas que ya hemos visto en el campo de la discapacidad.

En el campo de la salud, la confianza ciega (sumisión, pasividad, despersonalización, etc.) genera en primer lugar estancias hospitalarias más prolongadas, lo que equivale a un aumento del gasto sanitario. Un enfermo 'incapaz' e inactivo no puede ser dado de alta hasta que se asegure su autonomía. En segundo lugar, la promoción de la pasividad así como el miedo a hacer un mal uso del sistema sanitario ("no me van a hacer caso", "me darán una pastilla y para casa", "tendré que esperar mucho...") incide en los diagnósticos tardíos en casos en los que la detección precoz elimina-

ría riesgos y costes innecesarios. El desgaste físico y psicológico de un ingreso hospitalario prolongado así como la dependencia fomentada incrementa notablemente los días de baja laboral dedicados a la recuperación. Los errores y las negligencias, por pequeños que sean, se suceden sin apenas repercusión porque no se denuncian: “no vale la pena”, dicen los actores, “nada vamos a ganar frente al sistema”.

El hospital es para el usuario un medio tecnológicamente complejo donde – ya lo he mencionado – *tenemos la suerte (no el derecho) de ser atendidos*. Con estas premisas sabiamente sostenidas por los profesionales sanitarios se mantiene un estado de las cosas inamovible por más que se formulen leyes. ¿Con qué objetivo se mantienen esos estereotipos y se evita incluso difundir las formulaciones de derechos?

La información es poder: a menor información mayor poder a ejercer sobre el usuario. Viceversa: un usuario informado es un usuario peligroso que puede hasta interponer querellas. Cuanto más ignorante en materia médica sea el cliente más libre será el ejercicio de la profesión, se impondrán menos trabas para la investigación y se establecerán menos lazos emocionales con el paciente facilitando un mayor distanciamiento. En otras palabras, cuanto más vulnerable se sienta el paciente mayor poder se podrá ejercer sobre él. Como algunos médicos creen que en determinadas circunstancias los derechos podrían poner en duda el papel de los profesionales, resulta más práctico no hacer difusión de los mismos porque los colectivos sanitarios creerían que la institución que lo hiciera vulneraría su profesión y sus intereses.

Sin embargo, la asistencia sanitaria para ser eficaz como servicio público debería conocer y respetar los derechos del individuo y su individualidad como persona. En palabras del Doctor Maglio (MAGLIO F. 2000: 114) «desbiologizar las historias clínicas para biografíarlas y convertir la identidad jurídica del enfermo en identidad social para así atenderle mejor».

Para concluir, en este estado de cosas, ¿qué puede hacerse?. Es evidente que una vez conseguida la formulación de derechos, la vigilancia de su cumplimiento depende por un lado de la iniciativa de los ciudadanos a través de las asociaciones de enfermos y de otros colectivos que aglutinen afectados, consumidores y usuarios; y, por otro, de una pedagogía que debería partir de los departamentos y las escuelas de enfermería así como de las facultades de medicina en el caso de las cuestiones sanitarias y de los gestores sociales y de las inspecciones laborales en el caso de la discapacidad.

Notes

- ⁽¹⁾ Ver bibliografía
- ⁽²⁾ En España, las Comunidades Autónomas tienen amplia capacidad legislativa por lo que voy a hacer referencia a los items que incluye la Ley 21/2000, 29 de diciembre aprobada en el Parlament de Catalunya, cuya referencia aparece en la bibliografía. Esta ley fue pionera en el Estado Español y tuvo en poco tiempo repercusión en otras comunidades autónomas del Estado.
- ⁽³⁾ Los enfermos crónicos frequentadores de los servicios de salud efectúan más reclamaciones pero también disponen de recursos para gestionar mejor las adaptaciones secundarias por conocer el sistema. No obstante, las encuestas hospitalarias trabajan con los resultados de la información que proporcionan los pacientes agudos que son mayoría no con la de los crónicos.
- ⁽⁴⁾ En los últimos años médicos y algunas enfermeras se han quejado del uso que los pacientes hacen de Internet para conocer 'algo más' de sus dolencias, en consecuencia, suelen desaconsejarlo.
- ⁽⁵⁾ Este documento, descrito en la mencionada Ley 21/2000 es un testamento vital donde se manifiesta la voluntad del firmante en relación a la toma de decisiones relacionadas con la atención médica al final de su vida.
- ⁽⁶⁾ El consentimiento debería darse por escrito «en los casos de intervenciones quirúrgicas, procedimientos diagnósticos invasivos y en general los que comportan riesgos e inconvenientes notorios para la salud del paciente» (GENERALITAT DE CATALUNYA 2001).
- ⁽⁷⁾ El uso de la primera persona del plural en estas frases se debe a que yo misma formo parte del colectivo de personas con discapacidad.
- ⁽⁸⁾ Denomino "válidos" a las personas sin discapacidad.
- ⁽⁹⁾ Uno de mis informantes perdió la renovación del contrato de trabajo en un ayuntamiento porque las dependencias 'tenían barreras arquitectónicas': *si usted no se adapta nosotros no podemos correr el riesgo de que se lesione.*

Bibliography

- ALLUÉ Marta (2001), *Derechos de los pacientes: una perspectiva antropológica*, "Medicina Antropológica. Órgano de la Sociedad argentina de medicina antropológica", n. 2, 2001, pp. 13-19.
- GENERALITAT DE CATALUNYA (2001), *Llei 21/2000, de 29 de desembre, sobre els drets d'informació concernent la salut i l'autonomia del pacient, i la documentació clínica*, "Doc. Diari Oficial de la Generalitat de Catalunya", n. 3303, 11/01/2001, p. 464.
- DI GIACOMO Susan (1987), *Biomedicine as a Cultural System: An Anthropology in the Kingdom of the Sick*, pp., en BAER H. (ed.) *Encounters with Biomedicine. Case Studies in Medical Anthropology*, Gordon and Breach, Amsterdam.
- MAGLIO Francisco (2000), *Reflexiones (y algunas confesiones...)*, Propulsora Literaria, Buenos Aires.
- VEIL Claude (1978), *Minusvalía y sociedad*, Temas de Rehabilitación, Madrid.
- Vv. AA. (2001), "Boletín de la Asociación Española para el Derecho a Morir Dignamente", n. 46, 2001.



1.5 *Tapping the sources of healing.*

Some themes of distress narratives in towns and villages of contemporary Latvia

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Introduction

In recent years there has been a major shift of emphasis in the way depression and other forms of mental suffering are perceived, explained and reacted to in post-Soviet Latvia. Whereas during the socialist regime and the first post-Soviet years explanations for ill-being were sought primarily in interpersonal, moral and socio-political sphere, since the introduction of free-market economy in early 1990s esoteric, psychological, and bio-medical explanatory models or causal ontologies have won an increasing popularity. Even though the new folk theories based on them attract a lot of attention and often figure in public discourses that account for mental distress or ill health, the moral and socio-political dimension of theorising suffering has not been discarded. It surfaces in the in-depth interviews where the storyteller is struggling to grasp a deeper meaning of her affliction and to situate her story within the history of her family, her peer group or her country. The speaker's preference for one or another causal ontology depends on both the context in which mental distress has manifested itself and on the context in which it is narrated. At times, however, silence or ambiguity surrounds the quest for meaning and threatens the coherence of the narrative.

Drawing on the debates in medical anthropology and cross-cultural psychiatry I will argue that co-existence of divergent explanations of (mental) distress often reflect two contradictory discourses that nevertheless both inform the sufferer's agency. To demonstrate this I will analyse some narratives entrusted to me during my fieldwork in Latvia where I conducted participant observation, expert and life-story interviews in several towns and villages for nine months in 2002 and 2003. As a participant-cum-

researcher I listened to the stories people told in three different types of setting, one being a support group, the other a psychiatrist's consultation, and the third a life-story interview initiated by myself. Altogether I have recorded thirty-six life-stories and participated in four support or self-help groups. My research participants' age ranges from twenty to eighty, but most are in their forties⁽¹⁾. In this paper, looking at the ways in which interviewees' accounts of their distress embody their aspirations for healing, I will introduce four narratives. First of all, however, let me set my inquiry into the broader context of anthropological studies of suffering.

1. The embodied knowledge of suffering

Kleinman introduced the concept of 'explanatory model' in 1980 referring to a cognitive structure on which both illness experience and clinical practice are based (KLEINMAN A. 1980). He admitted that biomedical as well as indigenous explanatory models are cultural constructs. The cultural system of health care, he argued, shapes illness through the categories that label and explain disease and influence the way symptoms are experienced. Cultural determinants may yield diverse types of somatisation and different illness manifestations, but behind cultural diversity there nevertheless exists a stable identifiable disease entity, for example, clinical depression.

Shweder questioned the distinction between illness and disease in Kleinman's early work. As an alternative, he proposed to distinguish between «forms of suffering» and «the causal ontologies invoked to explain them» (SHWEDER R. 1991: 315). To become meaningful, suffering needs to be interpreted. The interpretation of suffering as an abnormality in some nosological system constitutes a *causal ontology*. The latter term, according to Shweder, signifies the events and processes that are going on in a separate and logically different order of reality (moral, socio-political, biomedical, or psychological) and are thought to cause the experience of suffering.

For Shweder the Western biomedical discourse with its concept of disease is ill suited for representing and comprehending some major forms of suffering. Besides, Shweder critiques Kleinman's later suggestion that socio-political ontology would explain neurasthenia and depression as forms of suffering worldwide (KLEINMAN A. 1986). He refers to his own field research among Hindus in Orissa, India where the most common has been moral causal ontology (relating suffering to transgression, sin, retribution, karma etc.). Other explanations have been related to an interpersonal causal on-

tology (with references to sorcery, evil eye, magic, spirit attack), to a biomedical [Ajurvedic] causal ontology (with references to humours, bodily fluids and substances that affect brain), to a psychological causal ontology (associated with unfulfilled desires) and to an astrophysical causal ontology (with references to horoscopes). In sum, the experience of illness, as it is shaped by culture, can only be comprehended within the context of each society's systems of knowledge, moral values and cosmologies.

Shweder's way of reasoning brings to mind an earlier work by Lutz who claimed:

«For cross-cultural investigators to approach the question of suffering or distress via the ethnotheories that make particular kinds of situations culturally meaningful and that link those situations to cultural values and institutions is to begin with a less culturally specific set of meanings and correlations than that contained in the concept of depression» (LUTZ C. 1985: 75).

Like Shweder, Lutz argues that culturally constituted knowledge systems determine how people experience themselves and each other. One type of such ethnotheory, relevant for understanding mental suffering across cultures, is ethnopsychology, or the culturally specific symbolic systems and conceptualisations surrounding the person (LUTZ C. 1985: 68). Ethnopsychological ideas, and in particular those related to the local theories of illness causation, determine the kinds of therapy chosen in case of distress.

Both Shweder and Lutz have rightly pointed to the ethnocentric nature of privileging Western biomedical perspective on mental distress over other frames of reference that conceive of suffering and ill health rather differently. At the same time, what they juxtapose are primarily diverse cognitive systems, in one case ontologies, in the other ethnotheories, that attempt to comprehend, explain, and predict certain events, phenomena and processes, each employing a set of culture-specific categories. Of the two, Lutz seems more sensitive to the embodied nature of cultural knowledge. Although the term ethnotheory primarily refers to a set of conceptually or symbolically articulated cognitive statements, she remarks that *premises of a certain ethnopsychology may be available to varying degrees of awareness and examination [emphasis of the author]*. Assessment of reality status of the knowledge incorporated in an ethnotheory, according to her, is very much determined by the way the inner and outer are conceptualised. Consequently the reality status ascribed to such cognitive method as introspection may considerably vary across cultures. For instance, the Ifaluk, the people among whom Lutz did fieldwork on an atoll in Micronesia, doubt that one can access the inner life of another person while for Americans

the inner is associated with almost sacred marker of the self. Likewise, in contrast to the dominant Western view that posits emotions as natural, pre-cultural facts of the individual psyche, for the Ifaluk emotions are meanings that people negotiate in attempts to understand the relationships they encounter as well as the roles and behaviour appropriate for each situation. Thus experiencing righteous indignation may be viewed as a morally correct response² rather than as a deviation from the state of pleasure or happiness that for a long time has been considered normative in Euro-American ethnotheory.

Arguing that an essential aspect of emotional life is constituted by meanings, and for that matter, values embodied in human interactions and responses, Lutz has pinpointed the implicit nature of cultural knowledge (BLOCH M. 1998, BOURDIEU P. 2003). Neither Lutz nor Shweder, however, elaborate on the ways in which premises of an ethnotheory, a cosmology or a causal ontology become a motivational force, i.e., are translated into vocabulary of habitual actions. Hastrup has attempted to reach such an understanding viewing the mind as a «dynamic zone of contact between embodied knowledge and contested evidence» (HASTRUP K. 1995: 181). Like Lutz, Hastrup argues that cultural knowledge is most often expressed in action rather than discursive statements. However, Hastrup develops this argument further. As people incorporate more and more knowledge, she argues, culture becomes sedimented in their bodies and forms their habits. In this sense culture becomes naturalized in the process of socialization. The body is motivated by this naturalized experience that is beyond words. According to Hastrup, awareness and consciousness are twin sources of agency. Awareness «refers to an explicit understanding, while consciousness is largely an implicit vector of knowing» (HASTRUP K. 1995: 183). Whereas awareness relates to a specific moment in time, consciousness is a timeless dimension of knowledge. Hastrup illustrates these statements drawing on two anthropological studies: Abu-Lughod's ethnography of the Awlad 'Ali Bedouins of Egypt and Scheper-Hughes book *Death without weeping* on the shantytown dwellers of north-eastern Brazil (SCHEPER-HUGHES N. 1992). In both communities agency is informed by two contradictory discourses, one derived from awareness, the other premised on consciousness that is incorporated in shared bodily experience, affect in the former case and hunger in the latter. Awareness can be subject to illusion and confabulation even though it runs counter social experience. Within consciousness, on the other hand, «the desirable order of things is collectively sensed, even when silence or secrecy prevail» (HASTRUP K. 1995: 192).

Here I would like to draw on Hastrup's argument in order to qualify Shweder's thesis about the 'styles of suffering' as embedded in moral values and cosmologies. I agree with Shweder that there are always a variety of causal ontologies that can be invoked to account for suffering even though some would be culturally more preferred than others. At the same time, along with Hastrup I doubt that mere explanations, based on folk-theories, cognitive or nosological systems, or discursive statements, can become a source of agency. Causal ontologies and explanatory models may as well derive from discourses based on the historically contingent awareness and thus contradict consciousness sedimented in bodily experience. To illuminate this relationship between causal ontology and embodied knowledge, in the following chapters I will examine the ideas of causality that Latvian narratives of mental suffering reveal, as well as the meanings, values, and beliefs they incorporate.

2. Causal ontologies of suffering in the 20th century Latvia

Until the restoration of national independence in 1991 distress and suffering in Latvia were often seen as rooted in the moral and political sphere. Skultans demonstrates that social and political causes dominate illness accounts of the people born in the first decades of the 20th century (SKULTANS V. 1998). Narratives of the body and its sufferings have been used to articulate a political critique of the society of Soviet Latvia (SKULTANS V. 1999). Illness in this perspective ceases to be contained solely in the private and medically manageable realm. Also my previous research (McKEVITT C. - LUSE A. - WOLFE C. 2003) suggests that the older generation often view their health through the prism of shared historical experience.

One of my interviewees, Mirdza, now eighty, belongs to this age cohort. Mirdza approached me after a lecture on my current research topic that I delivered to board members of a retired persons' association in a regional town. Later I visited her at home and learnt that in 1946 when she was twenty-two and had just entered university, Mirdza was arrested. Military tribunal charged her with 'membership in a counterrevolutionary organisation' ⁽³⁾ and sentenced to ten years imprisonment whereupon she was sent to one of the GULAG ⁽⁴⁾ sites of confinement in the Sverdlovsk region in Russia. Initially, though, Mirdza wanted to tell me not about herself but about her acquaintance. From the ten-year period of slave labour and extreme need in Siberia during which she was sent from camp to camp and met hundreds of people Mirdza could only remember one person who had

succumbed to depression. Mirdza recalls that Aina, a young woman then, had been sentenced to twenty-five years in labour camps and deported to Siberia in 1949⁽⁵⁾:

«Thus you had to spend all your life there. And you would not know where you will settle, what awaits you, for it was not freedom, we were behind the fence, there always was a guard with a gun around. [...] And that Aina was sent to Krasnoyarsk. The heavy labour, the meagre food, and so she spent her days – and she had left a little baby in Latvia. [...] And with that depression of hers, not sharing with anybody she became so poorly that she was no more able to walk or to move, she did not want to talk to anyone, just was in tears all the time. [...] And she – she had no hope anymore. And then finally came that day, it was in [nineteen] fifty-four, after Stalin's death, when one day she was told she was released. That she could go to Latvia. [...] Yes, and then that Aina – looking back to it now – when she was released she was kind of out of her mind. She did not believe she was free!»

This story sympathetically relates the misery and despair of a young woman innocently sentenced to seemingly endless years of coercive labour and hunger in a foreign land. Her lot was even more aggravated by the fact that she was separated from her loved ones. Yet the account also reveals much about the storyteller who seems to have comprehended Aina's suffering but at the same time stresses what allowed her, Mirdza, not to give up, namely, her sense of inner freedom and sense of justice as well as an almost metaphysical sense of belonging. That contrasts sharply with Aina's reported state of withdrawal:

«If a human being was still in a sound [mood] – if THAT did not happen – there still was a hope, there was a dream about homeland, about future. We still were able to admire stars».

Now what helped Mirdza, who in many respects shared Aina's lot, still preserve a hope for the future? In our conversations Mirdza several times referred to the ten years she spent in Siberia as to "my study years". Figures of speech like this are quite common in the narratives about deportations (SKULTANS V. 1998). Inferring the deportees' shared, embodied quality of experience they convey a moral and political perspective on suffering. Mirdza describes her unjust lot just by implication, as if jokingly. It seems that the capacity to adopt a wider socio-political perspective has been for her, as well as for many of her contemporaries, a source of moral empowerment and for that matter also of mental endurance. Unlike Aina (and like the Bedouin women in Abu-Lughod's ethnography), Mirdza was able to articulate her painful consciousness of the losses she had suffered in the 'emotional discourse' of songs and poems (she recited to me some from heart and others from her Siberian notebooks). Moreover, this consciousness of a plight was balanced by her awareness that she shared her

anguish with hundreds of others as well as by her deep love for her native country. That attachment, even though it can be partly attributed to Mirdza's patriotic upbringing and thus a discourse *on* feelings (HASTRUP K. 1995: 185-186), seems to have substantially contributed to Mirdza's endurance, inner freedom and agency⁽⁶⁾.

Other life-story interviews I recorded suggest that younger people in Latvia formulate their experience, concerns and problems in quite different terms than representatives of Mirdza's generation. Mirdza sees ill health and suffering as caused by the conditions of imprisonment and subjugation whereas inner freedom for her is something taken for granted. By contrast, for Latvian women now in their forties it is rather the sense of inner freedom and agency that has become problematic thus contributing to suffering. As Putnina too has observed in her recent ethnography of maternity practices, in post-Soviet Latvia structural positions still count more than the individual voice for it is still believed that those are structures that possess agency (PUTNINA A. 2001: 383). Drawing on my interview data I will argue, however, that despite this general tendency, people, especially those who undergo a personal crisis, seek to reclaim their voice, their self-worth and agency.

3. New tendencies in understanding the causes of ill health

Since the early 1990s a process of polarisation of causal ontologies has begun in Latvia. On the one hand, the psychological mode of reasoning is gaining an increasing popularity⁽⁷⁾. On the other, the biomedical discourse is encroaching upon popular understandings of mental health and illness often obscuring unequal power relations as a ground for moral indignation that also contributes to distress and depression.

3.1. Psychological understanding of causality: Eva's analysis

According to psychological understanding, depression signals a threat to the self. For several of my interviewees to overcome depression has meant to recover the inner voice and to articulate its message. These people told me how they endeavoured to start speaking and acting in the way they felt rather than according to what others expected. Other interviewees emphasise the healing and empowering potential of their commitment to make a common cause with their peers (most often within a non-governmental or charitable organization). In both cases there emerges again the

theme of inner freedom. For these people, to recover the voice of the self has meant to attain a higher level of freedom, and for that matter, agency. For some of them, the change in outlook has been brought about by psychotherapy. Eva's story gives us an insight in a healing process conceived as reclaiming authenticity in experience.

Eva (born in 1956) trained as paediatrician and worked on a hospital ward for 17 years. She recalls that even though her work involved taking on great responsibility, her salary hardly sufficed to provide for the family. As soon as an opportunity arose, in 1997, Eva decided to embark on training as a psychotherapist.

«I completed [the training] in 1980. Thus I trained – studied purely in Soviet time. And psychology, psychotherapy was non-existent. Nil. There was a void. [...] And then one feels a need to fill that void».

Thus the feeling that something was missing stemmed not just from lacunae in her education, for Eva it also signalled an emotional void. In our conversation Eva admitted to having suffered from depression. In her narrative she focused on her private crisis yet one can nevertheless discern a mighty echo of past political events that have had far-reaching effects on the minds of more than one generation:

«Overall I feel like a post-war child. [...] Such a period. Namely, the 1950s - well, the post-war – looking back now, it still was a post-war feeling then. And my granny was with me, the closest relative, my carer, dear and kind. Nevertheless she is – looking back now – absolutely depressive. She gave birth to six children, just two survived. Husband went to fight, well, in fact he died in a concentration camp... One son lost his life as a legionary [...] These opposite camps – and children split between them⁽⁸⁾ and... I think that involves such an immense distress – and losses. And my father was deported to Siberia, for example, and the two little daughters – both died too. That is that life of a woman. What can she feel like...».

Eva interprets the impact of these political and family circumstances of her early years on her mindset from her present vantage point as a psychotherapist. Interestingly, in that she as if distances from her immediate memories using the third person pronoun:

«'Cause it is almost forbidden there, well, not exactly forbidden, just unconsciously so, but still, overall there is no joy, you see, one cannot experience joy, fulfil one's wishes, 'cause there is another person whose lot is much heavier than mine...».

Beside this unconscious prohibition of wishes and enjoyment, those born in 1950s are also likely to know fear well. For Eva, her father's life-world embodied it:

«It is a matter of survival. If he survived in Siberia, then how can he afford to [oppose] somebody here and now? [...] And that's what the period was like, you see. I think that to afford or wish something...[...] It did not exist, it was not allowed! And repression of wishes, in turn, results in depression...»

A year later, in our second conversation Eva, having read my interpretation of her account, emphasised: «That's what that emotional milieu is like: fear as a background of depressivity, and it cannot be integrated into the selfhood for it is never spoken about. Fear resides in the unconscious, it's not explicit». I see the fact that Eva relates her own past experience in the present tense as implying a deep significance. As a psychoanalytically trained person Eva understandably speaks about the emotions deposited in the unconscious as motivational forces behind her own and her relatives' past words and deeds. At the same time, the story of her family can readily be interpreted in the theoretical framework advanced by Hastrup, namely, as an example of the way in which consciousness and awareness intertwine engendering motivation and agency. «Silence or secrecy may be imbued with value and thus with motivational force. The absence of direct and public articulation points not to lack of consciousness of the values or desires implied but to a lack of means to act explicitly upon it...» (HASTRUP K. 1995: 192). Thus the depth of the suffering caused by silencing and repressing desires, in fact, affirms the centrality and value of the desired for the sufferer. In the case of Eva's family, freedom, spontaneity and safety of the loved ones have been such desired objects. As we have seen, Eva does not discard the socio-political causal ontology, as one would expect from a person in her trade. Rather, her training as a psychotherapist has made her able to break the silence and articulate the dominant, but deeply subdued mode of consciousness with which she grew up. Her narrative convincingly demonstrates that self-exploration does not inevitably preclude due attention to political and moral aspects of distressing experience. To understand herself Eva had to understand her genealogy, and that inevitably raised the question of justice, in interpersonal, as well as in a moral and political sense. In spite of the oppression and losses her predecessors went through and the sediments that that has left on her embodied emotional experience, Eva has reclaimed her sense of inner freedom and agency. Having felt the heavy weight of injustice and fear as a child she has chosen to do herself justice now, as an adult:

«I was kind of bored with lamenting and blaming the government, and was wondering: could it really be that nothing depended on myself?».

Few of my interviewees, though, have been so articulate in analysing their lives. Besides, a competing perspective, that of psychopharmacology, at

times overshadows the importance of self-analysis in terms of history, genealogy and power relations.

3.2. Ambivalence about the biomedical approach: Pärsla's case

As elsewhere in the world (LUHRMANN T. 2001) also in Latvia the biomedical perspective has recently been gaining in authority. In this discourse, not only disease but also illness appears to be little more than a biochemical process. For instance, in an interview with a Latvian psychiatrist published in a local newspaper in 2002 we can read: «Worries, stress, abuse of alcohol, drugs or medicines are just factors that contribute to the onset of illness. Its cause is a disturbance of the chemical balance in the brain»⁽⁹⁾. Although not all doctors in Latvia interpret depression in such a narrow way, the biochemical approach has become more established owing to pharmaceutical industries' marketing strategies (HEALY D. 1998). Notions of psychopharmacology are also leaking into lay knowledge, as browsing through newspaper columns in Latvia suggests. At the same time, from among dozens of people who entrusted their life-stories to me no one admitted that antidepressants had helped them to overcome depression: in most cases they had just stabilised it. I will illustrate this by referring to a psychiatric consultation in a regional health centre at which I was present in January 2003. During the consultation the doctor invited her patient, Pärsla, to tell me about her illness.

Pärsla is about 30, she is married with two children. Her health problems began in 1996, after her youngest child was born. Pärsla recalls backache, fits of dizziness, nausea, weakness, and increasingly also anxiety. Concerned but perplexed about her condition Pärsla consulted a neurologist, a surgeon, an endocrinologist, a gynaecologist, as well as several healers. In summer 2002 Pärsla eventually visited the psychiatrist who diagnosed her with a prolonged post-partum depression. Treatment with antidepressants finally seemed to alleviate her condition. During the consultation the doctor carefully asks Pärsla to tell about both her past and present feelings:

«Doctor: *You were weeping because you felt nobody understood you, weren't you?*

Pärsla: *Uhm – also – and also because, you see ... I was bored with myself...*

Doctor: *Also your social status had changed? You had lost or quitted your job – felt estranged from your friends?*

Pärsla: *Nnn... that hardly left any great impact on me, since I have grown up in countryside, you see, the youngest child. I have always been independent, from chil-*

dhood. And... I am not especially keen on making friends for I have had a bitter experience...

Doctor: *Since when have you started feeling better and hope that all will be well?*

Pärsla: *... Well, it was when I began – began taking [the name of an antidepressant]».*

This dialogue leaves an impression that for the time being Pärsla has no other option than to rely on psychiatrist's prescriptions. At the same time, listening to Pärsla, one could not help noticing her deep ambivalence about her own condition. Upon her arrival Pärsla complained that she was bored with the domestic routine and eager to 'come out of her shell'. That wish sounded well justified once I learnt that Pärsla had to quit her work as a florist a year ago and had stayed at home since. Moreover, she claimed to have received little understanding or support from her husband. A few minutes later, though, Pärsla described herself as an "independent human being": being the last child of her parents and having grown up on a lonely farmstead, she was used to coping on her own. Nevertheless, the bitterness with which she spoke suggested that this self-image was constricting and largely based on a popular, normative discourse emphasizing the value of self-sufficiency and personal independence. Thus what prevents the young woman from 'coming out of her shell' is not a biochemical imbalance in the brain, as the biomedical discourse would suggest. Rather Pärsla's difficulties can be attributed to her awareness of her role as a wife and mother expected to care for the family more than for herself. Such a stance has prevented her from articulating and sharing with others her resentment about having not fulfilled her desires. Luckily, Pärsla has found a psychiatrist to help her acknowledge and articulate her concerns and feelings and draw upon her inner reserves to find the motivation for healing.

3.3. The contextual nature of causal ontology: Gunta's narrative

Psychological discourse is not the only alternative to biomedical discourse in Latvia. In a number of narratives a type of causal ontology can be discerned that I would characterise as "esoteric" or "spiritual". In today's Latvia it is most closely associated with alternative therapies or healing ("*dziedniecība*"). Although there are more and more suppliants who set their hope in either biomedical or psychological solution of their crises, a great number of people draw on what can be termed "spiritually esoteric ontology" in their attempts to make sense of distress. Thus several of my inter-

viewees mention visits to healers, while even more people refer to what they have read about healing. At times, the spiritual perspective complements the socio-political one, as Gunta's narrative suggests.

Gunta (born in 1959) looks back to her thirty to forty years of age as to a period of her life crisis. There was a pre-history to that, however. Gunta was trained at an agricultural college where she also met her future husband. After graduation both moved to the husband's native village. There Gunta gave birth to their three children and stayed at home to look after them for several years. She returned to work in the late 1980s when collective farms had just begun to dissolve:

«[...] Thus I fell out of the process, and thereafter the time had come when the kolkhoze's property was being divided. [...] And there I damaged myself. Now one would ask: what for? In fact, because of the property, even though I did not need property for its own sake, I just desperately wished to be a farmer!».

Eventually Gunta and her husband set up a farm of their own but because of a disadvantageous bank loan they got into debt. Her daughter's problems at school marked the culmination of her anguish:

«And thus one such little neurosis, another one – something you swallow. That all accumulates – not because of a catastrophe, it just gradually accumulates. [...] And you are not able to do anything at all, just walk around like a fool and look, all over that burning sensation, headache, that's all. I have read about that, I realise: that's depression. Must go and see the doctor».

A family doctor prescribed her antidepressants and that really helped. Shortly afterwards, however, unbearable joint aches set in and Gunta took the opportunity to go to a sanatorium. Having joined a group of gymnastics there, Gunta praised the coach:

«Yes, she taught us those exercises that help relax the spine, you see, things like that... But she also knew how to bring in order your mind at the same time, you see. How badly you need that exercise and how you can enjoy it [...]».

«Plus the library: there was such – either I accidentally came across it or somebody suggested – that book by Lüle Vilma⁽¹⁰⁾. That was right for the brain – to put it in order. And when you also talk to others, from what conditions they have been restored, you see, I thought then: have to strive. I did exercises at home once I returned – I took it very seriously. Just have to stand up, that's it! My brain has completely changed since then...»

Thus for Gunta depression was not just as an illness to be treated with antidepressants but an urge to revise her whole mindset and habits. Phys-

ical exercise and 'psycho-hygienic discipline', to borrow her own words, helped her a lot in that. Besides, like the people of Mirdza's generation, Gunta discovered an empowering potential in sharing her experience of suffering with others. Upon the resolution of her crisis Gunta actively engaged in the local sports club and became a member of jury in the county orphans' court. Now she sees these activities as a precondition of her mental well-being.

This story too can be interpreted in terms of twin sources of agency, one being largely discursive, another an embodied and experiential one. Having read quite extensively, Gunta is well aware of multiple discourses around depression (socio-political, psychological, biochemical, esoteric) and able to relate those to her own life-story. However, only when she turned her attention towards her ailing body and repositioned it as a 'mindful' one, endowed with soul, embodying knowledge and signalling distress, did she tap her source of healing. Sharing her lot with others and articulating the moral and spiritual meaning in suffering was a decisive step towards affirming agency.

Conclusion

As has been established in medical anthropology and cross-cultural psychiatry, the experience of illness and suffering is shaped by culturally grounded knowledge and shared moral values. Drawing on these resources can help one attain a coherent statement about the meaning of adversity and, by the same token, dissipate the sense of distress (KEYES C. 1985). In this paper I explored narratives of four Latvian women and analysed the ways in which their accounts of mental distress reflected their efforts to find a meaning that could lead towards empowerment and eventually towards healing.

To comprehend the variety of ways in which mental distress can be perceived, experienced and responded to, I employed Schweder's concepts of 'styles of suffering' and the respective causal ontologies. I conceded that since they acknowledge multiple culturally grounded perspectives these concepts allow to eschew ethnocentric approaches that privilege the biomedical perspective over other frames of reference. At the same time, as a conceptualisation of cultural cognition Schweder's approach is a rather static one in that does not it clarify why one ontology should be preferred over others at a given social and historical

time and space nor how it can become a motivational force for people aspiring to healing.

I attempted to qualify Schweder's conceptualisation of multiple 'styles' and causal ontologies of suffering drawing on Hastrup's approach to motivation and agency as informed by cultural cognition. According to Hastrup, «experience and description are bound together in a constitutive relation that admits of causal influences in both directions» (HASTRUP K. 1995: 192). Awareness, or explicit understanding, and consciousness, the implicit vector of cognition, are two intertwined sources of agency and motivation. I argued that in the case of mental distress, representations, decisions and actions might derive from awareness as well as from consciousness. One or another causal ontology may at times contradict consciousness that has been sedimented in bodily experience. The potential to attain healing and empowerment depends not so much on the coherence of a causal ontology behind each narrative than on the sufferers' ability, through "suffering in style", to draw on shared moral understandings and bodily experienced meanings.

Analysing illness narratives of four women I attempted to demonstrate that in spite of the increasing popularity of biomedical and psychological explanations of mental distress in the post-socialist Latvia, it is within the moral and socio-political framework that the storytellers manage to both make sense of their suffering as other than an individual malady and affirm their agency. Thus Mirdza's story, cast in the form of a moral critique of inhumane political regime, attributes mental ill-health to the conditions of subjugation and powerlessness. Psychological and spiritually-esoteric perspectives on suffering prove most empowering when they are complemented by the moral or socio-political one. For example, Eva's account of her crisis, even though expressed largely in psychoanalytic terms, powerfully conveys her sense of a regained agency precisely because it also contains a moral critique of the repressive society of her childhood. Gunta, in turn, challenges her own earlier resentment at economic and political injustice and discovers her creative potential as well as new ways of connecting to others, having shared with fellow sufferers the bodily dimension of knowledge and repositioned her ailing body as a 'mindful' one. Pärsla's narrative, in contrast, has largely been shaped by the biomedical causal ontology and thus detached from the shared horizon of embodied knowledge. The engagement with consciousness in it is silenced.

Notes

- ⁽¹⁾ The interviewees' names have been changed here, in order to protect their identities.
- ⁽²⁾ Lutz's approach to emotions is supported by Nussbaum's argument according to which emotions embody beliefs about value, worth and salience of the object they are focussed on (NUSSBAUM M. 1999).
- ⁽³⁾ While still at school, Mirdza had taken part in the youth organization *Mazpulki*. The origins of this patriotic and educational organization can be traced to the *4H Club* (acronym for "head - heart - hands - health") founded in the United States in 1902. Main activities of *Mazpulki* consist of educating children and adolescents about household, agriculture and environment. In 1940 it had local branches in all primary and secondary schools of Latvia, comprising 44.200 members. URL (accessed on 21/02/04): <http://www.mazpulki.lv/> The adjective "counterrevolutionary" was attributed to the political parties of the Republic of Latvia, youth organisations, anti-Soviet leaflets and songs (VIKSNE R. on URL *Crimes against Humanity. Latvian Site*: <http://vip.latnet.lv/lpra/viksne.htm>
- ⁽⁴⁾ GULAG is a Russian acronym, meaning "Mass Administration for Corrective Labour Camps".
- ⁽⁵⁾ Altogether ca. 94,000 people were deported from three Baltic countries on 25 March, 1949. These deportations were in part directed against the supporters and family members of the partisans. Cf. *Fourth Sub-Commission: Crimes against Humanity in the Territory of Latvia during the Soviet Occupation 1944-1956. The Progress Report of Latvia's History Commission: Crimes against Humanity Committed in the Territory of Latvia from 1940 to 1956 during the Occupations of the Soviet Union and National Socialist Germany*. URL (accessed on 21/02/04): <http://vip.latnet.lv/lpra/4subcomission.htm>.
- ⁽⁶⁾ According to Hastrup agency can be viewed as a «feature of continuing conversation in the community, embracing both a discourse on emotions and an emotional discourse» (HASTRUP K. 1995: 190).
- ⁽⁷⁾ What concerns psychology, the only university department of psychology in Latvia was closed by Soviet authorities in 1940s not to be re-opened till early 1990s, so that in Soviet times there were no more than a dozen professional psychologists in Latvia. Practically no psychotherapy was available. Since early 1990s, however, there has been an exponential growth of this industry in Latvia. The membership of psychotherapists' associations is approaching two hundred.
- ⁽⁸⁾ "Opposite camps": one of Eva's uncles was conscripted into the Latvian Legion, a subdivision of German Troops during the WWII, another into the Soviet Army.
- ⁽⁹⁾ *Alūksnes Ziņas*. 5 February 2002.
- ⁽¹⁰⁾ Lüle Vilma is an Estonian folk healer and author that became very popular in Latvia in mid-1990s.

Bibliography

- BLOCH Maurice (1998), *How We Think They Think. Anthropological Approaches to Cognition, Memory, and Literacy*, Westview Press, Colorado - Oxford.
- BOURDIEU Pierre (2003), *Participant Objectivation*, "Journal of the Royal Anthropological Institute", vol. 9, 2003, pp. 281-294.
- HASTRUP Kirsten (1995), *The inarticulate mind: the place of awareness in social action*, pp. 181-197, in COHEN A.P. - RAPPORT N. (eds.), *Questions of consciousness*, Routledge, London.
- HEALY David (1997), *The Antidepressant Era*, Harvard University Press, Cambridge.
- KEYES Charles F. (1985), *The Interpretive Basis of Depression*, pp. 153-174, in KLEINMAN Arthur - GOOD Byron J. (eds.), *Culture and Depression*, University of California Press, Berkeley.
- KLEINMAN Arthur (1980), *Patients and Healers in the Context of Culture. An exploration of the borderland between anthropology, medicine, and psychiatry*, University of California Press, Berkeley.

- KLEINMAN Arthur (1986), *Social Origins of Distress and Disease. Depression, Neurasthenia, and Pain in Modern China*, Yale University Press, New Haven.
- LUHRMANN Tanya M. (2001 [2000]), *Of Two Minds. An Anthropologist Looks at American Psychiatry*, Vintage Books, New York.
- LUTZ Catherine (1985), *Depression and Translation of Emotional Worlds*, pp. 63-100, in KLEINMAN Arthur - GOOD Byron J. (eds.), *Culture and Depression*, University of California Press, Berkeley.
- MCKEVITT Christopher - LUSE Agita - WOLFE Charles (2003), *The Unfortunate Generation: stroke survivors in Riga, Latvia*, "Social Science and Medicine", vol. 56, 2003, pp. 2097-2108.
- NUSSBAUM Martha C. (1999), *Sex and social justice*, Oxford University Press, New York.
- PUTNINA Aivita (2001), *Medicine and change: making agency count*, pp. 381-393, in VAN DONGEN Els - COMELLES Josep M. (eds.) (2001), *Medical Anthropology and Anthropology. Contributions of Medical Anthropology at Home to anthropological theories and health debates*, "AM. Rivista de la Societ  italiana di antropologia medica", vol. 11-12, 2001 (dedicado a las Actas de la Reuni n de la red Medical Anthropology at Home celebrada en Tarragona, 19-21 abril 2001, vol. I).
- SCHEPER-HUGHES Nancy (1992), *Death without weeping: the Violence of everyday Life in Brazil*, University of California Press, Berkeley - Los Angeles.
- SHWEDER Richard A. (1991), *Thinking through cultures. Expeditions in cultural psychology*, Harvard University Press, Cambridge.
- SKULTANS Vieda (2003), *From damaged nerves to masked depression: inevitability and hope in Latvian psychiatric narratives*, "Social Science and Medicine", vol. 56, 2003, pp. 2421-2431.
- SKULTANS Vieda (1999), *Narratives of the Body and History: Illness in Judgement on the Soviet Past*, "Sociology of Health and Illness", vol. 21, n. 3, 1999, pp. 310-328.
- SKULTANS Vieda (1998), *The Testimony of Lives. Narrative and Memory in Post Soviet Latvia*, Routledge, London.
- VIRKSNE Rud te, *Repressions against Latvian population in 1940/1941 -1944/1945: the common and the different*, URL Crimes against Humanity. Latvian Site (accessed on 21/02/04): <http://vip.latnet.lv/lpra/viksne.htm>.

1.6 *Risk, choice and self-management of type 1 diabetes.*

Reflections on medicalisation, resistance and the political ethics of agency

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The original title for this paper was *The political technology of in/formation and choice*. My aim was firstly, to present a key discussion in my dissertation on the operations of the risk concept in contemporary Norwegian diabetes care. This discussion relates to the practices through which individuals are “in-formed” into particular subject positions in the increasingly prominent medical regimes referred to as self-management⁽¹⁾. Essential to the establishment of such regimes are the specific practices, rationalities, and techniques through which risk is construed as a governable entity. Secondly, I wanted to link these discursive practices of medical information to a prominent rhetorical feature in Norwegian society, beyond the confines of health discourse strictly defined. This feature I refer to as the rhetoric of “choice”. It involves a burgeoning practice whereby the verb *to choose* is used actively and explicitly in accounts of actions, experiences and histories of oneself and others. It includes the use of the active verb even in contexts characterised by the opposite of choice, in the conventional sense; as when there are only illusory alternatives or when choice is between attractive and indisputably unattractive alternatives. Through this rhetorical practice, it appears, actions and experiences are grounded in the individual – now the determining source of what transpires – and made into the historical expressions of personal, individual natures.

However, as I pondered how to best present the argument, I was once again struck by a difficulty that arose in my original analysis of the tension between empowerment-based self-management regimes in serious illness

and the contemporary rhetoric of choice. The difficulty I believe is a general one affecting studies of contemporary medical practice in the so-called late modern societies, and it involves the problem of how to account theoretically for subjection in a social field dominated by widely endorsed philosophies of individual agency, empowerment and independence (CRUIKSHANK B. 1994). In the wake of the sweeping medicalisation critiques of the 1970s, as Margaret Lock has pointed out, ethnographic research in the 1990s has demonstrated that «the responses of individuals, families and communities to medicalisation are complex» (LOCK M. 2001: 481). In Lock's example from the context of fertilisation technologies, the dilemma is stated clearly:

«[When] women seek out and make use of biomedical technologies, this may not be evidence of independent agency on their part, although often it is or is claimed to be the case. Biomedical technologies can assist women in achieving a modicum of independence from oppressive circumstances, or they may permit them to fulfil personal desires, often to have a child. However, women's behavior can equally well be due to a desire to "please" others [...] or, alternatively, to untoward pressure exerted by others. It is clear that women frequently respond to the expectations of partners, extended families, women's groups, or communities rather than single-mindedly pursuing what might bring about their own personal desire or comfort» (LOCK M. 2001: 481-482, emphasis added).

According to Lock, these findings give rise to a call for a refinement of concepts such as agency and autonomy, medicalisation and resistance, to enable analysis to accommodate the pragmatism with which people appropriate medical knowledge and technologies (LOCK M. 2001).

This task is today complicated by the dominance of panoply of research undertaken by health behaviourists in the fields of (health) psychology, nursing, and medicine, but also certain sociologies and anthropologies of medical thought and practice (OGDEN J. 2002). Although it is rarely accounted for theoretically, this surging wave of research is one that treats their object of study to as rational consumers of what medicine has to offer, strips them of context or treats social environments only to the extent that the rational individual subject brings such forces into her/his narrative), and de-socialises the determinants of sickness and people's perceptions. It is characteristically carried out through quasi-quantitative research procedures, albeit frequently under a prominently advertised commitment to qualitative method (BOURGOIS P. 1999).

In my view, these researches are influential today in part because they operate with formalised and easy-to-use research protocols that make such studies seem replicable and capable of generating comparable results. In

other words, they appear to meet the hallmark criteria of scientific objectivity that make research findings palatable to many largely quantitatively oriented institutions responsible for health research and public health interventions. However, it seems plausible to suggest that their prominence is driven also by their correspondence with a historical, cultural and political moment that acknowledges only the individual body, that dissolves intermediary levels of community (between state and individual), insists on an ideology of individual responsibility, privileges the subjective point of view, and which is inherently sceptical to analyses that threaten the ideologically invested autonomous individual. It is a moment, therefore, in which analyses of intentionality, agency and autonomy sit uneasily. For, in such a setting, what can be said about participants in research that they do not already themselves articulate verbally? The tension is discernible in Lock's discussion of autonomy quoted above, in two conspicuous distinctions: on the one hand, the distinction between *real* and *claimed* individual agency, and, on the other, that between intentionality that emerge from within the individual ("single-minded pursuit" of "personal desire and or comfort") and intentionality that intrude, as it were, from (the social) outside ("responses" to the "expectations of others").

In what follows, I will present my argument concerning what we may call the moral informatics of the self-managing Norwegian subject, in order to question it from its own point of view, as it were; that is, from the ideologically charged questions of legitimate and illegitimate sources of individuality and agency. The discussion is based on data generated in the course of fourteen months of fieldwork in southeastern Norway, based primarily in two health care institutions (a local hospital and a specialised institution for patient education)⁽²⁾. In addition to participatory and non-participatory observation data from these contexts, the main bulk of the material was generated from following a group of 10 young adults with type 1 diabetes and their friends and families over a twelve to eighteen months period; attending national and international medical scientific meetings, analysis of textual and audiovisual material, and interviews with key informants in specific fields. A full description of the methodology and analysis of the study is available elsewhere (HILDEN P. K. 2003).

A normative practice of self-governance

As my original title reflected, I consider the phenomena of information and self-management to be part of a general economy of discourse through

which political functions are performed and political ends are pursued. In everyday usage, information has a simple meaning of imparting knowledge. However, in the context of the risk-epidemic (FUREDI F. 1997, SKOLBEKKEN J. A. 1995) and the audit explosion (POWER M. 1997, STRATHERN M. 2000) as emergent pivotal modes of governance in medical and meta-medical domains of Euro-American societies, the concept of information is accumulating moral and political (in Douglas terms “forensic”) weight well beyond its everyday innocence (CASTELLS M. 1999, DOUGLAS M. 1990). My analysis of patient education processes in this study demonstrates how the health education and training offered to persons with diabetes aim at *forming participants into particular roles or positions* through the projection of particular individualities. On this view, diabetes health education can be seen as a process which provides *the inner form of possibility and “choice”*. A person who is thus *informed* may be taken to enter a certain point or position from which some phenomena are within sight and others not, from which certain ‘facts’ emerge or triumph, and others do not, and, hence, from which certain “choices” are rational and others not. In order to mobilise this more subtle sense of the term, I proposed to speak of “in/formation” rather than the every day “information”⁽³⁾.

As my choice of terms indicates, my approach to these issues has been guided by a perspective derived from the conceptual framework of governmentality and biopower, as developed after Foucault⁽⁴⁾. Here, micro-level social lives in the context of neo-liberal European societies are not seen as minuscule objects upon which monolithic institutions of state power work but, on the contrary, the localised everyday sites of decentralised and, even, more or less unwitting and voluntary, self-policing exertions of power. In fact, the type of ethnographic questioning I have been involved in is centred on an attempt to raise a very Foucauldian type of question. What kind of subject does such a mode of governance require? How does this subject come about? What kind of subject is a morally integrated Norwegian person today? There are reasons for *medical anthropologists* to be particularly vexed by such lines of questioning. As has been pointed out by a number of sociological commentators, «‘health’ is a key concept in the fashioning of identity for the modern and contemporary middle class» (CRAWFORD R. 1994). Indeed, as Joao Biehl and colleagues will have it, «contemporary techno-scientific and medical developments are [not only] restructuring social interactions [but also] the very processes by which individual subjectivity is formed» (BIEHL J. - COUTINHO D. - OUTEIRO A. L. 2001, cfr. also DUMIT J. 1997, RABINOW P. 1992, RAPP R. 1999). In the view of one commentator, the downfall of collective ideologies of progress in

the West has turned Westerners in on their bodies, as the ultimate remaining site for late modern progressive projects; hence the public domain is saturated with “somatopic” imagery, activities, lifestyles (CHRYSANTHOU M. 2002) ⁽⁵⁾.

In line with a governmentality perspective, my analytical approach to the social phenomenon of therapeutic self-management regimes frames the phenomenon in the demands of a socially reductive model of subjectivity. Biomedicine is centrally involved in the production of this model. It permeates Norwegian health discourse and, eventually, contemporary Norwegian understandings of moral personhood. The model is one that imbues the individual with the responsibility of tracking down and controlling sources of health risk in her or his life. As Richard Crawford has pointed out, at the crucial centre of this model sit intensified mandates of self-control (CRAWFORD R. 1984). These mandates involve an insistence that such action on the part of the individual is not only possible but also the definitive trait of a morally integrated, rational, responsible and purposeful person.

This model subject has been scrutinized from many perspectives, not least of which are critical analyses of citizenship and neo-liberal politics (CRUIKSHANK B. 1994), and what Alan Petersen and Deborah Lupton refer to as the New Public Health (PETERSEN A. - LUPTON D. 1996). What is important to emphasise here is that the *wellspring of health* for the model subject of the New Public Health, is to be found intra-subjectively, in the optimal configuration and mobilisation of intra-subjective resources⁽⁶⁾. While the surroundings are of course of relevance to the health of the individual, the environment is here treated as a space from which information emerges, to be processed by the individual who “reads” it. According to this view, it is in the nature of the adequately constituted individual subject to act upon such information in specific ways once it is received and processed. We find the indications of this intra-subjective dynamic in the headings of a panoply of research programs undertaken under this paradigm, with the Health Belief Model (HBM) as the prominent point of departure (BECKER M. 1974, ROSENSTOCK I. 1966), but since then amended through notions such as “*locus of control*”, “*sense of coherence*”, “*self-efficacy*”, and so forth. The early critique of HBM denounced its rationalist bias, its lack of recognition of variations in symptom perception, its inconsistent operationalisation, and so forth. Soon, however, the main objection focused on the failure of HBM to include the question of the individual’s degree of confidence that what he or she set out to do could be accomplished. Hence Bandura famously introduced the tremendously influential (in health research) notion of self-

efficacy (BANDURA A. 1977, 1997). Building upon Bandura's work, we find amendments in programs such as Protection Motivation Theory (ROGERS R. 1983), the Health Action Process Approach (SCHWARZER R. 1992), among quite a few others. I suspect that a closer history of science review would reveal that a conspicuous proportion of these theoreticians have worked in the field of diabetes care.

In a recent essay, Jane Ogden has called the model of the subject involved here the model of the intra-active individual. This is a model, Ogden points out, that in effect localises *health risk* in the depths of the intra-individual psyche (OGDEN J. 2002). Thus, for example, although the HIV-virus was seen as the carrier of disease, AIDS prevention soon identified the ability of the individual to control sexual "behaviour" as the risk factor for infection. Hence, the determinants of behaviour were established as the appropriate target of intervention, and since these were localised internally in the individual subject, that internal psychological space was established as the site of intervention. In this perspective, «diseases such as cervical cancer do not constitute a risk to health in themselves but reflect the individual's ability to have regular screening and to take preventive action.» (OGDEN J. 2002: 27)

In my own research, I have called the figurehead of this model the *risk actor*, and emphasised the model's normative moral nature in self-management education, in addition to whatever methodological and analytical uses to which it is put as constituent of contemporary research programs. In fact, it is Ogden's argument that the normative moral thrust of the model derives in no small part from its apparent scientific origin in the social science disciplines⁽⁷⁾. The rhetoric of choice is conspicuously positioned with regard to this model in the context of self-managed diabetes. Type 1 diabetes is a chronic disease with fatal consequences lest the deficient insulin production is compensated. Thus, there is no choice but to adhere in some measure, to the treatment plans one is offered. Nevertheless, the rhetoric of choice permeates two dimensions of diabetes treatment discourse. On the one hand, rhetoric of choosing saturates self-management philosophy. The choice invoked here, however, refers to the choice to adhere to a particular treatment modality, namely intensive, multi-injection insulin therapy. This treatment modality involves a comprehensive set of daily practices through which a normalisation of blood glucose levels is pursued. Multi-injection insulin therapy, the default treatment modality in current diabetes care in Norway, is a treatment modality that takes its rationale not primarily from the wish to alleviate symptoms of diabetes in daily life, but from the prioritized objective to minimize the risk for late

complications. The treatment modality is comprehensive, and replaces daily life symptoms with daily-life self-doctoring practices of self-surveillance and self-medication.

When the term choice is used in this setting, its idiom is individual mastery and control. This discourse positions the attractive choice as the choice to “take control”, and the attractive subject as a masterful agent, in control of her/his own fate and circumstances. The marketing of diabetes pharmacological products and treatment technologies provide the perhaps most explicit and conspicuous examples of this, as illustrated in figure 1. Here, a computer software application that offers to perform statistical analyses on blood sugar measurements downloaded from portable electronic self-measurement devices, is advertised with a free-falling sky diver. The accompanying text reads: «Accu-Chek Compass. Full control and total overview/survey⁽⁸⁾.»



Fig. 1

The second practiced invocation of the action and possibility of choice can be found in the accounts of individual persons with diabetes themselves. In particular, the notion of choice occurs in accounts of self-treatment fail-

ures, in conversations and reflections triggered by poor clinical tests and laboratory measurements that point to poor risk status with regard to the development of diabetic late complications. Thus, one may admit to having performed poorly in that one has ignored blood sugar measurements, skimmed insulin injections, and so forth, yet gain recognition for such “failures” through reference to these actions as the results of choice. In fact, a normative pressure can be discerned in the following direction: adherence as well as non-adherence – or periodic skimping – *should* be accounted for by reference to active, individual choice, and this is the crucial point I wish to point to here. While in everyday clinical parlance compliance in the diabetes care context is understood as adherence to treatment plans, a second, more fundamental evaluation of compliance is in operation, whereby adherence to treatment plans may ultimately in fact constitute “non-compliance”. To make myself clear, it is an understanding according to which perfect adherence to treatment, accompanied by perfect, on-target, clinical and laboratory scores may nevertheless be in breach with the ideology of self-treatment. At the centre of this paradox is the notion and rhetoric of (individual) choice.

Choosing to be a chooser

Let me elaborate briefly. On the one hand, surrender to a comprehensive dependence on a medical regime is necessary. It is appropriate to speak of surrender here, in the sense that the viability of the dependence inheres in the medical knowledge, pharmaceutical substances and medical technologies that combine to make up the therapeutic regime. It therefore inheres in objects and knowledge whose production and constitution is mostly beyond the sphere of influence of the person whose survival relies on them. That person must trust in their capacity to perform the promised therapeutic effects; in short, she/he must take them or leave them.

On the other hand, this surrender “must” happen because the individual *wills it to happen*. In addition to the conventional explicit understanding of compliance, a tacit set of assumptions – a tacit ideology (YOUNG A. 1980) – is in operation that demand the individual surrender to come about as a result of an active, independent choice. Several narratives circulate in diabetes care to bring out this feature. For instance, one anecdote, which has the form of a hearsay tale, tells of a young girl who, a few years after diagnosis, has accomplished perfect blood sugar control. This is evident from her laboratory tests, which all demonstrate on-target average blood sugar

levels. Her diabetes diary, in which instant self-measured blood glucose levels and insulin dose adjustments are meticulously recorded, indicates it also. However, upon closer investigation, the story goes, the test results turn out to hide a peculiar everyday practice. Having been taught by medical personnel how to measure blood glucose levels, calculate rapid acting insulin doses, inject insulin, and so forth, the girl is revealed to have assumed a life in social passivity and seclusion, so as better to pursue the medical advice she had been given. Seated in front of a desk, with all her implements in front of her, she let her life be transformed into a self-less and ceaseless execution of self-doctoring practice: measuring, dosing, eating – measuring, dosing, eating.

The operation of the risk actor model of the subject in Norwegian diabetes care is indicative of a contemporary conceptual poverty with sinister consequences. By virtue of this model, the subject, whose diabetes self-treatment is inescapably embedded in social relationships that may obstruct its perfect operation, is left to be rescued by yet another appeal to inner nature. Yet it is a strange impasse, fraught with unarticulated dilemmas. It is evident to all that, firstly, occasional downs in self-management quality happen to the most knowledgeable among persons with diabetes. Few even among the most hardheaded diabetes educationalists would contest this proposition. Second, it is generally recognised also that the management of diabetes is inescapably embedded in social life. Indeed, the nature of the disease begs the question. Diabetes is a disorder in metabolism of glucose. Not only is “the metabolism of glucose” a medical technical term, one may say, for the social practice of nourishment and energy expenditure; the metabolic process is also considered sensitive to almost every imaginable aspect of life, including physical activity levels and emotional states. This means that perfect management, it is generally acknowledged, is a theoretical possibility, to be adjusted by real life concerns. The glass-of-milk anecdote indicates as much.

Type 1 diabetes and the operative notions of choice with the link between the paradoxes of freedom and contingency manifest my interest here. Needless to say, then, if self-management is self-doctoring, the story was unequivocally understood to exemplify self-medical “malpractice”. Countless illustrations could be given of this pattern of evaluation. Indeed, I would propose that, to medical personnel, a non-adherent patient who presented her or his non-adherence in the ideological terms of independence is less enigmatic and, in practice, an “easier” patient to deal with, than a person who refuses to emulate the risk actor model by refusing to assume a position of independent choice. This analysis is corroborated by

what I observed also dialogues and interactions in clinical settings. Briefly put, wrong choices are much more acceptable than no choices at all.

If reliance on others is an ideological liability, it is tempting to understand the insistent last-resort appeal to inner individual desires as an effective compensatory strategy. To claim that the demands of others are responsible for one's own poor blood glucose regulation would be as self-negating as the self-therapeutic failure it was mobilised to explain in the first place. Instead, any reference to the demands of others must be made via the active, unrestrained will of the individual to accommodate these demands. Only then is the ideological compliance realized and this, I concluded, is what is accomplished by the rhetoric of choice. The ultimate non-compliance would be to abdicate one's position as a "chooser", to insist that others should choose on one's behalf. Thus, the ideological demand, permeating diabetes treatment discourse may be stated as a command: "Thou hath no choice but to be a chooser." In this matter, and in this matter only, there is no viable choice.

Power, resistance, and the subjective point of view

While I wish to sustain the basic argument, I reread literature while preparing this paper that made me question it in a crucial respect. The problem is related to resistance, and it is made more alarming by two related implications of the analysis. First, the analysis in effect contradicts the understanding of moral subjects expressed, even celebrated, in the cultural world it describes. Among other things, it therefore raises the question of what grounds one may invoke in defence of a differential epistemological status of researcher and researched. Secondly, the analysis may be taken to suggest by implication the possibility of an emancipated, extra-discursive space for human subjectivity. Thus, it raises problems related to positionality and grounds for criticism.

These issues are of course each too large to be considered adequately in this paper. The Norwegian situation presented here may nevertheless contribute a dimension to an understanding of how the problems of positionality and criticism are currently situated. It is my contention that social studies of medical phenomena are under the influence today of an ethics of representation that promotes a simple *re*-presentation of verbalised reflections elicited in the course of quasi-quantitative, structured qualitative research to the detriment of the development of analytical linkages, interpretation and analysis. In terms of the old anthropological problem of

emic understandings and etic analyses, that is, the problem of the relationship between indigenous models of reality on the one hand, and those described and compared according to the anthropological observer's criteria on the other, we are under pressure to stick to the emics of our research. That is, in research undertaken under the aegis of individualist consumerism, etics are done away with, as it were, by appeal to the articulated interpretations offered by participants ("informants") themselves. At the basis of this ethics of discourse is an epistemological privilege on subjective experience; it is an epistemological outlook that translates Geertz' "native point of view" into "the subjective point of view". It is an orientation that prioretises the utterances of individuals and undermines the power of observation. Thus, to my view it is an outlook that not only castrates ethnography but, more gravely, one that misrepresents the process of social science research through strategies of legitimization that cloak interpretation in quotations, and obscures the nature of analytic work through rhetoric styles that overstate the co-authorship of participants in research.

A large and growing corpus could of course be reviewed to substantiate and nuance these claims. I do not wish to overrate the dominance of these orientations in actual processes of investigation, although I fear it is great and increasingly adopted in research among impoverished and underserved populations. Moreover, as I have indicated, the emergence of this ethics of investigation is historical and its historicity deserves proper investigation. While these tasks cannot and should not be taken lightly, neither is my task here. What I wish to emphasise is that, however influential this wave of research may turn out to be in terms of practiced research models in health research, it seems plausible to suggest that it is indicative of a general epistemic turn towards the individual as a self-contained unit of psychosocial analysis, and one that impedes our current ability to integrate in research a sensitivity to the "messy actualities" (BARRY A. - OSBORNE T. - ROSE N. 1993) of power in micro-social relationships.

On the other hand, analytical modesty may also be warranted. In my own analysis, I view the rhetoric of choice as an ideological device, a discursive technology of governance. Thus, the use by individuals of this rhetoric in discourses like the ones described here, is seen to provide ideologically sanctioned «moments of verification of moral aptitude», to use Monica Greco's phrase (GRECO M. 1993). I took great pains to elucidate empirically the discursive means by which the hegemonic discourses were challenged, resisted and subverted. But the question is how instances of resistance and subversion can be understood analytically, given the pervasive nature of the ideology of individualism that characterises the contexts in which it

occurs. Indeed, how can resistance be conceptualised if the basic tenets of the risk actor model saturate all available concepts for animating the subject? For, there is an uncanny congruence of concepts here; if choice is used to ground submission to medicine in the will of the subject, it is certainly used also to ground resistance! Thus, for instance, a 38 year old driver and self-declared workaholic, who suffered several strokes, the onset of diabetic blindness and several other, severely debilitating developments in the course of our acquaintance, accounted for his demise with reference to his own “bad choices”. On the other hand, these choices were also “right” since, *qua individual choices*, they were linked to his true desires and inner nature. Hence they mobilised an underlying dimension of the rhetoric of individuality and choice, by which truthfulness to inner nature may be turned against the pressure to conform to standards set by others, including biomedical others⁽⁹⁾. Thus, the driver could turn his problems to be the outcome also of the “bad choices” of others, such as “insensitive doctors” and “moralising nurses”. It seems to me that there is a danger in analyses of such cases, to simply view them as instances of cultural, subcultural or other “difference”, and thereby reproducing assumptions of boundaries built into the intra-active risk-actor model itself.

I believe my problem here to be illustrative of a general difficulty in medical anthropological research. This difficulty is embodied in the tendency to assume a too dichotomous perspective on hegemony and resistance. Among the consequences of such rigid binaries are, firstly, that we thereby complicate the analysis of change. Secondly, failure to situate resistance within the discursive field dominated by hegemony may lead us to underestimate the mutual complicity of hegemonic and resistant discourses. As Lorna Weir points out, we thereby run the considerable danger of erasing the history of counter-discourses from the histories of the programmatic, hegemonic discourse in question (WEIR L. 1996, quoted in O'MALLEY P. - WEIR, L. - SHEARING C. 1997). This would lead to a serious impasse for any account of the history of diabetes and diabetes care in Norway. Here, perhaps more than elsewhere, the evolution of treatment and care has moved through a series of disputes and collaborations between grass roots lay advocacy and biomedical expertise, both incorporated in one diabetes organisation since the inception of the Norwegian Diabetes Association in 1948. Thirdly, a too dichotomous perspective on hegemony and resistance risks mystifying the sources of resistance. In effect it suggests the possibility of an extra-discursive subjective space for the “truly independent” person with diabetes. While this is admittedly in line with what Giddens refers to as the emancipatory politics of

Western modernity (GIDDENS A. 1991), it is fraught with analytic difficulties (cf. McNAY L. 1994, ROSE N. 1996).

In conclusion, then, I would like to suggest that what is needed is an approach capable of integrating a privilege on the subjective point of view with an analysis of how subjection is *linked also to the possibilities of resistance*. This integration may fruitfully approach hegemonic discourses, such as that of self-management on diabetes and other chronic diseases, and resistance to hegemonic discourse as existing within a commonality of discourses. Examples of such a mode of analysis can be found among a segment of studies in the so-called governmentality literature (cf. e.g. ASHENDEN S. 1996, DEAN M. 1999, GRECO M. 1993, WEIR L. 1996, for a review of the governmentality literature from the perspective of resistance, cf. O'MALLEY P. - WEIR L. - SHEARING C. 1997). But a similar logic can be found also in Richard Crawford's article, *A cultural account of 'health'*, published in 1984, in which he explores the central prominence of notions of self-control *as well as* notions of release in North-American health-discourse (CRAWFORD R. 1984). Crawford does not situate the notion of release as external to the imperative to execute self-control prominent in medical and public health discourse. Rather, he places these notions in a mutual cultural dialectic, and links that dialectic to the larger structural opposition in American society between discipline – as workers, on the labour market – and indulgence – as consumers of commodities. Contemporary Americans, Crawford writes,

«[...] are the objects and subjects of two opposing mandates, two opposing approaches to the attempt to achieve well-being. The opposition is structural. At the level of the social system it is a principal contradiction. The culture of consumption demands a modal personality contrary to the personality required for production. The mandate for discipline clashes with the mandate for pleasure» (CRAWFORD R. 1984: 92).

Despite significant cultural differences between the Norwegian and the North American societies – the persistence in Norway of a pietistic scepticism towards indulgence perhaps being among them – I believe a similar dynamic can be discerned also in the Norwegian situation.

In other words, resistances may be envisaged as generated by, or at least embedded in, the same discursive technologies that generate biomedically proscribed self-management (DEAN M. 1999). A useful starting point for such an analysis may be to add to Foucault's notion of technologies of self a notion of *technologies of agency*, as suggested by Lorna Weir (WEIR L. 1993) and others⁽¹⁰⁾; that is, the symbolic, discursive and practical means by which subjectivity is continuously achieved⁽¹¹⁾.

The evocation of choice, then, may very well function to align the person with type 1 diabetes with the individualizing and privatizing ethics of responsibility that characterises the treatment regime to which she or he is expected to surrender. On the other hand, one may see subjection and resistance as mutually reliant on a set of discursive technologies of agency. Hence, the evocation of choice – both to surrender to medical regimes and to resist them – may be understood as dimensions in a ritual of identity and justification, without overstating the ideology of self-determination that remains foundational to action and moral justification in the cultural order of our societies.

Notes

⁽¹⁾ The English term self-management is translated into *selv-behandling* (lit. “self-treatment”) in the Norwegian context from which this paper is drawn, which corresponds with the sometimes synonymous use of “self-management” and “self-treatment” in English language literature on treatment of diabetes and other chronic disease. A distinction can be drawn between self-treatment regimes, and self-care, as a more general term denoting practices directed towards self-protection and self-sustenance as defined by individual actors. Following Foucault, the philosophy and practice of self-management that is considered in this paper, may be seen as a historically and culturally specific example of a notion of self-care that has long antecedents in Western thought (FOUCAULT M. , 1988, 1990).

⁽²⁾ The hospital unit featured an endocrinological ward as well as an out-patient clinic. With the exception of patients hospitalised because of acute diabetic complications (hyperglycaemia and hypoglycaemia), and also of elderly patients with diabetes hospitalised for other reasons, diabetic patients were to be found in the out-patient clinic, where they come for routine consultations with a medical doctor responsible for their treatment (normally once a year), diabetes nurse (every 3-4 months) and, in some cases, consultation with other health personnel (dietician, physiotherapist). The specialised institution for diabetes patient education.

⁽³⁾ I am grateful to Thomas Csordas who first pointed out to me the etymological potential of the term information. The verb ‘to inform’ derives from the Latin *in-* and *formare*: to form, to give form to, to put into form or shape. Among the historical uses of information in English, the entries of the Oxford English Dictionary mentions “to give form to the mind, to discipline, instruct, teach, furnish with knowledge,” and “the action of forming or moulding the mind or character” (SIMPSON J. A. - WEINER E. S. C. 1989).

⁽⁴⁾ Various branches of Foucault’s interests are drawn upon by these authors, but his later work on sexuality and technologies of the self on the one hand (1990, 1988), and selected lectures and writings on governmentality and biopower on the other (cf. FOUCAULT M. 1991 and several selections in RABINOW P. 1994 and in MARTIN L. H. - GUTMAN H. - HUTTON P.H. 1988).

⁽⁵⁾ Chrysanthou proposes the neologism *somatopia* to refer to this phenomenon, since, in his view, it involves the replacement of collectivist *utopic* political projects of the modernist past, with *somatic* projects of postmodern individuals (CHRYSANTHOU M. 2002).

⁽⁶⁾ This dimension of the model subject is analysed by OGDEN J. (1995), who traces its production and maintenance also in social science health research (OGDEN J. 2002), cf. below.

⁽⁷⁾ While Ogden speaks of social science broadly, her analysis is in fact based on the rather restricted fields of health psychology and selected subfields of medical sociology.

⁽⁸⁾ The Norwegian term used, *oversikt*, is a combination of the preposition “over”, equivalent to the English “over”, and *sikt*, which can be translated as view/gaze/sight/visibility.

⁽⁹⁾ I describe elsewhere the sinister psychological paradoxes that are generated by this phenomenon, since it positions the subject both as his own master and executioner (HILDEN P.K. 2003).

⁽¹⁰⁾ Cf. e.g. Cruikshank’s discussion of the technologies of citizenship (CRUIKSHANK B. 1994).

⁽¹¹⁾ Vincent Colapietro’s book, *Peirce’s approach to the self*, provides an eloquent and instructive discussion of the semiotic approach to subjectivity that underlies my reformulation of agency technologies here (COLAPIETRO V. 1989).

Bibliography

- ASHENDEN S. (1996), *Reflexive government and child sexual abuse: liberal welfare rationality and the Cleveland Inquiry*, “Economy & Society”, n. 25, 1996, pp. 64-88.
- BANDURA A. (1977), *Social learning theory*, Prentice-Hall, Englewood Cliffs NJ.
- BANDURA A. (1997), *Self-efficacy: the exercise of control*, Freeman, New York.
- BARRY A. - OSBORNE T. - ROSE N. (1993), *Liberalism, neo-liberalism and governmentality: an introduction*, “Economy and Society”, n. 22, 1993, pp. 265-266.
- BECKER M. (1974), *The health belief model and personal health behavior*, “Health Education Monographs”, n. 2, 1974, pp. 324-508.
- BIEHL J. - COUTINHO D. - OUTEIRO A. L. (2001), *Technology and affect: HIV/Aids testing in Brazil*, “Culture, Medicine and Psychiatry”, n. 25, 2001, pp. 87-129.
- BOURGOIS P. (1999), *Theory, method and power in drug and HIV-prevention research: a participant-observer’s critique*, “Substance Use and Misuse”, n. 34, 1999, pp. 2153-2170.
- CASTELLS M. (1999), *The information age: economy, society and culture*, 3 vols., Blackwell, Oxford.
- CHRYSANTHOU M. (2002), *Transparency and selfhood. Utopia and the informed body*, “Social Science and Medicine”, n. 54, 2002, pp. 469-479.
- COLAPIETRO V. (1989), *Pierce’s approach to the self. A semiotic perspective on human subjectivity*, State University of New York Press, Albany.
- CRAWFORD R. (1984), *A cultural account of “health”: control, release and the social body*, pp.60-103, in MCKINLEY J. B. (ed.), *Issues in the political economy of health care*, Tavistock, London.
- CRAWFORD R. (1994), *The boundaries of the self and the unhealthy other: reflections on health, culture and Aids*, “Social Science & Medicine”, n. 38, 1994, pp. 1347-1365.
- CRUIKSHANK B. (1994), *The will to empower: technologies of citizenship and the war on poverty*, “Socialist Review”, n. 23, 1994, pp. 28-52.
- DEAN M. (1999), *Risk, calculable and incalculable*, pp. 131-159, in LUPTON D. (ed.), *Risk and sociocultural theory: new directions and perspectives*, Cambridge University Press, Cambridge.
- DOUGLAS M. (1990), *Risk as a forensic resource*, “Daedalus”, n. 119, 1990, pp. 1-16.
- DUMIT J. (1997), *A digital image of the category of the person*, pp. 83-102, in DUMIT J. - DOWNEY G. L. (eds.), *Cyborgs & citadels : anthropological interventions in emerging sciences and technologies*, School of American Research Press, Santa Fe NM (School of American Research Advanced Seminar Series).
- FOUCAULT M. (1988 [1984]), *The history of sexuality*, vol. III. *The care for the self*, Vintage Books, New York [orig. ed.: *Histoire de la sexualité*, vol. III. *Le Souci de soi*, Gallimard, Paris, 1984].
- FOUCAULT M. (1990 [1976]), *The history of sexuality*, vol. I. *An introduction*, Vintage Books, New York [orig. ed.: *Histoire de la sexualité*, vol. I. *La volonté de savoir*, Gallimard, Paris, 1976].
- FOUCAULT M. (1991), *Governmentality*, pp. 87-104, in BURCHELL G. - GORDON C. - MILLER P. (eds.), *The Foucault effect: studies in governmentality*, Harvester Wheatsheaf, Hemel Hempstead.

- FUREDI F. (1997), *Culture of fear: risk taking and the morality of low expectation*, Cassel, London.
- GIDDENS A. (1991), *Modernity and self-identity: self and society in the late modern age*, Polity Press, Cambridge.
- GRECO M. (1993), *Psychosomatic subjects and the "duty to be well": personal agency within medical rationalities*, "Economy and Society", n. 22, 1993, pp. 357-72.
- HILDEN P.K. (2003), *Risk and late modern health: socialities of a crossed-out pancreas*, Dr. Philos., Universitetet i Oslo.
- LOCK M. (2001), *The tempering of medical anthropology: troubling natural categories*, "Medical Anthropology Quarterly", n. 15, 2001, pp. 478-492.
- MARTIN L. H. - GUTMAN H. - HUTTON P.H. (eds.) (1988), *Technologies of the self: a seminar with Michel Foucault*, Tavistock, London.
- MCNAY L. (1994), *Foucault: a critical introduction. Key Contemporary Thinkers*, Polity Press, Cambridge.
- O'MALLEY P. - WEIR L. - SHEARING C. (1997), *Governmentality, criticism, politics*, "Economy and Society", n. 26, 1997, p. 4.
- OGDEN J. (1995), *Psychosocial theory and the creation of the risky self*, "Social Science and Medicine", vol. 40, n. 3, 1995, pp. 409-415.
- OGDEN J. (2002), *Health and the construction of the individual: a social study of social science*, Routledge, London.
- PETERSEN A. - LUPTON D. (1996), *The new public health: health and self in the age of risk*, Sage, London.
- POWER M. (1997), *The audit society: rituals of verification*, Oxford University Press, Oxford.
- RABINOW P. (1994), *Michel Foucault. Ethics, subjectivity and truth*, The New Press, New York.
- RABINOW P. (1992), *Artificiality and enlightenment: from sociobiology to biosociality*, pp. 234-252, in CRARY J. - KWINTER S. (eds.), *Incorporations*, Zone Urzone, New York.
- RAPP R. (1999), *Testing women, testing the fetus: the social impact of amniocentesis in America*, Routledge, New York.
- ROGERS R. (1983), *Cognitive and physiological processes in fear appeals and attitude change: a revised theory of protection motivation*, pp. 153-176, in CACIOPPO J. - PETTY R., *Social psychology: a source book*, Guilford Press, New York.
- ROSE N. (1996), *Inventing our selves: psychology, power and personhood*, Cambridge University Press, Cambridge.
- ROSENSTOCK I. (1966), *Why people use health services*, "Millbank Memorial Fund Quarterly", n. 44, 1966, p. 94.
- SCHWARZER R. (1992), *Self-efficacy in the adoption and maintenance of health behaviours: theoretical approaches and a new model*, pp. 217-244, in SCHWARZER R. (ed.), *Self-efficacy: thought control of action*, Hemisphere, Washington.
- SIMPSON J. A. - WEINER E. S. C. (1989), *The Oxford English dictionary*, 2nd edition, Clarendon Press, Oxford.
- SKOLBEKKEN J.-A. (1995), *The risk epidemic in medical journals*, "Social Science and Medicine", n. 40, 1995, pp. 291-305.
- STRATHERN M. (ed.) (2000), *Audit Cultures. European Association of Social Anthropologists*, Routledge, London.
- WEIR L. (1996), *Recent developments in the government of pregnancy*, "Economy & Society", n. 25, 1996, pp. 373-92.
- YOUNG A. (1980), *The discourse on stress and the reproduction of conventional knowledge*, "Social Science and Medicine", n. 14B, 1980, pp. 133-146.

1.7 *The generalized sign of the atomized subject of mass media and public health*

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The not (fully) articulated generalized sign of a 'you'

We are ceaselessly confronted with messages and information on risk and (ill)health. In public discourse, we encounter and hence, at some level, necessarily interact with a never-ending stream of risk-related messages directed at us as individuals. In these messages the singular personal pronoun of 'you'⁽¹⁾ or the possessive singular 'your' is used extensively. Examples of this are: 'This is how you control your craving for sugar' or 'Check *your* risk of coronary heart disease'. This paper is based on the assumption that the endless series of similar (if not identical) images or signs which all targets a 'you', over time, will generate or produce a generalized sign which mediates meaning that goes beyond and is other than that which is conveyed by the single individual signs. I hypothesize that a generalized sign – *a type* – has been generated and, consequently, that the individual signs in public discourse on risk and (ill)health are currently functioning as individual instances or *tokens*⁽²⁾ of this generalised sign/type. It is in interaction with this type that the individual tokens gain their meaning. As a type, the generalized sign is not (fully) articulated. Instead we encounter it through its individual instantiations, that is, through those (diverse) tokens, 'you' or 'your', we are confronted with, and through which we receive risk-related-messages. Hence, we are engaged in ongoing interaction with the type through its tokens. As the meaning of the type is not explicitly articulated, an exploration of some of the meanings it nevertheless conveys and with which we interact is what is aimed for in this paper.

This discussion draws upon a study on cultural perceptions of risk and (ill)health in contemporary Norway. In that study, mass-media served as the main ethnographic case. Over a period of three months the coverage on (ill)health and risk in six newspapers were examined closely. Subsequently, two newspapers and also colored magazines were examined for two years albeit not on a daily basis. Health education materials were also

scrutinized. As food figures prominently in public discourse on risk and (ill)health particular attention has been given to material and coverage that address food and risk.

Is it possible to claim that a non-articulated sign is in operation, and to investigate such a sign and its operations? Of course, no one has ever seen an implicit or unarticulated image, at least, not if we limit ourselves to speak very concretely. But to limit ourselves to explore, conceptualize or speak only of that which can be concretely perceived can hardly be the task of anthropology. No one has ever seen the unconscious. We nevertheless hold the unconscious be a decisive force in our lives (since Freud). It is inherent in the very nature of phenomena such as habit, tacit knowledge, unconsidered certainties, implicit or non-articulated signs that we identify them by making inferences from their manifestations, or hypothesize their existence on the basis of that which is already known to us empirically or theoretically. This is the case with regard to the tacit knowledge and the cultural signs by which we habitually interpret and understand phenomena of everyday life. Neither have 'cultural models' ever been 'seen'. What we have seen is what we perceive to be their expressions. It is from these expressions that we make inferences about the existence of such models. That we cannot measure and/or describe exactly such phenomena cannot prevent us from attempting and even striving to identify and understand them. If we should refrain from doing so, anthropology would be merely a discipline of concrete ethnographic descriptions.

The theoretical framework that guided the investigation and informs the discussion here is semiotics in the tradition after the American philosopher Charles Sanders Peirce and especially as it has been interpreted and adumbrated by David Savan (SAVAN D. 1987-88) and Vincent Colapietro (COLAPIETRO V. e.g. 1989), but also as it has been developed into a formal semiotic anthropology by Milton Singer (SINGER M. 1980, 1984, 1991). In this tradition, 'sign' designates the dynamic triadic sign and is anything that stands for something (called its object) in such a way as to generate a new sign (its interpretant). Insofar as something carries significance it might be called a sign or more precisely, a *sign-vehicle*: it is that by which something is conveyed or carried (COLAPIETRO V. 1993). A sign is consequently defined by 'function', its capacity to convey and mediate meaning and significance. Anything, for example, images, words, concepts, gestures, events, objects, sounds, inscriptions or (complex) collections or generalized entities of such signs, can function as signs. It is through signs that the world takes on meaning for us. Importantly, our ability to produce and interpret relevant, effective signs in diverse, shifting situations (our semiotic compe-

tency) does not entail semiotic consciousness, that is, our focal awareness of signs *as such* (POLANYI M. 1983). On the contrary, such competency depends upon our signs being 'transparent': normally we look *through* them – not *at* them (MIDDELTHON A. L. - COLAPIETRO V. 2004). The ease of looking through signs, however, may seduce us into overlooking their importance. This may be even more so in cases like the one we are considering here: the emergence and work of a generalized sign or type that is not fully articulated in its individual instantiations.

The 'subject' of the public discourse on health and risk

A conspicuous feature of media's coverage on health and risk can be found in its presentation of risk, that is, one by one. Statistical correlations are harvested by, or presented to, the media in a piecemeal fashion. This reflects media's demand for 'stories' as well as the tools of epidemiology by which correlations are ceaselessly established and risk factors continuously identified: one by one. Further, mediated through public discourse, epidemiological data tend to be re-presented as knowledge about simple causal relations between individual 'risk factors' and disease. We are exposed to endless series of identified 'risks' and, not infrequently, to withdrawals of 'risk factors' formerly conveyed to us as scientifically established facts.

It is not only our risks that come to us one by one; in this discourse, the addressees are approached one by one. The individual is the locus of control of risk associated with (ill)health, and expected to navigate cunningly and 'rationally' upon the information with which he or she is confronted: 'Know your risks and act accordingly!'. Such an individualisation or privatization of risk has been discussed by many (for example GASTALDO D. 1997, NETTLETON S. 1997, OGDEN J. 1995, 2002, PETERSEN A. - LUPTON D. 1996, HILDEN P. K. 2003 and in this volume, see also CRAWFORD R. 1977 for an early discussion). By making the individual person the target of information and the locus of risk-control, he or she appears as his or her own saviour or terminator; a (solitary) mediator of his or her own illness and health, life and destruction.

One of the ways in which the privatization/individualization of risk-control materializes in media and in public health or health education is found in a conspicuous use of the singular 'you' (*du*). When public health or health education material is scrutinized, one quickly realises that the plural 'you' (*dere* in Norwegian) is found only very rarely. It is the single 'you' that is addressed when information is offered about presumed 'risks' and how to

handle them. This is also the case when so-called target groups are approached, messages will still be addressed to individual members of the group. The 'you' is used to achieve a personalizing of risk; to make the recipient, reader or buyer *identify* with messages such as 'Sun can give *you* cancer' or 'Prevent *yourself* from sexually transmittable diseases' and hence replace the 'you' with a personal 'I' or 'me'. The techniques and tools employed in personalizing of risk and (ill)health in mass media and new public health have their roots in neither of them. It seems significant that this approach originated and was subsequently developed, in commercial marketing.

Norwegian journalists have termed the personalizing journalism '*DU journalstikk*' ('YOU journalism') or '*DUnyheter*' ('YOU-news') *etc.* These Norwegian terms do not have an English equivalent, some of them will nevertheless be used in (direct) translation so as to convey a sense of the particular location where this discussion evolved. However, regardless of the term employed, it is my unambiguous experience that as soon as the 'personalizing you-approach' is exemplified by text or image the phenomenon is recognized.

The current use of 'you' in media is a fairly recent development. An indication of just how recent is found in a textbook for students of journalism published in 1989 (ROKSVOLD T. 1989). In Roksvold's discussion of angles from where writers may approach their readers, *du-vinkel* (the 'you-angle') is categorized as an angle solely used in commercial marketing. According to Roksvold, this approach was not found in journalism or literature in the late eighties (ROKSVOLD T. 1989: 169). Even if this should not prove to be absolutely accurate, it indicates how recent a phenomenon this approach is. It is significant that this discursive style which today is taken almost for granted as being one among the major approaches of media, could hardly be found on its repertoire at the end of the eighties (at least not in a Norwegian context). Not only does this testify to the speed by which changes can happen, it also tells us something about how quickly a novel way of addressing people may turn into a seemingly inevitable mode of doing so. The change is reflected in today's textbooks for journalists. In their discussion of news genres, Østlyngen and Øvrebø (ØSTLYNGEN T. - ØVREBØ T. 2000: 374) include what they designate as *du-journalstikk* ('you-journalism') and *DU-nyheter* ('YOU-news'). They characterise this approach as intrusive in form, as an approach which makes our whole life their (the journalists') business and can be understood as a kind of 'life-education-journalism' (*livsanvisningsjournalstikk*). Østlyngen and Øvrebø (*ibidem*: 373) discuss how the voice of the 'you-news' and 'you-journalism' work by establishing a form of parental authority to their readers. While messages come forth as

decrees ('You' should do this if you want to protect yourself from ...!), the convincing potential of factual information is also exploited (Eat carrots and protect *yourself* against cancer). Østlyngen and Øvrebø (*ibidem*: 371) describe how the texts of media oscillate between instruction and information. It seems plausible to suggest that this is fairly close to the approach of health education or public health material.

It is not only in relation to risk and (ill)health that we are addressed through a 'you'. Parallel modes of address are found in the ways media relate to financial concerns. Some examples from the mass media may illuminate this, for example: 'Here are the banks that give *you* the best interests', 'Check how many years *you* have to work to get full pension' etc. Perhaps the realms of health and financial issues are the ones where the use of 'personalization' is most pronounced. 'Risk management' was indeed developed in the field of economy (BERNSTEIN P. 1996). The striking similarity in coverage between the areas of health and financial issues indicates that we are dealing with a cultural phenomenon of a somewhat general, or at least, rather encompassing character.



Fig. 1 Illustration text: Unique heart test can save your life. Take the new doctor's test in Dagbladet [name of newspaper]

The singular *du* and *ditt* (possessive pronoun) is not only found and used in headlines (cf. Fig. 1) in the coverage that follows them, most newspapers and magazines are dotted with small rubrics conveying information on risk aimed at a 'you'. In addition to the provision of (more or less factual) information about risk factors, simple and quick tests which the readers are encouraged to take in order to check their risk and/or (ill)health and, the readers are offered information on how to manage or control risks as for example what to eat, how handle the boss, how to sit correct etc. The information is sold/sent/offered to countless numbers of viewers/listeners/readers, all addressed or approached as a single 'you'.

What subject, what self?

The manner in which the language of market economy and its logic have penetrated public discourse is a much discussed and analyzed phenomenon. Work has been done on concepts and signs such as 'market', 'selling' and 'product', and, the transposition of these from the realm of liberal market economy to operate in new fields or contexts (e.g. VON DER LIPPE B. 1999). Little attention (if any) has been given to cases where signs of the market – e.g its 'you' – starts operating in realms where the same term is already in operation as a sign-vehicle for a meaning quite other than that which the sign of the market conveys. In such cases, nothing in the term itself will suggest whether the newly introduced 'you' carries meaning which is different from the meaning conveyed by the designation(s) already in operation in this context. It may not be immediately clear whether a 'you' is a token (an individual instantiation) of the neo-liberal type of 'you' (and hence gains its meaning from that type), or a token of a type which mediates quite another understanding of what it is to be a human being. Hence, the 'self' or 'subject' of the personalized journalism and also of health information material needs to be explored. Questions need to be posed as to whether that 'self' is the 'self' of everyday experience (or a phenomenon similar to it?)

In order to approach this question I need to briefly sketch the approach to the phenomenon of subjectivity that I draw upon here. The approach to subjectivity developed after the semiotic of Peirce, emphasizes our capacity for self-reflection, performativity (the capacity to take on and discard roles) and also our self-division (the self is not merely a conscious agent but also an unconscious being). Moreover, in the same manner as there is no 'I' without a 'me' (no subject without a capacity for self-reflection), there is *no*

'I' without a 'we' (no subject apart from relations, community or society). Importantly, this 'we' is not a 'we' external to the subject but a 'we' which is *both* internal and external to the subject. In sum, this subject is a corporeal (embodied), historic, inter-subjective (communal), meaning making (sign using and sign interpreting), self-reflecting, enculturated, social and political being. She or he has a body and a history, possesses and uses signs and language(s), live in relation to others (individuals and collectives), has power and is subjected to power, and is an agent - a 'doer' (cfr. for example COLAPIETRO V. 1989, SILVERMAN K. 1983).

Interesting contrasts appear once we apply such dimensions to the individual that is presented in mass media health discourse. If such an application is to be pursued, an inquiry into only those features which are *manifestly present* will *not* suffice. There is a need also to search for *thoroughgoing absences*. Is something *consistently lacking* in the images or signs we are continuously confronted with, compared to the dimensions emphasized in a semiotic understanding of subjectivity? It should be noted that 'absence' is *not* meant here to imply a complete lack of a particular phenomenon in the sense that that which is identified as being characteristically absent has *never* been present in *any* connection or at *any* time. 'Absence' is meant to convey that when or if the (generally) lacking dimension *has* been present; its presences have been far too insignificant and/or all too sporadic to have made a sustained impact on the generalized sign or type discussed here.

In my examination of media coverage and health information materials, at least three voids of relevance to the discussion of the 'you' or 'subject' of public discourse on risk and (ill)health emerged. The *first* void was encountered in a thoroughgoing lack of a 'we'. A community or something similar was hardly ever present in relation to the 'you' considered here. The 'I' which the singular 'you' is strategically used to evoke came forth as an 'I' without a 'we', that is, as a black boxed non-communal, non-social, and hence non-inter-subjective, being. It is not as if groups were never addressed in the media or by new public health. Rather, when they were addressed, they were so as 'collections of single individuals' and only very rarely as 'collectives'.

In fact, even where the subject matter might call for communal action on the part of members of a group, the possibility of such communal action is not engaged. For example, a news item reported⁽³⁾ on an epidemiological finding which seemed to suggest that *jordarbeidere* (construction workers working on and with soil) suffer a particular health risk through exposure to pathogens in the soil. Of course, such workers share not only this partic-

ular alleged elevated level of risk to their health, they also share a particular relationship to powerful 'other'; viz. those to whom they sell their labour, their employers. Thus, the headline for the news report could conceivably have called upon these workers to *organize* at the face of this threat. Such was not the case. Instead, the headlines read «The workers (*Jordarbejdere*) should get themselves vaccinated». In other words, on the basis of an epidemiological finding, individuals (belonging to a collection of individuals) were called upon to act; not the collective as such. The distinction between a collective and a collection of individuals is crucial here. I should be noted that at times families were addressed but when they were they too were related to as insulated entities existing outside or not belonging to any larger 'we'⁽⁴⁾. After having been exposed to series of signs, images or tokens of the 'you' in mass media and health information material, the image that emerged was an image of a self *without a life world*; a self-contained and insulated self. Such an absence or lack of life world can be seen as one property of the generalized sign (or type) of mass media and health education and new public health.

The *second void* concerns the body. Of course the 'you' of public discourse on risk and (ill)health has a body, but that body is not just *any* body. The focus of the health messages and media coverage is indeed to a large extent on the body, for example, on what you should and should not eat, and on how you should and should not conduct yourself physically in order to become or stay healthy, and/or to keep or get a fit body. But the image of the body with which we are addressed and by which messages are given, is nothing like our own (at least this is the case for the vast majority of us). The body of the risk and (ill)health discourse is either the idealized body or the despised body (for example the extraordinary fat or 'misshaped' one cfr. COULTER L. 1996, PITTS V. 1999). In general, the body of health materials and mass media is not *corpo* "real" but *corpo* "ideal" (or the antithesis of such an ideal e.g. the very fat body). Hence, people on whom messages concerning their bodies are ceaselessly thrust, will search in vain for their own bodies in these messages and images.

The *third void* concerns time and history. Only very rarely did the 'you' or 'subject' have the kind of history we often, in everyday life, refer to as 'personal history'. Neither did this 'you' live in what we more generally term 'history'. The 'subject' of mass media and new public health did not come forth as a historic being except in one particular sense; with regard to health, it had a future which it colonized, or by which it was being colonized (what you eat today will eat you tomorrow). Giddens (GIDDENS A. 1991) discusses how (in late modernity) we colonize the future (*ibidem*: 111)

and how the future colonizes the present (*ibidem*: 3). In this regard, but in this regard only, the 'subject' has temporality.

That the generalized sign – or type – of the 'subject' is not fully articulated does not mean that nothing is openly conveyed by it. As discussed above, it is certainly articulated and conveyed beyond doubt that this 'you' is the locus of risk management and control. The most dominant of its manifest traits is indeed the position of this 'subject' as being its own risk controller/manager. Castel's (CASTEL R. 1991) description of contemporary public health strategies as ones which in practice have replaced the notion of an individual self with the notion of the individual or the self as a certain combination of risk factors captures this phenomenon well. Based on what is argued above, his description may be taken even further. The inherent notion of the 'self' or 'subject' of new public health and mass media is one which relates to the self as an "atomised" or "insulated manager" of its own particular cluster of risk.

At least some properties of the generalized sign may now be summarized. Besides that it openly points at the individual as a solitary controller of its own risks, it seems that the sign of the 'subject' we encounter in the personalised journalism and new public health carries with it an image of its 'subject' as an atomized 'subject'. It conveys an image of a self-sufficient, solely self-reliant, utterly self-contained as well as fully self-maintained and self-sustained subject. A 'subject' without a body of its own which operates outside history and independently of others; a non-communal 'subject'. It is not without significance that inherent in this sign we will also of necessity find the notion that you can trust no-one but yourself. Consequently, everybody else become a potential enemy. Hence, the 'subject' mediated by this 'type' through its 'tokens' is not of our world. But can we nevertheless say that this figure – which none of us have encountered in our lived lives and most would claim to be an impossible figure – is a living creature? It seems to me that this fantasy figure is very much alive and at work as the subject and hero⁽⁵⁾ of neo-liberal capitalist thinking and practice.

Lastly, and even if not the theme here, the personalizing approach cannot be discussed without also mentioning the one who is (constantly) pointing at me with the aim of making me identify with the 'you' by which I am addressed. Somebody seems to possess an institutional right to talk to you in a manner normally reserved for e.g. a family situation. While 'sender' is the term conventionally used to express this position, in this case 'pointer' seems to be a more accurate designation. Of course, individual health education or health information pamphlets have a sender or named pointer,

and often quite a visible one; such as a governmental body or a non-governmental organisation. The message of the media also have a named sender or pointer like *TV2 Hjælper deg* ("TV 2 helps you") or *Dagbladet* (tabloid newspaper) *is on your side*. But on a general level the omnipresent pointer seems to be a nameless one.

Conclusion

I have argued that the endless stream of messages and coverage directed at a single 'you', over time, will have generated or produced a generalized sign/type of this 'you', a sign which carries meaning that goes beyond that which is openly conveyed by the individual signs. As a type, the general sign is the one from which the single individual signs, its instantiations or tokens, gain their meaning. The *type* of the 'subject' of mass media and that of new public health share defining features with neo-liberalism's self-contained and self-maintained type of 'subject'. The similarities between the two are striking to such a degree that it seems reasonable to suggest that the 'subject' (type) of mass media and public health – in practice – are merged with that of neo-liberalism – at least, in the context of risk and (ill)health

I have tried to show that with regard to risk and (ill)health we are addressed through signs which mediate 'selves' and 'subjects', which in decisive ways are different from the 'selves' and 'subjects' of our lived lives. While the type of the 'subject' of mass media and new public health does not have a life world, such a person has never been encountered in real life (this, of course, does not omit the fact that life worlds may be felt as unsatisfactory, too small or even evil). As it is omnipresent, the sign of the atomized 'subject' is a sign by which we might come to think and communicate without being fully aware of doing so. Hence, we may come to mediate – to ourselves and others – implicit meanings which are not only alien but also potentially detrimental.

We are currently experiencing serious threats to the welfare state and other communal modes of organisation and practice. While the welfare state was founded on reciprocity of the kind we are trained to name 'generalized reciprocity' (SAHLINS M. 1988), the logic of the neo-liberalist kind of 'reciprocity' may be seen as its inversion. It is a fundamental principle of the 'reciprocity' of the market that its 'subject' takes out exactly what it has put in – plus of course, interests and/or profit. This logic runs contrary to the whole idea of the welfare state and communal ways of thinking. In sum,

much may currently be at stake with regard to how we perceive 'selves' and 'subjects' and consequently with regard to the potential for communal action and practice, community and society.

Notes

- ⁽¹⁾ It should be noted that in Norwegian "du" designates only the singular "you", the plural one is termed "dere".
- ⁽²⁾ Charles Sanders Peirce developed the type token distinction: «Type is a sign considered as an indefinitely replicable entity or function; token, an individual replication or instance [...] There can be numerous tokens of a single type» (COLAPIETRO V. 1993: 200).
- ⁽³⁾ Dagsavisen 19. April
- ⁽⁴⁾ Calls for changes at structural levels are also rare. Such is the case both in public health and in media coverage. In media, there are certainly cases where authorities are called upon to act or accused of neglect, but this does not eliminate that fact that, in general, messages on risk and health target the individual person.
- ⁽⁵⁾ An important discussion which I cannot pursue here relates to shame. For even if this 'subject' is the hero of neo-liberalism it is also a very shameful subject. That is the trap of this figure. This 'subject' is one that is completely on its own. And that is in many ways a shameful position to be in. To be self-sustained and self-contained is to not need anybody and not be needed by anybody. To be atomised and self-sufficient is to be outside love as this is a position outside or without a 'we'. (e.g. PIERS G. - SINGER M. 1953).

Bibliography

- BERNSTEIN Peter L. (1996), *Against the Gods. The Remarkable Story of Risk*, John Wiley & Sons, New York.
- CASTEL R. (1991), *From dangerousness to risk*, pp. 281-299, in BURCHELL G. - GORDON C. - MILLER P. (eds.), *The Foucault Effect. Studies in Governmentality*, Harvester Wheatsheat, London.
- COLAPIETRO Vincent M. (1989), *Peirce's Approach to the Self*, Suny Press, Albany NY.
- COLAPIETRO Vincent M. (1993), *Glossary of Semiotics*, Paragon House, New York.
- COLAPIETRO Vincent M. (1999), *Subject Positions and Positional Subjectivity: A Pragmatic Approach*, "Semiotische Berichte", n. 23 (1-4), 1999, pp. 13-28.
- COULTER L. (1996), *The deviance of obesity: the fat lady sing*, pp. 136-139, in LESTER D. M. (ed.), *Images that injure: pictorial stereotypes in the Media*, Praeger, Westport CT.
- CRAWFORD R. (1977), *You are Dangerous to Your Health: The Ideology and Politics of Victim Blaming*, "International Journal of Health Services", vol. 7, n. 4, 1977, pp. 663-680.
- GASTALDO D. (1997), *Is health education good for you? Re-thinking health education through the concept of bio-power*, pp. 113-133, in BUNTON R. - PETERSEN A. (eds.), *Foucault, health and medicine*, Routledge, London.
- GIDDENS Anthony (1991), *Modernity and Self-Identity. Self and Society in the Late Modern Age*, Polity Press, Cambridge.
- HILDEN Per Kristian (2003), *Risk and Late Modern Health, Socialities of a Crossed-Out Pancreas*, University of Oslo.

- MIDDELTHON Anne-Lise - COLAPIETRO Vincent (forthcoming 2004), *Absent Signs, Elusive Experiences: On young gay men and absence of adequate signs and cultural images*, in COLUMBUS Frank (ed.), *The Psychology of Gender Identity*, Nova Science, New York.
- NETTLETON S. (1997), *Governing the risky self: how to become healthy, wealthy and wise*, pp.207-223, BUNTON R. - PETERSEN A. (eds.), *Foucault, health and medicine*, Routledge, London.
- OGDEN Jane (1995), *Psychosocial theory and the creation of the risky self*, "Social Science and Medicine", vol. 40, n. 3, 1995, pp. 409-15.
- OGDEN Jane (2002), *Health and the construction of the individual: a social study of social science*, Routledge, London.
- PETERSEN A. - LUPTON Deborah (1996), *The new public health: health and self in the age of risk*, Sage, London.
- PITTS V. (1999), *Body modification, self mutilation and agency in media accounts of a subculture*, "Body and Society", vol. 5, n. 2-3, 1999, pp. 291-303.
- PIERS Gerhart - SINGER Milton (1953), *Shame and guilt: A psychoanalytic and cultural study*, W.W. Norton, New York.
- POLANYI Michael (1983), *The Tacit Dimension*, Peter Smith, Gloucester Mass.
- ROKSVOLD Thore (1989), *Retorikk for journalister*, J. W. Cappelens Forlag, Oslo.
- SAHLINS Marshall (1988 [1972]), *Stone Age Economics*, Routledge, London [orig. ed.: Aldline, Chicago, 1972].
- SAVAN David (1987-1988), *An Introduction to C. S. Peirce's Full System of Semeiotic*, Toronto (Toronto Semiotic Circle Monograph Series, n. 1).
- SILVERMAN Kaja (1983), *The Subject of Semiotics*, Oxford University Press, New York.
- SINGER Milton (1980), *Signs of the Self: An Exploration in Semiotic Anthropology*, "American Anthropologist", vol. 82, n. 3, 1980, pp. 485-507.
- SINGER Milton (1984), *Man's Glassy Essence. Explorations in Semiotic Anthropology*, Indiana University Press, Bloomington IND.
- SINGER Milton (1991) *Semiotics of Cities, Selves, and Cultures. Explorations in Semiotic Anthropology*, Mouton de Gruyter, Berlin.
- ØSTLYNGEN Trine - ØVREBØ Turid (2000 [1998]), *Journalistikk. Metode og fag*, Gyldendal Akademisk, Oslo.
- VON DER LIPPE Berit (1999), *Metaforens potens. Essays*, Oktober, Oslo.

1.8 *Antonio Gramsci and medical anthropology now: hegemony, agency, and transforming persons*

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Introduction: Antonio Gramsci Today

This paper pursues a single objective: to demonstrate the urgency within contemporary medical anthropology of a direct and reflexive re-reading of the works of Antonio Gramsci (1891-1937). In 1984 Michel Foucault declared that Gramsci was our most quoted and least known author. At a distance of twenty years from this evaluation, Gramsci continues to be evoked, in an indirect way, by some influential currents of Anglo-American medical anthropology⁽¹⁾. One important contribution was made in 1988 in an issue of the "Medical Anthropological Quarterly," edited and directed by Ronald Frankenberg (FRANKENBERG R. 1988, FRANKENBERG R. ed. 1988); a testimony of how essential a direct reading of Gramsci can be to the critical renewal of a discipline grounded in a closer relationship between anthropological theory, ethnographic practice, and political commitment. In the English-speaking world, Gramsci came to be known primarily through the cultural studies and reinterpretations of Raymond Williams (WILLIAMS R. 1977), studies whose "textual" limit seems to produce contradictions with Gramscian thought, which is strongly anchored in praxis. There is a dramatic and reflexive attention in Gramsci for the understanding of subjective aspects and forms of embodiment of the social dialectic in which he is intimately involved through participation in political struggles. But there is also a participatory attention, which I do not hesitate to call ethnographic, for the microphysics of social transformation, the hegemony of the state, as well as individual and collective agency. Just last year a valuable study by Kate Crehan of Gramsci's concept of culture, was published in the United States (CREHAN K. 2002). Crehan's work demon-

strates how a direct reading of Gramsci allows anthropologists to defamiliarize themselves with the classic vocabulary of the discipline and gain access to a theory that is radically critical of the concept of culture. As early as the first decade of the last century, in his youthful, pre-prison writings, Gramsci elaborated a breakdown or deconstruction of the concept of culture, which precludes any essentialist notion of the term and leads to the consideration of culture as thought in action, as a dialectical process involving knowledge, production, and transformation of the self, within a field of historical forces.

In Italian anthropology the situation appears to be different since there have been decades of debate on the importance of Gramsci's writings for anthropological research, beginning in 1948 and immediately following the publication of his letters from prison and the first prison notebooks⁽²⁾. Yet today, Gramsci seems to be neglected in general anthropology. This situation is in contrast to the extraordinary growth in historical, philosophical, and political studies of Gramsci in the last ten years in Italy and around the world, and particularly in Brazil and throughout Latin America⁽³⁾. But in Italy as elsewhere this rich reflowering of research has in turn found it difficult to interact and dialogue with anthropology. In the early 1950s the young Tullio Seppilli⁽⁴⁾, in parallel with Ernesto de Martino, laid the groundwork for the foundation of a Marxian-Gramscian medical anthropology, freed from ideological reductionism and mechanical positivism. Pursuing that same line of research he is engaged today is a scientific anthropology that reflects critically on health policies and on their strategic centrality both in the restructuring of contemporary capitalism and in the imagination of new perspectives of political commitment.

In this context, I have begun a seminar on a direct reading of Gramsci's works (PIZZA G. 2001-2002). As we have read Gramsci in our seminar we have found ourselves trying to come to terms with a dialogical and experimental way of thinking that eludes all the interpretive classifications furnished by the exegetes or by anthropological theory. What has emerged from our reading is not so much the importance of an "anthropological use" of Gramsci but his outright *anthropological vocation*. I should add immediately that it was Gramsci himself who defined his philosophy of praxis (a term with which he referred to historical materialism) as a "living philology" and, in another section of the notebooks, as an "anthropology." Here's a quote from Gramsci's text:

«One may say that the economic factor [...] is only one of the many ways in which the more far reaching historical process is presented (factors of race,

religion etc.), but it is this farther reaching process that the philosophy of praxis wishes to explain and exactly on this score it is a philosophy, an 'anthropology', and not a simple canon of historical research» (Q17§12).

In Gramsci, the term "anthropology" has to do with his idea of man as "historical product," and with his rigorous critique of the naturalistic reductionism of the biological sciences. This involves a political attention for the "living," which has not always been understood. As Athos Lisa (Gramsci's fellow prisoner) recalls in his memoir, Gramsci «never posed for himself abstract problems, which had no place in people's lives or had no connection to them» (LISA A. 1973: 77). But this capacity to institute in one's own political and intellectual action a unitary, critical, dialectical relationship between theory and praxis is, on the one hand, diametrically opposed to the idealist approach which separates the will from historical subjects, while on the other hand it is far removed from empiricism, from pragmatism, from a mechanical view of materialism which reduces social and cultural life to the question of productive relationships. The interpretation of Gramsci's work has often been translated into the imposition of external grids that have sometimes forced Gramsci's suggestions into a classical anthropological framework that was foreign to him. Gramscian anthropology and classical anthropology do not coincide. Gramsci's extraordinary interweaving of thought and life, his continuous striving to elaborate a living theory, constantly draws its strength from an unceasing dedication to study, but also from knowledge produced in working class struggles and the bodily experience of his personal vicissitudes and the physical suffering that accompanied him throughout his life. With respect to this last point, some scholars have even tried to psychologize and medicalize the figure of Gramsci and, incredible as it may seem, an Italian psychiatrist (RUDAS N. 1999) has recently written an essay proposing a sort of *Sardinian culture-bound syndrome* to explain the interrelationship of genius and suffering in Gramsci! What we have tried to do in our seminar, instead, is to "understand and feel" (as Gramsci conceives the duty of the intellectuals) the "living" quality that pervades his works. We have interpreted his "living philology" as an eminently anthropological imperative to place concepts at the point most intimately connected to the "experience" of flesh and blood historical subjects. Consider this example. In one of his letters from prison, Gramsci reflects on his isolation and expresses with great clarity the tension which to us appears to be human, political, and ethnographic all at the same time.

«I have lost much of the pleasure in reading. Books and magazines only offer general ideas, sketches (more or less successful) of general currents, in the world's life, but they cannot give the immediate, direct, vivid impres-

sion of the lives of Peter, Paul and John, of single, real individuals, and unless one understands them one cannot understand what is being universalized and generalized». (GRAMSCI A. 1996)

In contrast to many masters of contemporary critical thought, Gramsci is not interested in the foundation of a new theory of social reality which can then provide the instruments for taking action in praxis. He is interested in elaborating a living theory which reflects from its very constitution the concrete experience of real life and which gives rise to practical activity, an initiative of will, a dialogue of transformation.

It is the emotion I have felt in the direct reading of Gramsci that moves me to communicate to you the urgency of a return to his works. I will do this by following the points indicated in the subtitle of my paper: hegemony, agency, and the question of transformation.

Hegemony: The State as a Body Factory

Hegemony has been the most fortunate Gramscian concept but also the most misunderstood. Sometimes it is interpreted solely as the function of domination of consciousness exercised in the framework of the opposition between dominant and subjugated classes. This dichotomy constitutes one of the most misleading interpretations of what Gramsci wrote. Those who read Gramsci directly will never find in his thought a separation between hegemonic culture and subjugated culture, but an underlining of the minimal, intimate dimensions of the hegemonic dialectic observed above all in its contradictions. Gramsci's thought is constantly denaturalising and anti-essentialist. It is no coincidence that he makes use of sarcasm and irony as strong dialogical and critical instruments. His one is a dynamic way of thinking that insists on not viewing as eternal realities provisional power structures reflected in the concepts themselves. The dominant/subaltern opposition is a misunderstanding that has also been reproduced in American medical anthropologies that have often proposed a mechanical image of criticism of biomedical hegemony, neglecting forms of resistance and transforming creativity exercised by subaltern agents. Hegemony is not only State power exercising its authority in coercive action and in the organization of a consensus naturalized by its subjects as "spontaneous." Hegemony is also the politics of transformation exercised through the critical capacity to denaturalize, starting with one's own body, the modeling action of the State, thus bringing to light the dialectical interaction

between the State and the intimate life of individuals. The State functions as a “body factory”, an “anthropological workshop” (BURGIO A. 2003: 101). It takes on the task of elaborating, as Gramsci writes, “a new human type” (Q22§2), transforming the body and producing the idea itself of individual subjectivity. The State acts, therefore, in the intimacy of subjects. In 1934 Gramsci wrote in *Notebook 22*, dedicated to the analysis of Americanism and Fordism, «“State” means especially conscious direction of the great national multitudes; thus a sentimental and ideological ‘contact’ with such multitudes is necessary». In *Americanismo e fordismo* the attention for the State as a body factory is grounded in the centrality of workers’ bodies, of their exposure to transformation in the process of production. But the hegemonic relationship is still dialectical because it is also active on the side of the critical and antagonistic capacity of the subjects acted upon by the State. For this reason the understanding of hegemonic relationships depends on the concrete and situated analysis of relations of force that act, not on the already constructed subject but on subjectivity in construction. This scientific analysis of relations of force has no value for Gramsci unless it is connected to the motivated action of the embodied subject. This is why, though starting from the centrality of the working body, Gramsci reviews, in *Americanismo e fordismo*, various fields of bodily experience acted upon by the “permanent cultural activity” of State hegemony, and he identifies them in the “sexual obsession”, in the construction of the female body and personality and the family. These are strategic fields in which one is acted upon, and at the same time where one can also act with a view toward transformation. It is in this part of the notebooks that he elaborates a theory of psychological afflictions (that is neurosis), that rejects the naturalism of Freudian explanations and that considers mental illness as a process of embodying historical contradictions determined by relations of force.

Agency: The Will of the “trained gorilla”

In the elaboration of his cultural and social criticism Gramsci breaks down the abstract concepts of culture and society into more concrete elements such as the individual, the person, the self, the subject, and embodiment. But then even these concepts are exploded, unveiled as constructions to be denaturalized; constantly changing historical products, in the grip of relations of force that define them and orient them. The radical conceptual

renewal offered by Gramsci is current precisely because his breaking down of the criticized concepts (culture, for example) does not produce concepts that are equally rigid (the “body,” the “individual,” the “person,” the “self,” as it happens with some contemporary medical anthropologies) but reflects on the material dialectic internal to the very formation of the concepts, thus bringing to light the political dimension of the theory. The theory reflects the relations of force and the power structure and only if it chooses to declare and not conceal its involvement in real contradictions, placing itself inside the concrete flow of real experience, can it be joined to transforming praxis.

His constant attention to processes of subjectivization produced in the hegemonic dialectic leads Gramsci to a pioneering criticism of Freudian psychoanalysis. Gramsci strongly criticizes with sarcasm and irony the invention of the unconscious and the construction of the psychological self⁽⁵⁾. The question of psychological suffering, according to Gramsci, is the result of a process of embodiment of the conflicts acting in the relations of force that regulate social experience. The outlines of this critique are scattered throughout the letters and the notebooks. In the letters the primary motivation of the critique regards the fact that his wife, Giulia Schucht, prey to nervous disorders, had decided to undergo psychoanalysis⁽⁶⁾. The Gramscian critical perspective on psychoanalysis is of great interest despite its synthetic and intuitive nature. Neuroses, in Gramsci’s view, are to be traced directly to that “fabrication” of a new human type brought into play by Fordist capitalism.

After having demonstrated how Fordist capitalism aims at the construction of a “new human type,” through the physical transformation of workers, he also emphasizes how this process is deconstructible. Taylor’s cynical expression labeling the factory worker as a “trained gorilla” is ironically deconstructed by Gramsci to show how it can be completely overturned by the agency of the worker who not only can resist but can also orient the physical transformation to which he is subjected toward non-conformist actions. The “trained gorilla” has a will. And also the “animality” of the worker’s body cannot be easily domesticated:

«“Animality” and Industrialism. The history of industrialism has always been a continuing struggle (which today takes an even more marked and vigorous form) against the element of “animality” in man. [...] A two-fold situation can then create itself in which there is an inherent conflict between the “verbal” ideology which recognises the new necessities and the real “animal” practice which prevents physical bodies from effectively acquiring the new attitudes» (Q22§10).

Transforming Persons: Molecular Processes and Body Politics

Those who have read Gramsci might have been struck by a new word that he uses quite often both in his letters, with reference to himself, and in his analysis of political and cultural criticism. I'm referring to the adjective "molecular." The frequent presence of this term in the *Prison Notebooks* is not coincidental. This term is evidence of the experimental nature of Gramsci's writings, his constant effort to seek out new expressions that elude the deceptions of language. Personally engaged in working class struggles and searching for new expressive forms linked to this transformative experience, Gramsci uses the term "molecular" for the possibility it offers of referring to the minimum unit of life experience, to the immediate detail, drawn from daily life. Gramsci's frequent use of the term shows how intent he is on capturing processes of transformation by positioning himself as close as possible to lived experience, to the point of identifying them in his own body and his own person. The notion of "molecular," in fact, is used by Gramsci to observe the processes of molecular transformation both of society and the person⁽⁷⁾. So many passages from his letters are really phenomenological considerations drawn from Gramsci's own bodily experience and at the same time capital in his understanding of social processes. His embodied reflections and his accounts of his own illness interweave lived experience and socio-cultural criticism, in a continuous process of self-objectification. His body is objectified as a physical space in which processes of transformation act. I quote in sequence a part of a letter and a passage from the notebooks written in the same days of March 1933. In both texts the analysis of molecular transformations of the person becomes particularly dramatic because they are inspired by deterioration of Gramsci's illness, Pott's disease, and from his perception of being in a «phase of my life that without exaggeration I can define as catastrophic». It is a particularly hard moment. Gramsci has had crises of hemoptysis, he has been spitting blood, he's undone. It's March 6 1933, four years before his death. To describe his situation Gramsci evokes the apologue of the shipwreck survivor recounted by Edgar Allan Poe in *The Narrative of Arthur Gordon Pym*. In conditions of extreme hardship following a shipwreck some men who would have sworn they would kill themselves first, end up turning to cannibalism. But are they really the same persons? Gramsci asks. No. Because in the meantime they have undergone a process of molecular transformation by the effect of which the persons of before are not the persons of after. Here I quote a passage from the *Letters* and a passage from the *Notebooks*.

Here is the passage from the letter:

«Dearest Tania,

I still have a vivid memory (which no longer happens to me in recent times) of a comparison that I presented to you during our Sunday visit to explain what is taking place inside me. I want to go back to it, to draw from it certain practical conclusions that interest me. What I said to you was approximately this: imagine a shipwreck and that a certain number of persons take refuge in a large boat to save themselves without knowing where, when, and after what vicissitudes they will actually be saved. Before the shipwreck, as is quite natural, not one of the future victims thought he would become... the victim of a shipwreck and therefore imagined even less that he would be driven to commit the acts that victims of shipwreck under certain conditions may commit, for example, the act of becoming... anthropophagous. Each one of them, if questioned point-blank about what he would do faced by the alternative of dying or becoming cannibalistic, would have answered in the utmost good faith that, given the alternative, he would certainly choose to die. The shipwreck occurs, the rush to the lifeboat etc. A few days later, when the food has given out, the idea of cannibalism presents itself in a different light until at a certain point, a certain number of those particular people become cannibalistic. But are they in reality the same people? Between the two moments, that which in the alternative presented itself as a pure theoretical hypothesis and that in which the alternative presents itself with all the force of immediate necessity, there has been a process of "molecular" transformation, rapid though it may have been, due to which the people before no longer are the people of afterward, and one can no longer say except from the point of view of the state records office and the law [...] that they are the same people. Well, as I have told, a similar change is taking place in me (cannibalism apart). The most serious thing is that in these cases there is a split in the personality; one part of it observes the process, the other suffers it, but the observing part (as long as this part exists there is self-control and the possibility of recovery) senses the precariousness of its position, that is, foresees that it will reach a point at which its function will disappear, that is, there will no longer be any self-control and the entire personality will be swallowed by the new "individual" who has impulses, initiatives, ways of thinking different from the previous ones. Well, I am in this situation, I don't know what of me (will?) remain after the end of this process of change that I sense is in the course of development [...].»(GRAMSCI A. 1996)

Here is the passage from the *Notebooks*:

«**Autobiographical Notes.** How I began to use greater indulgence in judging the catastrophes afflicting character. Through experience of the process by which such catastrophes come about. [...]. Now the most dangerous movement is that at the 'molecular' level since, while it demonstrates the subject's will to resist, it allows one (whoever reflects on such things) 'to glimpse' a progressive change in moral personality which at a certain point stops being quantitative and becomes qualitative; in other words one is no longer really dealing with the same person but with two people. [...] The

truth is that the person of the fifth year is not the same as in the fourth, the third, the second, the first and so on; one has a new personality, completely new, in which the years that have passed have in fact demolished one's moral braking system, the resistute forces that characterised the person during the first year. [...]. This fact, relating to the individual, may be considered collective [...]. This fact is to be studied in its current manifestations. Not that the fact has not occurred in the past, but it is certain that in the present it has taken on a special and a voluntary form. That is to say that today one counts on this happening and – something which did not happen in the past – the event is systematically prepared (where systematically means however 'en masse', without of course excluding 'particular' attention paid to individuals). Without doubt an element has crept in today, an element that used not to exist in the past, a 'terroristic' element, an element of material and even moral terrorism, which cannot simply be disregarded. This makes yet more serious the responsibility of those who, although perfectly able, have not – because of inexperience, negligence or even their own perverse will – put a stop to certain matters» (GRAMSCI A. 1975: Q15§9).

Gramsci gives this passage of the notebooks the ironic title «autobiographical notes», irony that evokes his aversion to autobiography, a genre that he believes is dense with pitiful rhetoric. What he gives us is a dramatic objectification of the processes running through him and that, just because they frighten and affect him, allow him to refine his analysis of the mechanisms through which persons are subjected to transformations of the person within specific relations of force. This is certainly one of the most moving passages on the relationship between body and power in all of Gramsci's works. There is an immediate correspondence in his letters and notebooks in this period between the experience of his illness and his political criticism of the concept of person. He demonstrates with his own body the urgency of reopening the concept of the person so that these mechanisms can be understood. At the same time he emphasizes the fluidity of the transformative process which unfolds in a manner that is totally embodied, intimate, and uncontrollable. But the sense of this transformation is not psychological; it is strictly political. The body is the terrain of a conflict between hegemonies.

Concluding remarks

In his *Microphysics of power* Michel Foucault criticized orthodox Marxism for having «terribly concealed» (FOUCAULT M. 1977 [1972]: 141) the importance of body in Marx's work. Gramsci's work had the merit of fully recovering this importance, even though it has suffered the same fate. A reading of the question of the body in Gramsci is fundamental, in my view,

for understanding the hegemonic dialectic and the system of relations of force that act on processes of health/illness. My stress on the urgency of this re-reading of Antonio Gramsci is born out of the conviction that the scarce attention for Gramsci's critique of body, self and of the person constitutes a lost opportunity. I would like to underline at least three general points on which that critique is important for contemporary medical anthropology.

First, it seems to me that the Gramscian critique and its attention for processes of transformation of the embodied subject which occur in a system of relations of force, must push medical anthropology to put into question, more than it has been done in the past, the health-illness dichotomy, in order to overcome any tautological residue and to conceive it instead as a dialectic, that is, as a socio-political process. In this way the dichotomy reveals itself to be a historical ideological construct, the genesis, development, and strategic objectives of which must be understood, on the one hand, in the political terms of social control and conservation of the status quo, and on the other hand, in terms of the transformation of and the struggle against the structural violence that produces inequality and suffering. In a certain sense it could be said that Gramsci's reflections push medical anthropology to observe how much "health" there is in "illness" and how much "illness" there is in "health," and at the same time they invite us to reflect on the interaction between physical well-being and political economy, so as to show how, in the world system, the health of some is made possible by the illness of others⁽⁸⁾.

Second, it seems to me that by taking account of the *political* variability of the categories of health and illness, and showing the strong ties between the current definitions of health and the powers of the State, it may be possible to clarify how the identification of health and normality tends even today to reduce illness to the concept of deviance, turning it into pure abnormality. By illuminating this mechanism, which acts in a concealed and naturalized manner, illness will then be able to reveal itself as an "embodiment of inequality." On this point I believe that medical anthropology, though it has produced archives of information and indispensable studies for understanding the *cultural* variability of the processes of health and illness, must reflect today on the by now explicit risk that insisting on cultural differences may conceal the production of social inequalities.

Third, it must be kept in mind that the political commitment of medical anthropology is not to be considered as the "application" of research results or as their "social use" in the public sphere. Instead, such a political

commitment resides in the awareness of our unavoidable involvement in social praxis. This requires a reinforcement of a critical, reflexive, self-objectifying methodology inside the scientific field itself, in the academy, in relations with institutions and with the State, in the politics of scientific research, in the academic elaboration of theory. Structural forces tending toward the production of a “molecular transformation” of persons (anthropologists included) and the commodification of life are at work in these fields too.

On this last point I would like to conclude with an example that shows the current value of Gramsci’s reflections. In a piece entitled *Merce* (“Commodity”) written in 1918, at the age of 27, Gramsci deals, incredibly enough, with the traffic in human body parts. That’s right. Almost ninety years prior to Nancy Scheper Hughes (SCHEPER-HUGHES N. 2001), when the idea of an organ transplant was little more than science fiction, Gramsci addresses the issue in a text whose sarcasm and irony indicate the dialogic function of his critique. I’d like to read just the last part.

«[...] According to a communication received by the Academy of Medicine in Paris, professor Laurent has succeeded in replacing the heart of Fox with that of Bob, and vice-versa, without the two innocent dogs enduring great suffering, without disturbing in the least the life of the delicate internal organ. From this moment the heart has become a commodity; it can be exchanged, it can be bought. Who wants to trade their worn out heart, afflicted by palpitations, with a mint vermilion heart, poor, but healthy, poor but that has always palpitated honestly? [...] A new commercial road now open to the exploratory activity of individual initiative [...] Life, all of life, not just the mechanical activity of the limbs, but the very physiological font of activity, thus detaches from the soul and becomes a good to be bartered; it is the destiny of Midas, he of the magic hands, the symbol of modern capitalism» (GRAMSCI A. 1918)

Notes

⁽¹⁾ See for example Marx and Gramsci’s references in BAER H. - SINGER M. eds. 1997, LINDENBAUM S. - LOCK M. eds. 1993, SINGER M. - BAER H. eds. 1995.

⁽²⁾ For the Italian anthropological debate on a Gramscian approach to “popular” culture starting from DE MARTINO E. 1949, see ANGELINI P. ed. 1977, CIRESE A. M. 1976, CLEMENTE P. - MEONI M. L. - SQUILLACCIOTTI M. eds. 1976, DI NOLA A. M. 1978, LOMBARDI-SATRIANI L. M. 1980, PASQUINELLI C. ed. 1977, RAUTY R. ed. 1976, SEPPILLI T. 1979.

⁽³⁾ Recent interesting political and philosophical re-reading of *Prison Notebooks* are BARATTA G. 2000, RAGAZZINI D. 2002, BURGIO A. 2003, FROSINI F. 2003, but these studies unfortunately do not dialogue with the anthropological Gramscian debate. For Latin America see AA.VV. 1991.

⁽⁴⁾ See at least SEPPILLI T. 1959, 1979, 1996. For a direct re-reading of Marx and Gramsci and their importance for medical anthropology see SEPPILLI T. 1998, 2002.

⁽⁵⁾ «Freudianism is more a 'science' to be applied to the upper classes and it might be said, paraphrasing Bourget (or an epigram about him), that the 'sub-conscious' only begins at an income level of some tens of thousands of lire» (Q15\$74).

⁽⁶⁾ See two important contributions on Gramsci's criticism of Freud: MESSA RUIZ E. 1998 and STONE J. 1984. Stone's article is a very interesting reconstruction of Gramsci's reaction to his wife's psychoanalysis, in the framework of an "Italian Freud". See also BUCI-GLUCKSMANN 1976: 109-115.

⁽⁷⁾ These two passages were not published in the first editions of *Letters* and *Notebooks*, because they seemed too strange and embarrassing to Palmiro Togliatti who was the editor together with Felice Platone of Gramsci's writings. The first important comment on these passages is GERRATANA V. 1990. See also SZABO T. 1989, RAGAZZINI D. 2002 and CAVALLARO L. 2002 who discuss Gramsci's notion of person. Even if these articles are interesting they do not discuss the anthropological notion of person but only its western philosophical meaning. In my opinion in Gramscian passages we can find a critical approach to the notion of person, which is anthropologically relevant and which comes some years before Marcel Mauss' classic essays on body techniques and on person. Gramsci does not separate between body and person as Mauss did.

⁽⁸⁾ In a letter from prison written to reassure his sister-in-law about his health Gramsci begins with an ironic image that points directly to the false pairing of health and normality: «When I don't write anything about my health, it means that all is as normal as it can be in the prison environment». In an important passage from his posthumous work, Ernesto de Martino defined the couple health-illness as a «double falsehood, which brings to anthropology a series of misunderstandings, deformations, and mistaken interpretations» (DE MARTINO E. 1977: 18). De Martino had seen very clearly the risk of remaining trapped in the back and forth ping pong between definitions of health and illness. «What's involved is not 'explaining health with illness'; any such attempt would already be illnesses». The judgment of health or illness cannot be separated from consideration of the relationship between behavior and historical environment. To get around this *impasse*, de Martino suggested, one needs to assume as the criterion for distinguishing the healthy from the ill, not "reality," but "historical reality."

Bibliography

- AA. VV. (1991), *Gramsci en America Latina. Del silencio al olvido*, Fondo Editorial Trópikos, Caracas.
- ANGELINI Pietro (ed.) (1977), *Dibattito sulla cultura delle classi subalterne (1949-50)*, Savelli, Roma.
- BAER Hans A. - SINGER Merrill - SUSSER Ida (1997), *Medical Anthropology and the World System. A Critical Perspective*, Bergin & Garvey, Westport.
- BUCI-GLUCKSMANN, Christine (1976 [1975]), *Gramsci e lo Stato. Per una teoria materialistica della filosofia*, traduz. italiana di Claudia MANCINA e Giuseppe SAPONARO, Editori Riuniti, Roma [ediz. orig.: *Gramsci et l'État. Pour une théorie matérialiste de la philosophie*, Fayard, Paris, 1975].
- BARATTA Giorgio (2000), *La rosa e i Quaderni. Saggio sul pensiero di Antonio Gramsci*, Gamberetti Editrice, Roma.
- BURGIO Alberto (2003), *Gramsci storico. Una lettura dei "Quaderni del carcere"*, Editori Laterza, Roma - Bari.
- CAVALLARO Luigi (2002), *La "trasformazione molecolare". Sul concetto di persona in Gramsci*, "Critica Marxista. Analisi e contributi per ripensare la Sinistra", n. 1, gennaio-febbraio 2001, pp. 51-60.
- CIRESE Alberto Mario (1976), *Intellettuali, folklore, istinto di classe. Note su Verga, Scotellaro, Gramsci*, Einaudi, Torino.
- CLEMENTE Pietro - MEONI Maria Luisa - SQUILLACCIOTTI Massimo (eds.) (1976), *Il dibattito sul folklore in Italia*, Edizioni di Cultura Popolare, Milano.
- CREHAN Kate (2002), *Gramsci, Culture and Anthropology*, Pluto Press, London - Sterling.
- DE MARTINO Ernesto (1949), *Intorno a una storia del mondo popolare subalterno*, "Società", anno V, n. 3, 1949, pp. 411-435.

DE MARTINO Ernesto (1977), *La fine del mondo. Contributo all'analisi delle apocalissi culturali*, edited by Clara GALLINI, Einaudi, Torino.

DI NOLA Alfonso Maria (1978), *Varietà degli oggetti della cultura subalterna religiosa del Mezzogiorno*, pp. 35-39, in SALIA Francesco (ed.) (1978), *Questione meridionale, religione e classi subalterne*, Guida, Napoli.

FOUCAULT Michel (1977 [1972]), *Microfisica del potere. Interventi politici*, FONTANA Alessandro PASQUINO Pasquale (eds.), Einaudi, Torino [ediz. orig.: 1972].

FRANKENBERG Ronald (1988), *Gramsci, Culture, and Medical Anthropology: Kundry and Parsifal? or Rat's Tail to Sea Serpent?*, pp. 324-337, in FRANKENBERG Ronald (ed.) (1988), *Gramsci, Marxism and Phenomenology: Essays for the Development of Critical Medical Anthropology*, "Medical Anthropology Quarterly", n.s., vol. 2, n. 4, december 1988.

FRANKENBERG Ronald (ed.) (1988), *Gramsci, Marxism and Phenomenology: Essays for the Development of Critical Medical Anthropology*, "Medical Anthropology Quarterly", n.s., vol. 2, n. 4, december 1988.

FROSINI Fabio (2003), *Gramsci e la filosofia. Saggio sui Quaderni del carcere*, Carocci, Roma.

GERRATANA Valentino (1990), *Unità della persona e dissoluzione del soggetto*, pp. 189-202, in MOSCATELLO Biagio (ed.), *Gramsci e il marxismo contemporaneo, relazioni al convegno organizzato dal Centro Mario Rossi, Siena, 27-30 aprile 1987*, Editori Riuniti, Roma, ripubblicato con il titolo *Contro la dissoluzione del soggetto*, pp. 127-141, in GERRATANA Valentino (1997), *Gramsci. Problemi di metodo*, Editori Riuniti, Roma.

GRAMSCI Antonio (1918), *Merce*, "Avanti!" [socialist newspaper], 6 giugno 1918 [pp. 406-407, in GRAMSCI Antonio (1960), *Sotto la mole. 1916-1920*, Einaudi, Torino].

GRAMSCI Antonio (1975), *Quaderni del carcere*, edizione critica a cura di Valentino GERRATANA, Einaudi, Torino [written in prison under the fascist regime between 1929 and 1935, published in a first thematical edition Einaudi starting from 1948; published in first critical edition Einaudi in 1975; English translations: HOARE Quentin - NOWELL SMITH Geoffrey (ed. and trans.) (1971), *Selection from the Prison Notebooks*, Lawrence & Wishart, London, and BOOTHMAN Derek (ed. and trans.) (1995), *Further Selections from the Prison Notebooks*, Lawrence & Wishart, London].

GRAMSCI Antonio (1996 [1947]), *Lettere dal carcere*, Sellerio, Palermo, 2 vols. [orig. ed.: Einaudi, Torino 1947; English translation: ROSENGARTEN Frank - ROSENTHAL Raymond (ed. and trans.) (1994), *Letters from Prison*, Columbia University Press, New York, 2 vols.].

LINDENBAUM Shirley - LOCK Margaret (eds.) (1993), *Knowledge, Power & Practice. The Anthropology of Medicine and Everyday Life*, University of California Press, Berkeley

LISA Athos (1973), *Memorie. In carcere con Gramsci*, Feltrinelli, Milano.

LOMBARDI SATRIANI Luigi Maria (1980 [1974]), *Antropologia culturale e analisi della cultura subalterna*, Rizzoli, Milano.

MESSA RUIZ Erasmo (1998), *Freud no "divã" do cárcere. Gramsci analisa a psicanálise*, Editora Autores Associados, Campinas.

PASQUINELLI Carla (1977), *Antropologia culturale e questione meridionale. Ernesto de Martino e il dibattito sul mondo popolare subalterno negli anni 1948-1955*, La Nuova Italia Editrice, Firenze.

PIZZA Giovanni (2001-2002), *Antonio Gramsci nelle antropologie contemporanee, seminario di Storia dell'antropologia, Sezione antropologica del Dipartimento Uomo & Territorio, Università degli studi di Perugia, anno accademico 2001/2002*.

RAGAZZINI Dario (2002), *Leonardo nella società di massa. Teoria della personalità in Gramsci*, Moretti & Vitali Editori, Bergamo.

RAUTY Raffaele (ed.) (1976), *Cultura popolare e marxismo*, Editori Riuniti, Roma.

RUDAS Nereide (1999), *Reclusione, solitudine e creatività in Gramsci*, pp. 27-41 in VACCA Giuseppe (ed.), *Gramsci e il Novecento, volume secondo*, Carocci, Roma.

SCHAPER-HUGHES Nancy (2001 [2000]), *Il traffico di organi nel mercato globale*, Ombre Corte, Verona [orig. ed.: *The Global Traffic in Human Organs*, "Current Anthropology" vol. 41, n. 2, 2000, pp. 191-211].

- SEPPILLI Tullio (1959), *Il contributo dell'antropologia culturale alla educazione sanitaria*, "L'Educazione Sanitaria", vol. IV, n. 3-4, pp. 325-340.
- SEPPILLI Tullio (1979), *Neutralità e oggettività nelle scienze sociali. Linee per una riflessione critica sul rapporto tra conoscenza e prassi*, pp. 77-91, in *Orientamenti marxisti e studi antropologici italiani. Problemi e dibattiti (1)*, "Problemi del Socialismo", IV serie, anno XX, 1979, Franco Angeli, Milano.
- SEPPILLI Tullio (1996), *Antropologia medica: fondamenti per una strategia*, "AM. Rivista della Società italiana di antropologia medica", n. 1-2, 1996, pp. 7-22.
- SEPPILLI Tullio (1998), *La influencia de Gramsci en el desarrollo de la Antropología de la medicina en Italia*, conferenza tenuta il 10 giugno 1999 al III Master de Antropología de la Medicina 1998-2000, Tarragona, 10-11 giugno 1999.
- SEPPILLI Tullio (2002), *L'itinerario Marx - Gramsci nella fondazione di una antropologia scientifica*, conferenza tenuta il 18 aprile 2002, nel quadro del seminario tenuto da PIZZA Giovanni (2001-2002), *Antonio Gramsci nelle antropologie contemporanee*, seminario di Storia dell'antropologia, Sezione antropologica del Dipartimento Uomo & Territorio, Università degli studi di Perugia, anno accademico 2001/2002.
- SINGER Merril - BAER Hans (1995), *Critical Medical Anthropology. Critical Approaches in the Health Social Sciences Series*, Baywood Publishing Company, New York.
- STONE Jennifer (1984), *Italian Freud: Gramsci, Giulia Schucht, and Wild Analysis*, "October", n. 28, Spring 1984 (*Discipleship. A Special Issue on Psychoanalysis*), pp. 105-124.
- SZABÓ Tibor (1989), *Soggettività, alienazione e trasformazione*, pp. 340-348, in BARATTA Giorgio - CATONE Andrea (eds.), *Modern Times: Gramsci e la critica dell'americanismo*, Cooperativa Diffusioni '84, Milano.
- WILLIAMS Raymond (1977), *Marxism and Literature*, Oxford University Press, Oxford.

2.

Health in multicultural settings La salud en contextos multiculturales La salute in contesti multiculturali



2.1 *At the bottom of the gap. Repertoires and the creation of cultural differences in Dutch mental health care*⁽¹⁾

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Introduction

Research in health care for immigrants often suggests that there is a gap, a cultural gap, between immigrants and health professionals. This gap cause many difficulties in interaction and care, which have to be studied in order to bridge it and to provide solutions. It is also believed that under-representation of certain groups of immigrants in for example mental health care is linked to this cultural gap. While perceptions of health care and health seeking behaviour among immigrants have thoroughly changed in the Netherlands, many studies continue to stress the cultural gap, the different explanatory models, the language problems and the life styles of immigrants. Health professionals report similar problems. These ideas have a strong impact on the experience and the daily practices of health professionals and steer research and debates about interculturalisation of health care.

Basically, the discussion about interculturalisation is a discussion about differences and how to deal with them. Elsewhere it is argued that welfare states cannot deal well with differences (COMELLES J.M., this volume). I argue that in welfare states certain differences between immigrants and indigenous persons are used in a particular meaning and with a political-economic purpose. When those differences come into being, one is not able to deal with them.

A recent concept that is used to characterise the European states is multiculturalism. Welfare states are moving from an area of modernisation and development of "better worlds" based on rationality and progress into an era of "multi", in particular of multi-culturalism, an era of "self", in partic-

ular self-responsibility and self-steering (DEVISCH R. 2001). Multi-culturalism emphasises the existence of different cultural traditions in a society and promotes tolerance and understanding (SMAJE S. 1995). Although it is not clear what is meant by multi-culturalism – is it a cultural mosaic in a dominant culture (GUTMAN A. - TAYLOR C. eds. 1994); is it the recognition of different ethnic groups; or is it the recognition of all differences between groups in a society (OKIN E. 1999)? – ideas of multi-culturalism permeate health care and tend to promote ghettoization (KYMLICKA R. 1995). As a result, it happens that research and health care policies are aimed to specific groups of immigrants: the Moroccans, the Turks or the Africans. Country of origin is the most important marker, while categories such as gender differences or social class are often overlooked.

The ideology of multi-culturalism has emerged within the process of globalisation and localisation resulting in “glocalisation” (ROBERTSON R. 1995). Basic in this process is a process of incorporation and selection of external influences, and a process of creolisation, in which meaning systems and expressions are mapped onto structures of social relations. Hannerz (HANNERZ U. 1992) sees in this process a culture of a prestigious centre on the one side, and cultural forms of the periphery on the other. That puts to the fore questions of power, structure and agency. How do people succeed in imposing their definitions of reality on others and how do they attain their goals? Giddens (GIDDENS A. 1994) offers a “radical politics”; what ‘used to be fixed is now subject to human decisions’ and therefore, humans are engaged in disputes and struggles about how people should live in the world. De Ruijter (DE RUIJTER A. 1998, 2000) applies the metaphor of the arena to multi-cultural societies. In the arena, De Ruijter argues, each group has its own theories about reality that serve as a blueprint for action. The issue is then: which group with its own cultural logic and repertoire has the power to define a situation and will control and exploit the resources? Frameworks such as those of Giddens and De Ruijter show the ambiguity and “practical” use of culture. They show that people create cultural differences as «formative myths that sustain a social organisation of difference» (BARTHES 1994: 30), which will serve as a legitimacy for power and rights. Then, it becomes possible to ask the question: When and why use people culture and cultural differences?

In mental health care in the Netherlands these frameworks are useful, because they challenge the conceptualisation of culture. This concept is central in health care for immigrants and therefore it is necessary to discuss it. Culture, as it is perceived in health care in general, and in mental health care in particular, is a static concept. It is the distinction, the differ-

ence between immigrants and indigenous people, the difference between immigrant groups and the difference between immigrants and health professionals. It is the cause of a gap and the focus of research. The definition of culture in health care is largely influenced by anthropologists, who – in the past – contributed to this static concept by describing ‘the patchwork quilt blanket of mutually absolutely distinct cultures’ (VAN BINSBERGEN W. 1999). However, anthropology has developed a different conceptualisation of culture. Many argue that cultures do not exist per se but are the outcome of an interaction process, which engenders the position of cultural differences. Cultural diversity is claimed by performative and strategic use of difference.

In this paper I argue that in Dutch mental health care “culture” is used as a strategic concept, in particular to maintain the status quo of health care. The paper will go to the “bottom of the gap”, the reality of everyday mental health care practices for immigrants, to explore how culture and cultural differences are created and used to claim “reality”. This is not to argue that mental health care uses culture in an opportunistic way. The issue is more complicated. There are too many interests of different parties in this arena. (Pseudo) traditional identities of people from transnational communities – thus the communities of the immigrants – develop ‘cultural mixtures’ but at the same time they will confirm traditional identities. Mental health professionals will do the same. Although a form of multi-culturalism is strongly promoted in mental health care, differences are strategically used in a power play, which reinforce the status quo in mental health care by keeping the immigrant in a ‘betwixt and between’ position. In order to show the ‘work with culture’ I will discuss the historical development of the debates and discourses on mental health care for immigrants.

The role of anthropology and mental health care in the creation of the concept of culture in mental health care

Anthropology has contributed to a large extent to a static concept of culture, that enables a dynamics of inclusion – exclusion in mental health care. A general and persistent idea in the Dutch public opinion is that migrants have ‘exotic and strange’ ways of dealing with illness. This idea is reflected in the research reports and publications of policy makers and health professionals (DE JONG J. 1991, MEURS P. - GAILLY A. 1998). ‘Culture’ is a keyword, which expresses a concern with and persistence of differences

between the mental health and health care of 'autochthonous' and 'allochthonous' patients.

Anthropology has focused on the exotic health practices of the different immigrant groups that entered the Netherlands during the sixties and seventies of the previous century and seems to have become relevant when refugees and asylum seekers entered the country in the nineties and after. However, while in anthropology today culture is differently conceptualised, the static concept of culture is still widely used in mental health care and has remained the same for more than forty years of research tradition in health care settings that have to deal with migrant groups. How were those differences created, what was the repertoire and what were the effects on care for immigrants? In a contribution to *Health for All* (VULPIANI P. - COMELLES J. - VAN DONGEN E. eds. 2000) Van Dijk and Van Dongen give an overview of the development of perspectives since 1960.

In the 1960s the health problems and health situation of migrants were only discussed when public health was threatened. Large groups from Mediterranean countries came as "guest workers" in the country and were supposed to return "when the job was done". X-ray control and screening for tuberculosis was quite common. That migrants were perceived as a danger to public health, as contagious, becomes clear in the suggestion of Huisken, who insisted that immigrants should be x-rayed three times a year. (HUISKEN D. *et al.* 1966). Residence permits were connected to tuberculosis examination and control during the first years of stay. The repertoire of contagion has persisted over time up until today. Tuberculosis screening is the standard procedure in health care for recent refugees and asylum seekers, while doctors at asylum centres would like to extend screening to other diseases.

Since the 1970s, the time when it became clear that migrants would stay and families would be reunited, the focus of health care and health research shifted from contagion to deficiency and exoticism. Diseases such as rachitis, psychosomatic complaints (ulcers) and exotic diseases such as possession became the focus. Anthropology had to contribute with cultural knowledge about beliefs, practices and models of immigrants. Repertoires in research and health care centred around discussions on the strangeness of behaviour and the expression of complaints. The list of experienced 'problems' is illustrative: expressive presentation of complaints and symptoms, exaggeration of the problem or even simulating, vagueness of symptoms, non-compliance, improper use of medicines, taboos on certain examinations and psycho-social problems. Cultural differences were a core

cause of misinterpretations and ineffective care and became «an excuse for failing health care» (VAN DIJK R. 1998[1989]). The recipe was cultural knowledge (“Give us the tools, we do the job!”), to be delivered by anthropologists and experts of religion. A board for medical care for migrant workers was established in 1972. This board advised the minister and centres for interpretation. In 1977, an information service for foreigners was established. Additional services such as the Refugee Health care Centre (former Central Medical team of the Ministry of Health and Environment Hygiene) and the Social Psychiatric Service for Refugees (1978) focused on specific groups with ‘high health risks’. Numerous studies focused on cultural explanations of illness behaviour and migrants’ illness behaviours were reduced to ‘traditional cultures’. Migrants were “exoticised” and stereotyped. Cultural knowledge has not helped therapists, but according to Van Dijk the cultural difference of the migrants was helpful in concealing inadequate mental health care:

«The care provider cannot get a hold on the symptoms; he cannot interpret them and bring about a cure or alleviation of a problem. He does not succeed in passing on his view on the nature of the symptom. His feelings of impotence and frustration are softened and camouflaged by the cultural label. One could call this ‘tertiary illness profit’, but the profit does not fall to the patient.» (VAN DIJK R. 1998: 246)

Since the 1970s ‘culture’ is the focus of research. Conferences with suggestive names such as “Cultures within the walls of psychiatry” or “The cultural factor in medical care for migrants” attract dozens of mental health professionals, who experience constraints and problems with foreign patients.

During the 1980s Dutch policy changed from a facilitation of migrant groups (then called minorities) in the 1980s towards an integration of allochthonous individuals (change of terms for migrants!) in the 1990s. The Minority Bill of 1983 stressed that health care should be accessible for migrants, but no special services for migrants were needed. Exceptions were made for ‘new problem groups’ such as Vietnamese refugees. This did not mean, however, that in mental health care no problems were signalled. Somatization and communication problems – already widely discussed in the 1970s – remained topics of interest in both research and psychiatric practice. Differences between autochthonous and allochthonous persons were re-created with an important change: Migrants not only *explain* their afflictions in different frames; they also *experience* their afflictions differently. The main repertoire of exoticism and strangeness was transformed into a repertoire of inadequacy on the side of professionals. Similarities between migrant

and indigenous clients came into being, because studies stressed that the latter reported similar complaints and behaved in a similar way as the migrant clients. A general trend in mental health care was to improve knowledge and especially know how of professionals, so that they could 'decode' the messages sent by migrant clients. In other words, professionals had to become "culture (or culturally sensitive)-sensitive".

While the spotlight shifted from the migrants to the health professionals, old repertoires persisted. "Culture" and "cultural relativism", technical, anthropological concepts, which served – according to Van Binsbergen (VAN BINSBERGEN W. 1999) – as concepts that could sustain concurrence among anthropologists (every anthropologist his or her own village or "culture") and that have made fieldwork as a unique inter-subjective and uncontrollable experience, had become the most used and obvious terms to describe the world, its differences and conflicts (VAN BINSBERGEN W. 1999). Within mental health care (trans-cultural psychiatry) the debate on universalism and relativism and culture-bound syndromes continued to rage and finally resulted in the creation of the Cultural Formulation of Diagnosis in the Diagnostic and Statistical Manual, which infused mental health with the creation of cultural differences at the individual level, which in my opinion is more difficult to capture. The use of the Cultural Formulation of Diagnosis will probably strengthen the trend within Dutch mental health care to focus on case studies without relating these cases to other, similar cases, so that structural thresholds and constraints in the lives of migrants will not become visible. Anthropologists have contributed to the debate about the Cultural Formulation of Diseases.

In the meantime, the anthropological debate about culture changed into a debate about human rights, poverty, oppression, violence and the effects on mental well-being. These scholars plead for a collection of case studies "at the margin", which would clarify the relationship between mental health and the social-political-economic situation. Issues of discrimination and racism were put on the European agenda.

In the 1990s a remarkable change in repertoire took place. This change may be captured by the term "inter-culturalisation". It was believed that having a toolbox filled with cultural knowledge was no longer an option, since so many persons with different cultural backgrounds had entered the Netherlands. It is important to note that 'culture' is still an important trigger in the health process of migrants. The 1990-focus was on management of cultural diversity. Instead of 'fitting' migrants into the health system, the health system had to adapt itself to the needs of people (*inpassen* versus *aanpassen*). The Council of Public Health and Care published a report on

inter-culturalisation (2000). The repertoire in this report is characterised by “lacks”: the Council concluded that there were numerous shortcomings: lack of a shared vision (perspectives of professionals are too diverse), lack of structure, lack of connectivity between demand and need of care, lack of cultural competence, lack of cultural sensitive education and training, lack of proper registration, lack of epidemiological research, lack of participation of migrants in patient organisation, lack of information about care facilities, etc.

Within health policy it was believed that attuning organisational structures, procedures, personnel and care to the multi-cultural society would lead to cultural change in health care. Flexibility, openness to innovation and dynamics, training and education and diversification became core concepts in multi-cultural mental health care. Migrants were no longer a “constraint” or a “problem”; they became a *challenge* for management and professionals.

The arrival of large groups of asylum seekers and refugees from many parts in the world was followed by the establishment of new, special services that focused on enhancement of skills and knowledge of professionals (training and education). The ideal of the inter-culturalisation was involvement of and collaboration with migrants in a learning process. However, it is not clear what is meant by involvement and collaboration. Is it participation of professionals with a migrant background in treatment? Is it participation of migrant organisations in the process of attuning health care? Or is it the individual migrant who will have to take a role in the health arena? In any case, a repertoire of *zorg op maat* (care cut down to the patients' needs) suggests that individual migrants will have to ‘stand for their rights’. The arena-metaphor glooms....

While the official ideology seems democratic, another exclusion mechanism came into being; The *Koppelingswet* in 1996. This law connects the right to almost all provisions, thus also to health care, to a permanent residence permit. All governmental files are connected to those of the aliens department/police, so that the Dutch government can control foreigners. The result is that all migrants without such a permit and all persons who are in the procedure, or being tolerated or ‘un-deportable’, are excluded from the right to provisions. Thus, health care may have become an instrument of aliens policy. Professionals had to determine whether a mental problem was acute or not.

The minister of Health (Volksgezondheid, Welzijn en Sport, Vws) presented her vision on the future of health care. In a memorandum the minister

presented the answer to the problem of increasing diversification: rationalisation, standardisation and expansion. From mental health care the critique was that migrants were no longer a focus group. Particular stressors such as uncertainty about a residence permit, acculturation, disruption and uprootedness disappear behind evidence-based protocols for treatment (cf. KORTMANN F. 2003). It is striking that racism, discrimination and subordination were not discussed in the minister's memorandum. In a manifesto, Van Dijk and others (VAN DIJK R. *et al.* 2000) protested against the memorandum and presented a new orientation based on equality of migrants and professionals. A main argument for this new orientation was that migrants wrestle with future problems of the autochthonous Dutch population, such as increasing mobility, changes in life world, cultural fragmentation, disorientation or detachment. Instead of exotic others or persons with special needs, migrants now become "pioneers" for what possibly will happen with others in the Netherlands. They will have to carry the responsibility of representing an alienating, fragmented, disrupting and 'sick' society.

Kortmann (KORTMANN F. 2002) commented on the manifesto and presented the idea of "inter-culturalisation cut down to the patients' needs" and insisted on relative equality. Kortmann creates new differences based on an old dichotomy (universalism-relativism), because the nature of the affliction determines the relevance of cultural differences between professional and clients. Kortmann states that in cases with afflictions with known organic substrates, a dialogue about cultural differences or equality is not needed.

Both advocates and opponents of inter-culturalisation based on equality stress that mental health care will have to become more active in signalling health risks, preventive intervention, outreaching and exchange of knowledge with others such as primary health care and migrant organisations. Keywords are: reflection, dialogue, experiment and critical reconsideration of professional practice.

Because of a lack of theoretical frames, mental health care is characterised by intuitive practices as far as care for migrants is concerned. Research is biomedical and less based in a narrative approach. In personal interaction between professionals and migrants dialogue is the main way of interaction. At institutional and professional levels a struggle for paradigm change exist. At this level the arena metaphor is most applicable. Traditionally oriented professionals have interests in maintaining the status quo; pioneers in intercultural mental health (involuntarily) contribute to feelings of inadequacy of their colleagues; allochthonous professionals may avoid a discussion with their Dutch colleagues for different reasons or may think

that they have the correct perspective and reference frame, because they are allochthonous. In short, in mental health care a struggle over the power of definition and situation exists. It is this arena that De Ruijter has written about (DE RUIJTER A. 1998).

A general conclusion may be that repertoires have changed and migrants are approached differently. However, a recent research inquiry among Cape Verdean migrants in mental health care (BEIJERS H. 2003) suggests that repertoires may have changed but perspectives and difficulties in mental health care have not. Cape Verdean migrants and “learning communities” (composed of representatives of migrant communities, professionals and scientists) reported familiar and traditional bottlenecks and thresholds in mental health care that can be summarised as follows: cultural background of the migrants, lack of knowledge about health care facilities, experiences of being discriminated, reluctance to use mental health care facilities, language problems, lack of cultural knowledge of professionals. The results of this study were confirmed by studies in other European countries, such as Italy, Spain, Sweden and Belgium. They reported the same bottlenecks.

But it was also found that Cape Verdean migrants, like Chinese or Philippine migrants, belong to the so-called “silent migrants”; invisible, self-reliant, under-using mental health care. Why did they become of interest to mental health care? Was it because mental health care took the advice of the “inter-culturalisation movement” at heart and adopted a more active attitude towards migrants? Or was it because the Cape Verdean community itself – or a part of it – wanted to participate in the arena of mental health care?

Another recent issue, which is related to ‘inter-culturalisation’, must be discussed: cultural competence. This concept stems from an Anglo-Saxon background. Cultural competence aims at improving the performance and competency of health professionals thereby enhancing the capacity of a health system to respond to cultural diversity. It means that health professionals will have to be ‘sensitive’ to all aspects of differences and will have to develop reflective, self-critical and respectful attitudes. Del Vecchio Good (DEL VECCHIO GOOD M. 1995) made a typology of competence: she distinguished three repertoires that can also be found in recent debates in Dutch mental health care. The first is the intra-professional repertoire. In this repertoire, professionals are able to talk about inadequacies of mental health care and their colleagues. The second is the repertoire of professionals to the public. This repertoire is meant to affect public actions such as liability, legislative and financing reforms. The third form is reflective repertoire, meant to reflect on good and less good practices. Thus, cultural compe-

tence is an instrument for health professionals. Immigrant clients are the passive recipients.

In short, two aspects of inter-culturalisation deserve critical attention. One concerns the term culture. What is meant by culture? What is meant by cultural sensitivity? The other concerns the “inter” part of the term. What is meant by “inter” and why has it a special relation to health care for migrants? In order to address these questions, I suggest an alternative approach, which draws on the concepts of anomaly and liminality (cf. BARRETT R. 1998) in order to focus on how the category “migrant” is socially constructed.

The migrant as anomaly

There are two main ways in which mental health care uses the term “migrant” (equivalent “allochtonen”). First, it refers to a specific category of patients/clients and a spectrum of afflictions that are thought to be specific for this category. In this way, the word describes characteristic symptoms of the “condition migrante” such as rootlessness, alienation or cultural fragmentation. Second, the term is used to qualify a type of person rather than his or her condition. We can have “migrant clients” and “non-migrant clients” (cf. TER HAAR W. 2000). Clients are portrayed as individuals who have something quintessentially migrant-ish about them. It is as if their being-migrant infiltrates their illness with no alternative explanation. The problem (affliction) becomes the person. Such usage of the term “migrant” enables mental health care to lump diverse people together into a single group.

It must be said, that nowadays this qualification is refined, either geographically, in reason of migration or in time. Migrants have become “Ethiopian migrants”, “Turkish migrants”; they have become migrants, refugees or asylum seekers, or first, second and third generation migrants. Yet, they remain “migrants”. By using this qualifier mental health conveys the implication that all “migrants” have the potential to exhibit mental health problems (“risk groups”). Recognition that “migrant” refers to a category of person as much as to certain types of mental illnesses draws attention to institutional practices and their cultural traditions. It explores the extent to which the mental health institutions are embedded within a web of other, related institutions – universities, pharmaceutical industries, patient groups, insurance companies and governments – and how this web influences the production of knowledge of migrants’ mental health problems.

Sue Estroff (ESTROFF S. 1993) has published an important study of these issues. Although not focused on a “migrant population”, Estroff seeks to

call into question the authority of psychiatry and examines the structural problems inherent in mental health care. Starting with the question: Who does not get well and why, Estroff presents a political economy of mental health problems (i.e. chronic schizophrenia). She shows how a person who experiences an event of psychiatric treatment develops into a category of negatively valued and dysfunctional person. In our case, this is the “migrant” who by being-a-migrant is “at risk” and who is sometimes burdened with a label (such as schizophrenia) that is in itself negative and disabling. Estroff argues that social welfare and health policies codify cultural ideas about identity, illness and productive activity. In our case, this is expressed in memorandums and reports of inter-culturalisation that stress cultural differences and call for ‘respect’ and mutual definitions of the health situation of migrants. Estroff mentions several factors that contribute to the construction of this category: «the growing numbers of and demand for jobs by mental health professionals; ardent public and political advocacy and espousal of medical models of mental illness among family members; and income maintenance resources that are illness-tested» (ESTROFF S. 1993: 251). She observes a significant increase in the number of mental health professionals, their level of professionalisation and their unionisation, while «an odd coalition between employees who wish to protect jobs and relatives of persons with mental illnesses» is formed. For very different reasons professionals protect their personal and economic interests by affirming the severity of the illness. I am not aware of the existence of any statistical data on increasing number of Dutch professionals who work with migrant clients in mental health care, but some studies suggest that in the past decades mental health institutes are ‘flooded’ with migrants, while only a couple of professional ‘hobbyists’ arrange care for migrant clients. Institutions pay little attention to professionalisation in this field and they do not cooperate with each other, so that it becomes possible that different agencies are engaged in the assistance of one family (KORTMANN F. 2003: 46). Migrant organisations that cooperate with mental health care or “migrant professionals” often affirm the status quo.

Institutions and policies position the category “migrant”. This category is located at the margin, quintessentially because “culture” is the main threshold in mental health care for migrant patients. “Migrant”, however, is not just a marginal category; it is an anomaly in the sense that it refers to an irregularity. It does not fit into the Dutch system of classification (cf. DOUGLAS M. 1966). However, because a migrant is an anomaly, he or she can simultaneously be regarded as being-similar and being-dissimilar. This anomalous position is reflected in recent position taking in mental health

care. On the one hand, it is argued by some that “migrants” have (very) similar problems as autochthonous persons; on the other hand many insist that migrants can be distinguished from autochthonous clients by their specific problems and particular ways of presenting complaints and explanations. Migrants encounter avoidance and are associated with public danger, especially after the murder on the politician Fortuyn and September 11. If danger is fixed in people’s (minds)imagination, it would play its part in mental health care. Several studies suggest a higher incidence of psychotic and schizophrenic disorders in migrant groups (DE JONG J. 1996, SCHRIER *et al.* 2001, STRONKS K. - RAVELLI A. - REIJNEVELD S. 2001). Although it is not clear which factors contribute to this higher incidence, others have suggested that the different cultural background of migrants is an important contribution to differences in diagnosis (cf. LITTLEWOOD R. 1992). In mental health care, culture is still a static concept: homogenous, demarcated and used to characterise the Other: the migrants. This idea is expressed in repertoires such as those on “cultural distance”, cultural gap” or “living between cultures”. “Inter” as prefix of interculturalisation seems to express a horrifying and uncertain descend into the gap; who will be the first to make the step, the professional or the client? Bartels (BARTELS E. 2002, 2003) argues that transcultural psychiatry will have to actively act upon cultural differences in such a way that both, professionals and migrants have equal power over definitions. I argue that the immigrant’s position – a position ‘at the bottom of the gap’ – only becomes possible because the category “migrant” is constituted from the onset as an anomaly, while it is simultaneously argued that migrants are ‘equal’ to the ‘natives’. The hallmark is ambiguity and gives rise to a double interpretation. Are the migrants’ mental health problems defence of defiance? Are migrants actors or are they victims? Is there a “cultural problem” for mental health care or an organisational problem? Many more of such questions can be raised. Estroff (ESTROFF S. 1993) would arrange this question in the ‘can’t versus won’t controversy’ in mental health care and society at large (can’t we care or won’t we care for ‘migrants’?). Thus, “inter” as part of the term of interculturalisation can be seen as expression of this ambiguity.

Migrants as *liminal personae*

Placing too much emphasis on classificatory schemes such as DSM, stable cultural categories (“the migrant”) and on a society as a fixed structure denies the dynamics and the agency of immigrants. One should empha-

sise the dynamic social processes that generate and sustain such anomalous categories such as “migrants”. Trans-cultural psychiatry is a suitable domain to inquire into these processes because it remains, despite changes in repertoire that guide actions, the principal site where clients are diagnosed, receive treatment and will undergo radical changes in their personal identity.

I want to focus on the inter-structural situation (TURNER V. 1967: 93) of liminality, because it leads beyond the static concept of anomaly. A number of authors have used the concept of liminality to describe and analyse illnesses such as chronic illness, disability or schizophrenia. Moore and Meyerhoff (MOORE S. - MEYERHOFF B. 1977) have addressed this issue in *Secular Ritual*. They examine the distinctive nature of ritual in contexts of heterogeneity, fragmentation and change. Participants are often strangers to each other and the sacred (i.e. the unquestionable) reaches beyond the domain of religion. The authors refer to de-secularisation of ‘modern’ societies. I must add that – although the Dutch society seems to be a de-secularised society and religion does not play its part in psychiatry – religious aspects re-enter the mental health care stage through the backdoor: “Culture” as main part of the repertoire in trans-cultural psychiatry is limited to ways of life of Islamic migrants and refugees. Culture is used as synonym of religion and language and remains static.

If illness itself can be characterised as a period of anomie, alienation and angst, migrants will have to deal with a double pair of alpha sisters, because they are ill and are “migrants” who possess “culture”. The strong call for a “dynamic concept of culture” (VAN DIJK R. 1998) and for interculturalisation of mental health care may shift the focus to the performative dimension of care. Knowing HOW to do prevails in this repertoire over knowing WHAT. Words as “dialogue” (VORSTENBOSCH J. 2003), “active work with cultural differences” (BARTELS E. 2002, 2003) stress the performative and expressive dimensions of the work with migrant clients. Mental health care is increasingly conceptualised as a market. The much used concepts *zorg op maat* and *vraaggestuurde zorgverlening* (care steered by demand and need) suggest that migrants will have to become a party at this market in order to receive proper health care, limited by the conditions set by insurance companies and law. One thinks that migrants cannot take this role of self-confident consumer, which results in new templates such as empowerment and participation. Again the position of liminal personae is frozen, because they are defined as persons in transition. They are in a permanent state of decomposition and growth, a permanent limbo.

“Culture” as part of inter-culturalisation is in this view something that has to be produced, but cannot be produced, because it is argued that developments in health care and migrants’ culture hinder this process. Professionals complain that working (in a cultural sensitive way or inter-culturally?) is a “Sisyphus job” (BAARS J. - KAL D. 1995), because social contexts are neglected and “modern societies” are “risk societies”. The few studies that have explored migrants’ experiences and actions in mental health care (BEIJERS H. 2003, VAN DIJK R. *et al.* 2002) show that people in the first place need a “human”, “understanding” and “respectful” approach of professionals. This cry for humane treatment in medicine is nowadays very common in public discourse, but it also is the *point d’orgue* in medical anthropological research, philosophy and (yes) psychiatry. What does this mean? Does it mean that with “humanness” problems such as those mentioned here could be solved? Is it a counter movement of medicalisation processes within mental health care? I believe we have to be critical in accepting the idea that a “human approach” is a solution. Seeing migrants as “humans” with rights to “human treatment” might be an excuse just as culture might be an excuse for failing therapy. ‘Being nothing as human’ might be the greatest danger because it depoliticises, dehistoricises and displaces the fundamental inequalities and injustices between people matters in place and people matters out of place (AHRENDT H. 1973).

Immigrants seem to reaffirm and reinforce the social definitions and values to which they do not conform. Entrusting people with symbolising society, its structural elements, paradoxes, contradictions and definition of personhood is not uncommon. Although such a view may have the advantage of providing a way of understanding experiences and persons that are strange and disturbing, it also has limitations. It may reconfirm and reinforce the symbolism of liminality instead of the dilemma of those who are typecast as *liminal personae*. An alternative strategy might be to identify metaphors that migrants use to “make sense of their experience”. The category “migrant” is alienating and distancing, because it denies the creativity of the person. Understanding “migrants-with and migrants-as-problems” may better be pursued by studying how they force a connection with the cultural mainstream. I argue that they often do a better job than professionals.

Conclusions

Perhaps I replace repertoires by other repertoires without making substantial progress. However, I have showed that “migrants” in (mental) health

care run the danger of being defined as “migrant”, an anomalous category; the social avoidance (also in mental health care) they experience, and a subtler notion of contagious effect attributed to them (the cause of all problems mental health care experiences). Ambiguity and contradiction are features of the category, which is often described in terms of oppositions and contrasts (autochthonous versus allochthonous).

Can such concepts as anomaly and liminality as analytic tools be used to understand the way migrants experience their illness?

It may be important to explore with migrants the extent to which the notion of “migrant” (or refugee or asylum seeker) influences their self-concept and actions. That implies a totally different approach, in which the focus is not on health per se but on “ways of being-in-the-world”. If the idea of anomaly and liminality pervades thinking about being a migrant, it may be fruitful for them to consider other ways of thinking about themselves. By exploring this with migrants it may be possible to understand better what it means to be a migrant with a mental distress. This, in turn, may give rise to specific strategies to deal with the ambiguous limbo of migrants. But I am also sceptical about this enterprise. This mechanism explains the power of the unchanged concept of culture as it is used in mental health care, especially in trans-cultural psychiatry. This does not mean that culture is static; it means that culture is used to engender differences without questioning or investigating the answers the Dutch population have to their health problems. This needs research of concrete interactions and idioms used to talk about mental health problems. Underneath ‘culture’ there is a more serious problem. I agree with Singer and Baer, when they write: «Much of the tension in the [clinical] encounter does not derive from the existence of diverse health subcultures nor is it due to a failure in medical education to instil an appreciation of folk models of health and illness, but rather is a reproduction of larger class, racial, and gender conflicts in the broader society» (SINGER M. - BAER H. 1995). Remarkably, class, gender, ethnic or racial “clashes” are not a part of the mainstream debate of interculturalisation in Dutch mental health care. In the Netherlands, the debate on intercultural health care is not about racism, sexism or class differences; the debate is about “culture”. This implies that mental health is not linked to broader structures «as a configuration of power alignments» (SINGER M. - BAER H. 1995: 376). Thus, before discussing inter-culturalisation, we will have to have a debate on taboos in the Dutch society on gender, racism and discrimination; topics that are very sensitive in a society, which sees itself as “tolerant” and “open-minded”.

Note

⁽¹⁾ A reworked version of this paper is published in "Anthropology & Medicine", 2004, December issue.

Bibliography

- AHRENDT H. (1973), *The origins of totalitarianism*, Harcourt, New York - London.
- BARRETT R. (1998), *The 'schizophrenic' and the liminal persona in modern society*, "Culture, Medicine and Psychiatry" vol. 22, n. 4, 1998, pp. 465-494.
- BARTELS E. (2002), *Interculturele Hulpverlening. Het concept cultuur*, "Sociale Interventie", vol. 9, n. 1, 2002, pp. 14-22.
- BARTELS E. (2003), *Religie, levensbeschouwing en psychiatrie. Een antropologische benadering*, pp. 185-203, in VAN REE Frank (ed.), *Ggz en levensbeschouwing. Psychiatrische hulp aan Nederlanders en Medelanders*, Swets & Zeitlinger, Amsterdam.
- BEIJERS H. (2003), *'One hundred doors and only one key'. Exclusion of Cape Verdean migrants from mental health-care services in the Netherlands*, Report for "Partners in Health", Phase II, Amsterdam.
- DE JONG J. (1991), *Vreemde gezinnen? Systeem therapie met Marokkaanse, Turkse en Surinaamse gezinnen*, "Maandblad Geestelijke Volksgezondheid", n. 9, 1991, pp. 924-938.
- DE JONG J. (1996), *Psychodiagnostiek bij allochtonen: Vragen om moeilijkheden*, "Maandblad Geestelijke Volksgezondheid", n. 5, 1996, pp. 483-497.
- DEL VECCHIO GOOD M. (1995), *American medicine: The quest for competence*, University of California Press, Berkeley.
- DE RUIJTER, A. (1998), *Poverty from an international point of view*, Netherlands National Commission for UNESCO, The Hague.
- DEVISCH R. (2001), *Culture, sciences and endogenous knowledge practices: Some anthropological perspectives*, pp. 29-53, in *Science and tradition: Roots and wings for development*, Royal Academy for Overseas Sciences & UNESCO, Bruxelles.
- DOUGLAS M. (1966), *Purity and danger. An analysis of the concepts of pollution and taboo*, Routledge, London [reprint 1985].
- ESTROFF S. (1993), *Identity, disability, and schizophrenia: The problem of chronicity*, pp. 247-287, in LINDENBAUM S. - LOCK M. (eds.), *Knowledge, power & practice. The anthropology of medicine and everyday life*, University of California Press, Berkeley.
- FOSTER G. - ANDERSON B. (1978), *Medical Anthropology*, Wiley, New York.
- FRANKENBERG R. (1986), *Sickness as cultural performance: Drama, trajectory and pilgrimage root metaphors and the making social of disease*, "International Journal of Health Services", vol. 16, n. 4, 1986, pp. 603-626.
- GAILLY A. (1986), *Etnogeneeskunde en -therapie bij Turken*, "Cultuurleven", n. 1, 1986, pp. 67-80.
- GIDDENS A. (1994), *Beyond left and right. The future of radical politics*, Polity Press, Cambridge.
- GUTMAN A. - TAYLOR C. (eds.) (1994), *Multiculturalism: Examining the politics of recognition*, Princeton University Press, Princeton.
- HAAR TER W. (2000), *Afrikanen in Nederland: Een inleiding*, pp. 11-43, in VON KESSEL I. - TELLEGEN N. (eds.), *Afrikanen in Nederland*, KIT African Studies Centre, Amsterdam - Leiden.
- HANNERZ U. (1992), *Cultural complexity: Studies in the social organizations of meaning*, Columbia University Press, New York.
- HENDRIKS J. (1974), *Optimale deelname aan de Nederlandse samenleving*, "Medisch Contact", vol. 32, n. 6, 1974, pp. 591.

- HUISKEN D. *et al.* (1966), *Buitenlandse arbeiders en tuberculose*, "Tegen de Tuberculose", vol. 61, n. 5, 1966, pp. 24-31.
- JASPERS K. (1974), *Causal and 'meaningful' connexions between life history and psychosis*, pp. 81-93, in HIRSCH M. - SHEPHERD M. - KALINOWSKY L. (eds.), *Themes and variations in European society*, University Press of Virginia, Charlottesville VA.
- KORTMANN F. (2002), *Interculturalisatie op maat. Reactie op het manifest 'Interculturele geestelijke gezondheidszorg'*, "Maandblad Geestelijke Volksgezondheid", n. 57, 2002, pp. 52-64.
- KORTMANN F. (2003), *Interculturele gezondheidszorg in Nederland. Een studie naar de 'state of the art' van de transculturele hulpverlening*, Mikado, Rotterdam.
- KRAMER S. - BALA J. - VAN DIJK R. - ÖRY F. (2003), *Making sense of experience. Patronen van betekenisverlening en coping van asielzoekers*, Utrechtse School voor Bestuurs- en Organisationswetenschap, Utrecht.
- KYMLICKA R. (1995), *Multicultural citizenship*, Oxford University Press, Oxford.
- LAZARUS E. (1988), *Theoretical considerations for the study of the doctor-patient relationship: Implications of a perinatal study*, "Medical Anthropology Quarterly", vol. 2, n. 1, 1988, pp. 34-58.
- LITTLEWOOD, R. (1992), *Psychiatric diagnosis and racial bias*, "Social Science and Medicine", n. 34, 1992, pp. 141-149.
- MCALLISTER, P. (1997), *Cultural diversity and public policy in Australia and South Africa: The implication of 'multiculturalism'*, "African Sociological Review", n. 1, 1997.
- MEURS, P. - GAILLY A. (1998), *Wortelen in vreemde aarde. Migranten gezinnen en hulpverleners ontmoeten cultuurverschil*, Acco, Leuven.
- MOORE S. - MEYERHOF B. (1977), *Secular ritual*, Van Gorcum, Assen.
- OEI T. (2000), *In het slop geraakt*, "Medisch Contact", vol. 55, n. 39, 2000, pp. 1-3.
- OKIN E. (1999), *Is multiculturalism bad for women?*, in COHEN J. - HOWARD M. - NUSSBAUM M. (eds.) (1999), *Is multiculturalism bad for women?*, Princeton University Press, Princeton.
- ROBERTSON R. (1995), *Glocalisation: Time-space and homogeneity-heterogeneity*, pp. 25-44, in FEATHERSTONE M. - LASCH S. - ROBERTSON R. (eds.), *Global modernities*, Sage, London.
- SCHRIERS A. - VAN DE WETERING B. - MULDER P. - SELTEN J.P. (2001), *Point prevalence of schizophrenia in immigrant groups in Rotterdam: data from outpatient facilities*, "European Psychiatry", n. 16, 2001, pp. 162-166.
- SINGER M. - BAER H. (1995), *Critical medical anthropology*, Baywood Publishing Company, Amityville NY.
- SMAJE S. (1995), *Health, 'race' and ethnicity. Making sense of the evidence*, King's Fund Institute, London.
- SNEL E. (2003), *De vermeende kloof tussen culturen*, Oratio Universiteit van Twente, Enschede.
- STRONKS K. - RAVELLI A. - REIJNEVELD S. (2001), *Immigrants in The Netherlands: equal access for equal needs?*, "Journal of Epidemiology and Community Health", n. 55, 2001, pp. 701-707.
- TURNER V. (1967), *The forest of symbols: Aspects of Ndembu ritual*, Cornell University Press, Ithaca NY.
- TURNER V. (1982), *From ritual to theatre: The human seriousness of play*, Performing Arts Journal Publications, New York.
- VAN BINSBERGEN W. (1999), *Cultures do not exist*, Inaugural Adress, Erasmus University, Rotterdam.
- VAN DIJK R. (1998), *Culture as excuse. The failures of health care to migrants in The Netherlands*, pp. 243-251, in VAN DER GEEST S. - RIENKS A. (eds.), *The art of medical anthropology*, Spinhuis, Amsterdam [orig. ed.: *Cultuur als excuus voor een falende hulpverlening*, "Medische Antropologie", vol. 1, n. 2, 1989, pp. 131-44].
- VAN DIJK R. - BOEDIJARATH I. - DE JONG J. - MAY R. - WESENBEEK R. (2000), *Interculturele geestelijke gezondheidszorg in de XXI eeuw. Een manifest*, "Maandblad Geestelijke Volksgezondheid", n. 55, 2000, pp. 134-144.
- VAN DIJK R. - VAN DONGEN E. (2000), *Migrants and health care in The Netherlands*, pp. 47-69, in

- VULPIANI P. - COMELLES J.M. - VAN DONGEN E. (eds.), *Health for all, all in health. European experiences on health care for migrants*, CIDIS ALISEI, Perugia.
- VAN DONGEN E. (2002), *Walking stories. An oddnography of mad people's work with culture*, Rozenberg Publishers, Amsterdam.
- VAN DONGEN E. (2004), *Worlds of psychotic people. Wanderers, bricoleurs and strategists*, Routledge, London - New York.
- VAN GENNEP A. (1960 [1909]), *The rites of passage*, Routledge & Kegan Paul, London [orig. ed.: *Les rites de passage*, Paris, 1909].
- VORSTENBOSCH J. (2003), *Zorg voor kleur. Over ethiek, multiculturaliteit en zorg*, CELAZ, Utrecht.
- VULPIANI P. - COMELLES J.M. - VAN DONGEN E. eds. (2000), *Health for all, all in health. European experiences on health care for migrants*, CIDIS ALISEI, Perugia.

2.2 *Los dominios simbólicos de la inmigración.*

La dialéctica entre las demandas de atención socio sanitaria y la estructura de los dispositivos asistenciales en el caso de los inmigrantes ecuatorianos en la región de Murcia

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Introducción

Esta reflexión surge de los resultados parciales de una investigación que se está realizando desde el Departamento de antropología social y cultural de la UCAM y cuyo objetivo fundamental es el de establecer un contexto interpretativo, analítico y evaluativo *de los principales condicionantes socioculturales que determinan los procesos de salud/enfermedad/atención del Colectivo de Inmigrantes Ecuatorianos (CIE en adelante) en las comarcas murcianas del Alto y Bajo Guadalentín* ⁽¹⁾.

Obviamente la elección de esta temática para el desarrollo de nuestra investigación no es casual. Tampoco ha venido determinada por la influencia de determinadas corrientes ideológico-estratégicas y académicas que se han apropiado (con escasos márgenes de legitimidad en algunos casos) de un espacio social comprometido colectivamente como es el de la inmigración. El compromiso de analizar la inmigración desde el punto de vista socio sanitario obedece en nuestro caso, no únicamente a la necesidad de explicar los niveles de salud diferencial de los inmigrantes del CIE con respecto a la población local de las sociedades receptoras. Como vamos a intentar poner de manifiesto en el presente artículo, existen otros factores de carácter político, económico y social que se rebelan como determinantes en la comprensión global del fenómeno; la cultura político-sanitaria en materia de inmigración de nuestra comunidad autónoma, como en la mayor parte del Estado español, dista mucho de haber alcanzado un nivel míni-

mo de comprensión respecto a la emergencia y expresión de las nuevas expectativas sociales que se están generando en torno a esta temática. Y no solamente por las repercusiones que la misma provoca en el gasto (y consiguientemente en la estabilidad de los criterios extraordinariamente racionalistas que rigen la gestión sanitaria en los niveles asistenciales en la actualidad) y en la propia organización de los servicios sanitario como, con mucha razón, suele argumentarse desde los sectores más críticos; existe además, una cierta saturación ideológica que impide a los agentes sociales implicados reapropiarse de su papel como sujetos activos dentro de la complejidad del fenómeno. Los profesionales de la sanidad se encuentran limitados por la escasez de recursos ante un incremento desproporcionado de la demanda, además de coartados por unas estructuras sanitarias que, en la práctica, no se han adaptado a la heterogeneidad de los nuevos perfiles de estas demandas; los propios inmigrantes se encuentran desposeídos de cualquier capacidad de movilización que favorezca mecanismos de acción originales y adaptados a sus propias necesidades socioculturales. De hecho, existen ciertos grupúsculos organizados dentro del CIE que han dirigido sus esfuerzos, aunque sin éxito, hacia objetivos precisos, concretos y trascendentes para su organización y vida social: vivienda, empleo o la propia sanidad. Lo cierto es que la reivindicación de dichas acciones no ha sido tomada en cuenta ni en los debates públicos, ni en los espacios de discusión política a los que tímidamente han podido acercarse ⁽²⁾.

A pesar de los privilegios simbólicos (también materiales) que la investigación sobre inmigración reporta en la actualidad a todos aquellos que estamos implicados de una forma u otra en la misma, es cierto que existe una crisis de confianza en la fiabilidad de los estudios que están gestionando, desde las Ciencias Sociales (y concretamente, desde la propia Antropología) la complejidad del fenómeno migratorio. Las razones de esta desconfianza radican en la parcialidad de los enfoques en unos casos, y en el absentismo explicativo de las condiciones reales de producción de dicho fenómeno en otros. De ahí que nuestra intención inicial se centre en un intento por escapar de las simplificaciones explicativas e introducirnos en la complejidad del fenómeno en un esfuerzo por reconocer en los propios escenarios sociales de la inmigración determinados interrogantes preferenciales no cuestionados en los discursos políticos y político-sanitarios concretamente pero muy presentes en el imaginario y en la realidad en la que la inmigración se expresa cotidianamente.

La imposición de un modelo de recuento oficialista y sus consecuencias como "ilógica" de la inmigración.

Sobre la base de estas condiciones y a partir de un contexto de estudio más amplio que estábamos realizando sobre determinantes socioculturales del CIE en la Región de Murcia, hemos podido elaborar nuestras preferencias objetuales siguiendo como enclave reflexivo tres factores fundamentales: en primer lugar, el significativo incremento de inmigrantes ecuatorianos en las comarcas señaladas en el periodo 2000-2002; en segundo lugar, la interrelación entre determinadas condiciones estructurales del CIE y sus condiciones de vida junto con otros factores laborales y socioeconómicos que están repercutiendo de forma significativa en la conformación de determinados patrones de morbilidad diferencial y en ciertas condiciones y perfiles de demanda asistencial del colectivo; en última instancia, las enormes dificultades con que los dispositivos sanitarios se encuentran para asumir la cada vez mayor y diferencial demanda sanitaria procedente del CIE y de otros colectivos de inmigrantes.

Tal vez sea el primero de los factores apuntados el que más fielmente nos permita estructurar de forma descriptiva la evolución demográfica del CIE, con el objetivo de establecer los márgenes reales del escenario interpretativo en el que situar el contexto sociosanitario de la inmigración en nuestra comunidad autónoma.

Los ámbitos de invisibilidad formal provocados por el carácter ficticio de los datos con que se muestra oficialmente el fenómeno migratorio en muchos casos, así como la errónea e insidiosa certificación de las estadísticas y recuentos oficiales sobre el mismo, en otros, nos llevó a establecer un recuento propio⁽³⁾ para los años 2001 y 2002 de los individuos pertenecientes al CIE que conformaban el universo de estudio en las comarcas señaladas.

Dichas comarcas constituyen la cabecera de seis ayuntamientos con una población total de cerca de 200.000 habitantes de los aproximadamente 1.200.000 que posee la Comunidad Autónoma en su conjunto. No fue por tanto la significatividad numérica en términos absolutos de los habitantes de dichas comarcas lo que nos llevó a definir las como eje de la investigación, sino más bien la importancia y la presión de los flujos relativos al CIE en ellas durante los últimos años.

El recurso a los datos oficiales (fundamentalmente padrones municipales y Delegación del Gobierno en la Región de Murcia) nos permitió establecer inicialmente un mapa numérico de la inmigración en las comarcas del Alto y Bajo Guadalentín con respecto al conjunto de la Comunidad, pron-

to fuimos conscientes de que dichos datos opacaban, en cierto sentido, la situación sociodemográfica real a partir del cual debíamos definir nuestra investigación. Las razones fundamentales para ello radicaban en que los padrones municipales únicamente recogen a individuos ecuatorianos (o inmigrantes en general) con residencia declarada y acreditada en los respectivos ayuntamientos, sin tener en cuenta su situación de regularidad o irregularidad, mientras que otras fuentes oficiales solo recogen los datos de los individuos “con papeles”, esto es, con permiso de residencia o de trabajo y aquellos que han obtenido su situación de regularización administrativa mediante reagrupamiento familiar. Ello, sin lugar a dudas, reducía significativamente las posibilidades de establecer un contexto interpretativo real respecto al número de individuos de nacionalidad ecuatoriana susceptibles de acudir y ser atendidos por los dispositivos sanitarios del Servicio Murciano de Salud (SMS).

A este respecto, resulta preciso señalar que la todavía hoy vigente Ley de Extranjería, respecto al derecho a la atención y asistencia sanitaria de los inmigrantes, recoge en su artículo 12 las siguientes disposiciones:

1. Los extranjeros que se encuentren en España inscritos en el padrón del municipio en el que residan habitualmente, tienen derecho a la asistencia sanitaria en las mismas condiciones que los españoles.
2. Los extranjeros que se encuentren en España tienen derecho a la asistencia pública de urgencia ante la contracción de enfermedades graves o accidentes, cualquiera que sea su causa, y a la continuidad de dicha atención hasta la situación de alta médica.
3. Los extranjeros menores de dieciocho años que se encuentren en España tienen derecho a la asistencia sanitaria en las mismas condiciones que los españoles.
4. Las extranjeras embarazadas que se encuentren en España tendrán derecho a la asistencia sanitaria durante el embarazo, parto y posparto.

De este contexto legal, se desprende que las disposiciones referenciadas no hacen distinción alguna entre la situación administrativa (regularidad, irregularidad) de los inmigrantes susceptibles de recibir asistencia sanitaria. Por el contrario, especifica una serie de supuestos y posibilidades asistenciales que eluden la consideración “regular” o “irregular” garantizando un derecho que trasciende el anclaje ideológico con que comúnmente y colectivamente se representa el fenómeno migratorio. Y señalamos esta idea, fundamentalmente, porque cuando hacemos referencia a los conceptos de inmigración o de inmigrante suele reproducirse con demasiada frecuencia un consenso sobre los significados “oficiales” que objetivamente adquieren sentido en la estructura social y en el espacio social en el que se

presentan como realidad y como experiencia. La imagen socialmente construida sobre el inmigrante irregular escenifica simbólicamente el no reconocimiento en cuanto al acceso a determinados derechos sociales por el contexto trasgresor y delictivo con que se proyecta mediática, pero también políticamente en muchos casos, dicha imagen. La inmigración es uno de esos fenómenos que suelen mostrarse como estructura social objetiva y como categoría social subjetiva constituyendo el principio sobre el cual se asientan gran cantidad de acciones y de representaciones sociales, donde el estereotipo y la metáfora (con toda su rigurosidad y contundencia) adquieren rasgos ideacionales de verdad.

Para poder situarnos en unos márgenes más realistas y con el soporte metodológico apuntado más arriba (nota 103) construimos una estimación cuantitativa que nos permitiese combatir ese espacio interpretativo ficticio que generaban los datos oficiales.

De la estimación realizada y como apunte ilustrativo para tres de los ayuntamientos en los que estábamos realizando el estudio, se desprendía que el intervalo de inmigrantes ecuatorianos (tuviesen el estatuto de regulares o irregulares) se situaba entre aproximadamente 22748 individuos en su límite superior y 21020 aproximadamente en su límite más bajo. Al comparar estos datos con los que habíamos extraído de los padrones municipales de esos mismos ayuntamientos para el mismo periodo y que representaban un número total de 6161 individuos ecuatorianos empadronados⁴ encontramos un salto vertiginoso entre los criterios contables oficiales y la situación numérica real en lo que afecta al CIE. Estas enormes diferencias evidencian lo ya apuntado respecto a los datos oficiales y su *utilidad* para la comprensión y activación de medidas conducentes a la adecuación de las estructuras sociosanitarias a la situación real de la inmigración ecuatoriana en las comarcas de estudio.

Pero esta situación, no es exclusiva ni particular del contexto sociosanitario sino que muy al contrario, se hace extensible a todas las parcelas en las que la inmigración se muestra socialmente como hemos podido comprobar en nuestra investigación. De ahí que estas *bolsas* de inmigrantes no reconocidos oficialmente y por lo tanto no localizables en los espacios formales de clasificación de la ciudadanía, y sujetos a las condiciones que impone nuestro país, bien definido por Naïr como el «reino de la precariedad jurídica de los trabajadores inmigrantes»(GOYTISOLO J.- NAÏR S. 2000: 118), sean coparticipes involuntarios en la génesis de una especie de sensación de alarmismo social que se está generando y apoderando de los ciudadanos en las zonas de estudio (como en otros muchos lugares de la geografía española).

Si la marginación y la exclusión son aspectos fundamentales en la elaboración de prejuicios, la conformación de estas distancias numéricas tiene un sentido en el aquí y el ahora de la inmigración; porque obviar (y se obvia *oficialmente*) es marginar, aislar en los espacios profundos de esa *nada estatalizada*, y en esas condiciones se encuentran muchos de los inmigrantes como apuntan las estimaciones realizadas. Inmigrantes que han modificado con su presencia los escenarios y paisajes urbanos, que comparten los espacios simbólicos de las ciudades, que reclaman silenciosamente el derecho a unas condiciones de vida y existencia dignas, y sobre todo, que en su propia invisibilidad han sido “reclamados” para retomar el pulso y dinamizar los procesos de aceleración de las economías locales.

Las definiciones oficiales sobre la inmigración, además, se basan en una compleja arquitectura y estructura de palabras que incorpora, entre otros, aspectos identificatorios como la procedencia (magrebí, subsahariano, lituano, ecuatoriano, etc.), la situación jurídico-administrativa y laboral (regular, irregular, empadronado o no, etc.), la adscripción religiosa (católico, musulmán, ortodoxo, etc.), a los que se suman conceptos extraídos de otros ámbitos (sobre todo académicos) como multiculturalidad, pluriculturalidad, etnia, racismo, etc. Todo ello, bajo la apariencia de mera descripción, termina por construir una realidad social ambigua, en un espacio social aun por definir, pero que se traduce en forma de representación para los conjuntos sociales, una representación expresada en muchos casos, no sólo en términos de superioridad estructural, sino también socio-cultural.

Comparto por todo ello con Pierre Bourdieu (BOURDIEU P. 1999: 128) la idea de que las realidades sociales son una ficción sin otro fundamento que la construcción social y que existen como realidad en tanto que son reconocidas por la colectividad.

El “efecto llamada” como expresión de la lógica de los mercados

Uno de los aspectos fundamentales a tener en cuenta para poder explicar la situación particular de la inmigración en las comarcas referenciadas más arriba y su incidencia concreta sobre el sistema sanitario, pasa, en un primer momento, por la comprensión que el impacto de la internacionalización de las economías en las conexiones entre los países de la emigración e inmigración y en la reorganización de los mercados en ambos contextos. A pesar de que no es este el argumento ni el tema central que guía esta reflexión, es preciso detenernos un instante en ello para poder compren-

der en qué condiciones y a partir de qué razones se ha producido ese significativo incremento de la población ecuatoriana en las comarcas de estudio.

En el caso concreto de nuestra investigación, y por lo que hace referencia a las zonas de estudio, la implantación de una agricultura de carácter intensivista y comercial orientada a la exportación de productos de carácter hortofrutícola fundamentalmente a centroeuropa y el Reino Unido y con escasa incidencia en los mercados locales, ha convulsionado en poco tiempo las economías agrícolas tradicionales de estas comarcas. Los datos relativos al crecimiento de la población ecuatoriana en ellas (como en otras muchas zonas de nuestra geografía) evidencian en muchos aspectos cierto carácter de imprevisibilidad.

Pero la paradoja de esta imprevisibilidad viene determinada por la tendencia inductora de los mercados al “regular” laboralmente la continuidad de los flujos de mano de obra irregular. Se hace, hasta cierto punto, difícil de comprender la connivencia entre las estructuras laborales agrarias y los propios mercados, sobre todo, si tenemos en cuenta que ello ha llevado a convertir a los propios inmigrantes en una mercancía sometida a las leyes de la oferta y la demanda. Lo cierto es que a pesar de los discursos más o menos oficiales tendentes a colocar el acento en el carácter “invasivo” de los procesos migratorios actuales hacia nuestra comunidad de estudio, la sostenibilidad, no sólo de estos nuevos mercados agrícolas, sino también la estabilización de determinadas economías periféricas generadas en torno a ellos, ha dependido y depende de la continuidad de la entrada de inmigrantes con un bajo perfil de cualificación profesional y con un bajo coste salarial para continuar siendo competitivos. Además dichos flujos se sitúan en muchos casos bajo condiciones de vida marcadas por la invisibilidad respecto de las políticas sociales y sobre todo por la precariedad en cuanto al acceso a determinados recursos sociales.

No obstante y como ha indicado Sassen (SASSEN S. 2001: 94) los analistas de las políticas de inmigración, suelen tratar el flujo de mano de obra como el resultado de decisiones individuales, sobre todo en lo que se refiere a la opción individualista de emigrar en busca de mejores oportunidades. Tal criterio hace recaer toda la responsabilidad de la inmigración sobre los propios inmigrantes. Los comentaristas políticos y de los medios de comunicación hablan de “riadas” o “invasiones” de inmigrantes, y tratan al país como sujeto pasivo: la inmigración aparece desvinculada de los actos pasados o presentes de los países receptores, y la política de inmigración se presenta como más o menos benevolente hacia los inmigrantes.

Brilla por su ausencia, por ejemplo, toda advertencia de que las actividades internacionales de los estados o empresas de los países receptores de emigrantes hayan podido contribuir a la formación de vínculos económicos con los países de emigración, vínculos que pueden propiciar a su vez, tanto el movimiento de personas como de capitales.

Todo ello se acentúa con una concepción manejada por muchas sociedades de acogida (y de los propios estados políticos) acerca de que la inmigración sea algo transitorio con una cronología limitada en el tiempo y el espacio cuando, tal y como se está comenzando a comprobar, se produce un auténtico movimiento de poblaciones con un proyecto de retorno cada vez menos definido.

Estos procesos descritos están generando la copresencia de individuos que, en nuestra zona de estudio como en la práctica totalidad de las sociedades con un perfil similar de demanda de inmigración, se empieza a caracterizar por una continuidad y persistencia de los flujos que además suele establecerse en función de redes familiares y de afinidad social en muchos casos. Los vínculos establecidos entre las comunidades de origen y destino establecidos generalmente a partir de familias mixtas y estructuras de parentesco y sociales amplias son fundamentales para entender su continuidad e importancia en la regularidad de los flujos. Los inmigrantes ecuatorianos han comenzado a instalarse con mucha frecuencia en los trabajos domésticos, complementando así las ocupaciones generadas por el sector agrícola que fundamentalmente había constituido el nicho laboral por excelencia de los miembros del CIE. La creciente demanda que está generando este sector doméstico ha influido de forma determinante en ello y por razones muy complejas en las que no ha lugar incidir ahora; lo hacen de forma más o menos continuada a pesar de las características específicas del mismo: «exceso de movilidad y variedad, tanto en cometidos (tareas domésticas, cuidado de niños, disminuidos anciano, etc.) como en las modalidades y tiempos de trabajo (interna, por horas, media jornada, jornada completa, suplencias, etc.)» (CRIADO M.J. 2001: 350).

De la “mala salud” estructural de los dispositivos sanitarios a las condiciones de vida del Cie

Podemos afirmar, por todo ello, que la situación de la inmigración que estamos describiendo ha supuesto una discontinuidad institucional en el contexto político estatal y sobre todo, en el diseño de las políticas admi-

nistrativas comunitarias en lo que afecta a los ámbitos sociales y, particularmente a los sociosanitarios.

La ambigüedad con que los dispositivos sanitarios y la propia legislación han asumido el contexto de demanda sanitaria procedente de la inmigración ha representado, en la práctica, el surgimiento de una serie de estrategias informales por parte de los propios inmigrantes para integrar sus perfiles de demanda asistencial (condicionados fundamentalmente por sus propias condiciones sociolaborales, como veremos más adelante) en los diferentes espacios y cronologías de los ámbitos formales de atención sanitaria. Dichas estrategias han condicionado que, en la práctica, tanto Atención Primaria como la Asistencia Hospitalaria hayan tenido que acomodar en muchos casos sus rutinas y protocolos asistenciales a dichos perfiles.

Dicha situación, además, está generando que los servicios sanitarios de ambos sectores se encuentren en una situación límite en cuanto a sus posibilidades reales para cubrir la demanda existente; las urgencias hospitalarias suelen atender a un número de individuos que, en algunos casos, multiplica por cuatro el umbral de los recursos humanos y materiales que serían precisos para cubrir dichas demandas y lo mismo sucede con las urgencias dispuestas por Atención Primaria. Otros servicios como ginecología o maternidad se ven desbordados por el incremento de población femenina que acude con asiduidad a los mismos. Valga como ejemplo el incremento de nacimientos de niño/as ecuatorianos experimentado en el periodo 2000-2002, que ha supuesto, en términos porcentuales, que en la mayor parte de los ayuntamientos de referencia en los que se lleva a cabo nuestro trabajo, las cifras de nacidos, pertenecientes al CIE respecto al número total de los nacidos, se sitúe por encima del 20%, llegándose en algunos casos a cifras superiores al 25% para el primer semestre del año 2003.

Y todo ello, porque nuestro sistema sanitario, en términos de diseño político y económico continúa orientado exclusivamente al contexto de demanda local sin tener en cuenta, no sólo la diversidad de necesidades, sino de su incremento, surgidas del escenario pluricultural que hemos venido describiendo. Las necesidades sociosanitarias se multiplican al mismo ritmo que aumenta la llegada de inmigrantes mientras que las estructuras sanitarias son inadecuadas no sólo para cubrir la heterogeneidad cultural de la demanda, sino para dar respuesta, en términos absolutos, al número de solicitudes de atención sanitaria que se registran en los centros sanitarios.

Si las condiciones estructurales de los dispositivos asistenciales del sistema sanitario plantean las dificultades apuntadas, no menos compleja es la si-

tuación de los profesionales sanitarios que cubren las demandas en los servicios hospitalarios y de Atención Primaria. Si bien desde los ámbitos estamentales oficiales se tiende a proyectar una situación *normalizada*, lo cierto es que la capacidad para absorber la demanda se presenta cada vez más diezmada y determinada por algunos factores que ignoran el “culto” estrictamente economicista y racionalista de la productividad y la rentabilidad sanitaria.

Son los profesionales, en los niveles prácticos, los que han de hacer frente a la disparidad entre los recursos disponibles (materiales y humanos) y el incremento de los niveles de demanda sanitaria provocados por la inmigración. La *disidencia* profesional observada en el curso de nuestro trabajo respecto a las normas institucionales y las regulaciones que restringen los servicios sanitarios en los dos niveles asistenciales, pone de manifiesto la magnitud de un problema generado, en gran medida, en las instancias políticas y gerenciales de nuestro sistema.

A pesar de que determinados trabajos de investigación auspiciados por los niveles de responsabilidad política en materia de inmigración, hagan hincapié en la competencia normalizada y en la casi universabilidad asistencial que faculta a los inmigrantes empadronados para acceder a todos los servicios de salud, la realidad se muestra bien diferente bajo este impulso tan generoso como irrealista de la situación sociosanitaria de la inmigración.

En nuestra investigación hemos podido constatar en la practica totalidad de los casos analizados, cómo el contexto sociolaboral determina especialmente las condiciones en que se producen las citadas relaciones asistenciales en el caso concreto del CIE. Las condiciones de vida y de vivienda, los factores nutricionales y determinadas dinámicas de exclusión social aparecen como otros marcadores diferenciales que limitan igualmente el contexto relacional con los ámbitos sanitarios y con los profesionales. Para ilustrar esta reflexión, dirijamos un instante nuestra mirada al contexto socio-laboral.

La estructura laboral del mercado de trabajo en las comarcas de estudio y en el caso concreto del CIE, viene determinada por dos nichos laborales bien diferenciados: por una parte, y como ya hemos apuntado, el mercado de producción hortofrutícola, donde la proporcionalidad del empleo masculino es aun hoy, muy superior a la del empleo femenino; en un segundo plano, destaca la generalización del empleo doméstico por parte de la mujer ecuatoriana. Ambos dominios de *inserción* laboral se caracterizan por la precariedad, la inestabilidad y la provisionabilidad. Ello no sólo

afecta en gran medida y con carácter generalista, a los servicios sociales derivados de esta parcela: seguridad social, bajas por enfermedad o incapacidad y “paro” por ejemplo, sino que esta posición marginal y periférica respecto al sistema económico, determina unas condiciones socio-laborales muy concretas: jornadas laborales extensísimas, movilidad en las ocupaciones muy alta y precariedad de las propias condiciones laborales.

Estas dificultades *extrasanitarias* plantean la paradoja de que si bien la situación jurídico-legal de la asistencia sanitaria, ha alcanzado un grado de viabilidad razonable, las propias condiciones laborales impiden una adaptación socio-cultural a las rutinas y estructuras sanitarias. Las vinculaciones entre los procesos de enfermar y el tiempo improductivo, hacen que los primeros adquieran, en muchos casos, un peso relativo en función de los propios intereses dentro de la estructura representacional de los inmigrantes del CIE, pero no por ello irrenunciable y readaptable a las posibilidades formales e informales que les ofrece el propio sistema.

El recurso discursivo e ideológico dominante respecto al “desorden” con que los miembros del CIE asumen su posición dentro del sistema, al absentismo de las citaciones sanitarias o la falta de adhesión a los tratamientos por ejemplo, suele instalarse e interpretarse más por razones culturales o representacionales respecto a los procesos de enfermar o de concebir sus relaciones con los dispositivos sanitarios que a los verdaderos factores socioestructurales que se esconden, en muchos casos, tras esta realidad laboral desdibujada.

Es cierto que la práctica médica funciona enmascarando y/o escindiendo estas y otras variables y determinantes sociales (los factores riesgo implícitos en las propias condiciones de vida y trabajo de los inmigrantes o la falta de adecuación entre servicios y expectativas, como hemos apuntado), reintegrándolas en una lógica práctica que reproduce las particularidades de un Modelo Médico más centrado en una eficacia pragmática que en cualquier otro aspecto. Todo ello concede una autonomía casi ilimitada a la práctica médica respecto a los procesos de salud/enfermedad/atención. Pero sin recluirnos en los límites y los estrechamientos del Modelo Médico, el cuestionamiento aquí debería situarse en el análisis de las estructuras relacionales que se establecen entre el modelo médico, las dinámicas que definen el espacio social de la inmigración y el contexto ideológico y político por el que ambos se ven reorientados en sus aspectos fundamentales.

Como ya hemos apuntado repetidamente, los procesos de salud/enfermedad/atención vinculados a la inmigración se presentan como dependientes de las condiciones de vida y de trabajo impuestas a los propios inmi-

grantes carentes por el momento de otra salida que no sea la sumisión resignada que se les predica a veces bajo el buen nombre de la integración y que por lo tanto se plantean como un problema esencialmente político e ideológico.

Así lo hemos podido comprobar en nuestro trabajo. Sin caer aquí en la retórica de los datos, se ha constado en todos los servicios en los que hemos llevado a cabo nuestro trabajo que la mayor parte de las demandas de atención sanitaria (medicina general, urgencias o medicina especializada) han estado vinculadas a factores desencadenantes por el contexto laboral o por las condiciones de vida.

La medicina y el modelo médico sobre el que se asienta, al negar en la práctica estas dependencias relacionales, y ello solo es posible gracias al binomio biologicismo/individualismo con que se articula en la experiencia, elimina las posibles emergencias de lo social como factor explicativo de los procesos de salud/enfermedad de los inmigrantes. Ello provoca, en muchos casos, que estas circunstancias no trasciendan a los ámbitos de decisión y diseño sociopolítico y se continúe ocultando el verdadero rostro con que se muestra el problema en los niveles asistenciales.

Al mismo tiempo, los niveles de responsabilidad política parecen haber aceptado el curso ineluctable e indeterminado de esta realidad sin ofrecer alternativas concretas a las complejidades fundamentales con que ésta se muestra: la saturación asistencial en sus ámbitos de atención fundamentales (Atención Primaria y Modelo Hospitalario), la imposibilidad fáctica de atender a los procedimientos regulados legislativa y administrativamente en lo que hace referencia al derecho a la atención sanitaria de los inmigrantes, y en último lugar, y aspecto en el que pretendo centrarme a continuación, la desigual ubicación estructural entre los niveles de oferta de servicios de atención a la salud y la enfermedad y la demanda y expectativas procedentes de los propios inmigrantes respecto a esos servicios como también a los significados que estos les atribuyen.

Más que en cualquier otro contexto, la realidad sociosanitaria que estoy intentando describir define una estructura social y de significado determinada por las condiciones de desigualdad estructural y diferencia que el espacio social de la inmigración impone en la actualidad. No existen datos concluyentes todavía que permitan expresar las tasas diferenciales en cuanto a la morbilidad de los inmigrantes respecto a los conjuntos sociales integrantes de la sociedad receptora y esta carencia es especialmente significativa en nuestro ámbito regional, pero, como ya se ha puesto de manifiesto, a nadie escapa que las condiciones de vida (en lo que hace referencia a

vivienda, higiene, etc.) y los factores de riesgo implícitos a las condiciones laborales (jornadas que exceden en mucho lo tipificado, bajos salarios que condicionan el incremento de los ritmos autoimpuestos por los trabajadores inmigrantes, la falta de seguridad laboral y los riesgos en el trabajo, entre otros muchos factores) están generando condiciones objetivas para que las diferencias comiencen a mostrarse como apreciables.

Las significaciones socioculturales de los procesos de salud/enfermedad, deben ser referidas, como ha expuesto Menéndez (MENÉNDEZ E. 1997), a la estructura social para poder observar las condiciones donde se construyen, se desarrollan, se modifican y se utilizan esas significaciones culturales. Y hago hincapié en este aspecto porque aunque la intervención en las condiciones objetivas de existencia de ciertos colectivos inmigrantes y la modificación en ellos de, por ejemplo, una creencia etiológica o un ritual terapéutico ponga en cuestión órdenes ideológicos y equilibrios subjetivos profundos, el no tener en cuenta las condiciones estructurales y sociales (desigualdad, pobreza, etc.) imposibilita el análisis no sólo de las condiciones materiales, sino de los procesos simbólicos que están operando en este contexto.

Es por todo ello que la *delegación estatal* al modelo médico de los procesos de salud/enfermedad de los colectivos inmigrantes, por su propia naturaleza curativa y reparadora, elimina cualquier posibilidad de tener en cuenta los datos de carácter económico, social y político que están incidiendo y definiendo directa e indirectamente en esos mismos procesos. Pero si al mismo tiempo, esta *delegación* se convierte, por el curso de los acontecimientos proyectados a través de discursos “mediático-políticos”, en la única tendencia posible, en el signo inevitable de los acontecimientos, caeremos en un espacio de ambigüedad objetiva con un Estado más inclinado a ratificarla que a transformarla.

En el curso de nuestra investigación, hemos llegado a comprobar como las concepciones biomédicas respecto al proceso salud/enfermedad/atención se muestran como hegemónicas en un espacio social marcado por la heterogeneidad impuesta necesariamente por el decurso de la inmigración.

Sobre la base de las condiciones apuntadas, el modelo médico de atención a la salud y la enfermedad tanto como los colectivos profesionales adscritos al mismo, hacen homogénea esa heterogeneidad “ignorando” con demasiada frecuencia su valor respecto a los modelos culturales relativos al propio cuerpo, a la salud y la enfermedad y a su marco ideológico de valores; el imaginario, las representaciones y los valores simbólicos y emocionales referentes a cada uno de los padecimientos; su etiología y curso; las

vivencias subjetivas de la enfermedad como uno de sus componentes esenciales, a la vez que los componentes biológicos que la constituyen en el organismo, y las expectativas con los profesionales y los diferentes sectores sanitarios.

Las diferentes formas de desigualdad social en las que se expresa el fenómeno migratorio en la actualidad se traduce en necesidades objetivas y subjetivas que las propias condiciones de vida y trabajo imponen indiferenciadamente a la población inmigrante. Pero el modelo médico confirma las concepciones ideológicas y normativas dominantes en las que, como ya hemos intentado poner de manifiesto, el Estado juega un papel determinante en la normalización, codificación y homogeneización.

Todo ello determina la importancia de contextualizar la comprensión de los procesos de salud/enfermedad/atención y las posibilidades asistenciales respecto a la inmigración en un ámbito político, porque si bien es cierto, como hemos intentado demostrar en este trabajo, que las dinámicas de normalización estatales tienden a opacar y escindir lo político, social e ideológico que definen esos mismos procesos, mediante la concesión al modelo médico, eso no implica que esos niveles que se imponen como reales no sean tratados como tales desde la reflexión teórica, pero también desde las propuestas prácticas derivadas de la propia investigación antropológica.

Notes

⁽¹⁾ Dichas comarcas se sitúan en el sureste de la Comunidad Autónoma de Murcia y están conformadas por los ayuntamientos de Lorca, Totana, Alhama de Murcia, Mazarrón, Águilas y Puerto Lumbreras. El interés estratégico de nuestra investigación por dichas comarcas se sitúa en el extraordinario crecimiento que ha tenido la inmigración en los últimos cinco años, siendo ésta fundamentalmente de origen ecuatoriano y, en menor medida, procedente de los países del Magreb. Dicho crecimiento ha estado cerca de superar el 300% en el periodo de estudio en algunas de las localidades objeto de nuestro trabajo.

⁽²⁾ Existen asociaciones estatales de ecuatorianos como RUMINAHUI cuyo cometido ideacional fundamental es el de mejorar la calidad de vida del inmigrante ecuatoriano en España o canalizar determinados proyectos de cooperación al desarrollo con Ecuador que han intentado asumir un papel preponderante, pero tristemente y más que nada para focalizar la mirada mediática y reforzar al mismo tiempo su presencia simbólica en determinados espacios de reconocimiento social dentro del propio CIE. En el caso de esta asociación en la Región de Murcia, algunos de sus miembros se han visto salpicados en corruptelas o tráfico de irregulares, lo que supuso un duro golpe a sus pretensiones activistas en nuestro espacio de estudio. Otro estamento que ha intentado, con cierto margen de éxito, canalizar y construir propuestas de acción originales ha sido el Consulado de Ecuador en la Región de Murcia, con propuestas como la creación de la Casa de Ecuador y determinadas actividades que favoreciesen la integración de los miembros del CIE en la realidad social murciana.

⁽³⁾ Para poder calcular el tamaño de la población inmigrante ecuatoriana en el periodo señalado, utilizamos el método *captura-recaptura*, método indirecto basado en el cruce de dos o más fuentes de datos. Dicho método consiste en la estimación del número de sujetos que pertenecen a un grupo determinado, utilizando para ello dos o más fuentes de datos obtenidas a partir de la población a estudiar, posteriormente estas muestras se comparan y se determina el grado de solapamiento en las mismas (cuantos individuos hay repetidos en las diferentes listas). En el caso de nuestra estimación utilizamos dos fuentes independientes entre sí a partir de las variables sexo, edad y nombre de los sujetos para poder realizar el cruce. Dichas fuentes fueron el Hospital Rafael Méndez de Lorca y la Gerencia de Atención Primaria, puesto que aglutinaban en una proporción elevadísima el contexto de demanda de las zonas de estudio.

⁽⁴⁾ Empleamos como Fuente el Padrón Municipal de habitantes de la Región de Murcia del año 2001. Dirección General de Economía y Estadística.

⁽⁵⁾ Ver texto y bibliografía final.

Bibliography

BOURDIEU P. (1999^a [1994]), *Razones Prácticas. Sobre la teoría de la acción*, Anagrama, Barcelona [ediz.orig. *Raisons Pratiques. Sur la théorie de l'action*, Editions du Seuil, Paris, 1994].

BOURDIEU P. (1999b), *Contrafuegos. Reflexiones para servir a la resistencia contra la invasión neoliberal*, Anagrama, Barcelona.

CASTELLS M. (1999), *La era de la Información. Economía, Sociedad y Cultura, Vol. 3, Fin de Milenio*, Alianza Editorial, Madrid.

CRiado M. J. (2001) *La línea quebrada. Historias de vida de migrantes*, CES, Madrid.

FOUCAULT M. (1999), *Estrategias de Poder*, introducción, traducción y edición a cargo de VALERA Julia y ALVAREZ URÍA Fernando, Paidós Básica, Barcelona.

GOYTISOLO J. - NAIR S. (2000), *El peaje de la vida. Integración o rechazo de la inmigración en España*, Aguilar, Madrid.

IZQUIERDO A. (1996), *La inmigración Inesperada. La población extranjera en España (1991-1995)*, Trotta, Madrid.

MENÉNDEZ E. (1978), *El modelo médico y la salud de los trabajadores*, pp. 11-53, in BASAGLIA F. (ed.), *La Salud de los Trabajadores*, Nueva Imagen, México.

MENÉNDEZ E. (1997), *El punto de vista del actor. Homogeneidad, diferencia e historicidad*, "Relaciones. Estudios de historia y sociedad", n° 69, I invierno 1997, pp. 238-269.

SASSEN S. (2001), *Perdiendo el control. La soberanía en la era de la globalización*, Bellaterra, Barcelona.



2.3 *El rol del médico en la diversidad de culturas*

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Este artículo parte de una investigación en el 2003⁽¹⁾ sobre el impacto de las migraciones extra-comunitarias en el dispositivo sanitario de Cataluña. El objetivo general fue evaluar la práctica de los servicios sanitarios en relación con las personas inmigrantes e indagar prácticas o actitudes discriminatorias.

Como objetivo específico nos centramos aquí, en incidir en los problemas de comunicación e interacción entre usuarios inmigrantes y profesionales derivados de la falta de formación específica del personal asistencial a la diversidad, analizando "el papel o rol del médico" como concepto en la interacción que debe implicar el reconocimiento y la comprensión de representaciones culturalmente muy diversas de la salud y enfermedad. Relacionamos una multiplicidad de factores tratando de ver, de que modo opera en los individuos esta interacción, partiendo del concepto de visión social de Gellner (GELLNER E. 1993) entendida como estrategias o estilos de enfocar el mundo, y como se construyen en lo social estereotipos diversos conformando una imagen del inmigrante que Fassin D. dirá, se nutre de una percepción negativa de ilegalidad, restringiendo la legitimación de movimientos transnacionales (FASSIN D. 2000).

Elementos estructurales del modelo médico y las culturas organizacionales nos permiten detectar y analizar diferencias entre los dispositivos de Atención Primaria o Hospitalaria. Es en el trato de los médicos especialistas donde hemos centrado la atención a lo largo de tres años de investigación donde se percibe una lejanía específicamente a la población inmigrante que es expresada en términos de frialdad, dificultades de interacción además de lingüísticas. Disfunciones estructurales de los dispositivos propician la rigidez y distancia del especialista hospitalario, transformando en impotencia y contradicción, la concepción "del bien del individuo enfer-

mo". Intentamos profundizar en la situación del especialista situado en un engranaje complejo, en un lugar que puede traducirse como un lugar de pérdida de capacidad de interacción y atención con el enfermo, sin rol específico.

Introducción

El artículo que aquí se presenta es parte de una investigación sobre el impacto de las migraciones extra-comunitarias en el dispositivo sanitario de Cataluña⁽²⁾, una región autónoma bilingüe, con capacidad legislativa, dentro del Estado del Bienestar español. El objetivo general de la investigación en el 2003 ha sido evaluar la práctica de los servicios sanitarios en relación con las personas inmigrantes con el objeto de indagar prácticas o actitudes discriminatorias⁽³⁾. Los objetivos específicos se centran en este artículo a incidir en los *problemas de comunicación e interacción entre demantes y profesionales*, derivados de la falta de formación específica en atención a la diversidad del personal asistencial con especial énfasis en el papel o rol de los médicos, así como en la interacción en general que debe implicar el reconocimiento y la comprensión de representaciones culturalmente muy diversas de la salud y la enfermedad. Las interpretaciones de la patogenia y de la terapia son en su esencia variadas o variables de una sociedad a otra, de un individuo a otro y cambiantes incluso en una misma sociedad, pudiendo llegar ser infinitas a un nivel empírico, con lo cual no aceptamos la existencia de rígidas adscripciones categoriales basadas en clasificaciones étnicas, sino un constante tejer y destejer, construir y deconstruir de formas de hibridación cultural derivadas de la experiencia cotidiana de los individuos en entornos complejos. Estas concepciones las percibimos como complejas, cambiantes y articuladas en tiempos históricos determinados.

¿Discriminan los sistemas de salud del Estado del Bienestar Europeo?

En un artículo precedente hemos intentado ver los problemas que plantea la filosofía política europea en relación a la provisión de servicios⁽⁴⁾. La cuestión que se nos planteo en esta investigación desde el principio era la de establecer cuáles eran los límites de la palabra discriminación, y cuál podía ser el peso de una concepción taxonómica de lo *racial* de los profesionales en modificar el principio del derecho a la asistencia presente en los ordenamientos constituciones españoles⁽⁵⁾. En relación a la explora-

ción de esta discriminación la metodología de trabajo en el año 2003 fue implicar a todos los actores, profesionales de la salud e inmigrantes, sobre la base de tres escenarios distintos: observación en espacios de interacción, uso de entrevistas con informantes clave, y con *Learning Communities* mixtas que nos facilitaron un material que permite situar concretamente a los profesionales que ya han desarrollado estrategias relacionadas con la diversidad de culturas y a otros con menos o prácticamente ningún conocimiento acerca de la atención hacia estos usuarios. Estos grupos de trabajo estaban representados por médicos de familia, pediatras, ginecólogos, personal de enfermería, trabajadores sociales, personal de admisiones, y usuarios inmigrantes, de culturas asiáticas, africanas y del Magreb, junto con mediadores o agentes de salud⁽⁶⁾.

Las contradicciones del caso Catalán

Como destacamos en otro lugar⁽⁷⁾ el sistema de salud español, actualmente regionalizado en dieciocho organismos⁽⁸⁾, se rige por un mandato de la Constitución del 1978 y por la Ley General de Sanidad de 1986 que amplían el ámbito de protección al conjunto de la ciudadanía, que en la práctica posterior y en los hospitales y centros públicos, hasta la promulgación de la Ley de Extranjería de 2000, se extendía a cualesquiera se presentase a pedir socorro. Este principio general es recogido por las Leyes de ordenación sanitaria autonómicas que despliegan el dispositivo, de tal manera que en los “Pla de Salut” (*Health Plans*) bianuales de la Generalitat de Catalunya – el gobierno autonómico – el principio de la “Salud igual para todos” parecía excluir para siempre cualquier atisbo de discriminación por razones étnicas, culturales o religiosas. Y sin embargo este principio general universal topa con un fenómeno de discriminación estructural que deriva de la falta de recursos aplicados al sobre coste que inducen las variables culturales, étnicas o religiosas en el conjunto de los procesos asistenciales. La afirmación de *intangibilidad* económica de bastantes de esos costos, históricamente determinada, establece un escenario de discriminación. En el nivel más elemental, y más tangible, el retraso en dotar plazas de traductores para resolver el gap idiomático sería el caso más evidente. Los traductores nunca fueron previstos en el sistema de salud español – pero tampoco en el catalán – Como dice un médico “Este sistema no ha hecho ningún esfuerzo para un trato igual para todos, la actitud neutral es de hecho una discriminación en relación a la diferencia de grupos, es decir inmigrantes o extranjeros que no tienen las mismas oportunidades pues tienen dificultades para entender el sistema o el idioma”⁽⁹⁾. Esto, responde

a una filosofía de base que implicó desde la construcción del Seguro Social en 1942 hasta hoy la ignorancia de la diversidad cultural.

El concepto de “visión social” de Gellner (GELLNER E. 1993), es decir estilos o estrategias de enfocar el mundo y cuyos procesos de elaboración comprenden visiones sistematizadas frente a la duda, la conciencia del problema de la diversidad de visiones y la necesidad de dilucidar, responde a las construcciones o visiones en España – y en Cataluña – en el actual estado del Bienestar no ha hecho aún olvidar las actitudes de la beneficencia liberal, y el paternalismo a él inherente que si se aplicó a pobres, a la imagen del pobre o del gitano se le solapa el imaginario colonial y post-colonial de países empobrecidos y sin recursos que ya se habían construido antes de la llegada de inmigrantes. Este ideario benéfico, que sitúa a los inmigrantes en un plano de inferioridad se relaciona con otras construcciones previas, la idea de “enseñar” con la que estigmatiza a los países subdesarrollados y construye imágenes negativas de un inmigrado “ignorante” aunque un tercio de los que llegan a Cataluña tienen titulación media o superior. Estereotipos culturales muy arraigados, se asocian de una manera consciente, retóricas mediáticas y actuaciones legislativas que cargan de elementos negativos la imagen del inmigrante aumentando su precariedad o marginalidad, y que refuerzan los estereotipos aludidos cubriendo de retórica racionalista, los miedos irracionales, y construyendo fronteras allá donde es imposible construirlas (ALVITE J. P. 1995: 75) «en el momento en que se articula el entramado legislativo de las políticas de control de fronteras, se crea a su vez la figura del inmigrante como sujeto de control y es el momento en que se extiende socialmente el rechazo de los inmigrantes extranjeros ⁽¹⁰⁾».

«The illegitimated status of indocumented foreigners nurtures the negative perception of immigrants in general and, reciprocally, racism provides and ideological basis for restricting the legitimacy of transnational movements» (FASSIN D. 2001: 3). Una sociedad xenofóbica se construye con estos elementos citados y otros como las identidades que desde una doble perspectiva por un lado refuerza caracteres identitarios de diferenciación cultural ⁽¹¹⁾.

En Cataluña hay 328.461 inmigrantes censados y con permiso de residencia ⁽¹²⁾. El total sin permiso de residencia se sitúa en 600.000 personas en España. Tal proporción de ilegalidad favorece el incremento de actitudes xenofóbicas y racistas en la ciudadanía, con independencia de la discriminación estructural ⁽¹³⁾. El planteamiento analítico en relación a la discriminación nos muestra la dificultad de identificación de estos actos, se perci-

ben sutilmente manifestaciones discriminatorias a través las representaciones sociales construidas⁽¹⁴⁾.

En Cataluña el derecho a la asistencia sanitaria por los servicios públicos a extranjeros y personas sin recursos, se atiende solo con la tarjeta de empadronamiento y es gratuito. En el año 2002 se asistió sanitariamente a 6.310 adultos y 2.629 en menores. En 2003 a 196.162 Adultos y 6.319 Menores en situación de ilegalidad, sin recursos⁽¹⁵⁾. El aumento en un año de población asistida es importante a tener en cuenta como dato, hay población sin permiso de residencia y población sin recursos, asistir esta población y conocer la realidad de las personas “sin papeles” permite situar una aproximación de población que sigue estando en inferioridad de condiciones respecto al resto. Otro dato a tener en cuenta es el aumento de inmigrantes afiliados a la Seguridad Social que se ha producido en estos seis meses a un ritmo de un 20%. En Cataluña se sitúa en un 7% de población extranjera, según fuentes sindicales este aumento se debe a que a los cotizantes extranjeros no se les exige residencia para empezar a cotizar, la tarjeta de la SS, (seguridad social) se convierte así en su principal documento de acreditación y les facilita el acceso a la Sanidad Pública⁽¹⁶⁾.

La gestión de la salud en Cataluña esta en manos del *Department de Sanitat i Seguretat social* que tiene plenas competencias en la gestión de la salud. El dispositivo está jerarquizado en una red de *Àrees Bàsiques de Salut* que cubren la atención primaria y una red de hospitales basados en tres niveles de escalonamiento entre una red de dos docenas de hospital comarcales, siete u ocho hospitales de tamaño medio y media docena de centros de primer nivel situados todos en el área metropolitana de Barcelona. Los Equipos de Atención Primària (EAP) basado en médicos de Familia son los receptores directos de la población de una zona delimitada administrativamente. Se centran en actividades de promoción de la salud, la prevención y puntos de conexión con otros recursos asistenciales como la atención especializada, las pruebas diagnósticas o la atención hospitalaria¹⁷. Una de las principales características del modelo Sanitario público de Cataluña es la diversificación de proveedores A este respecto, un panorama cambiante del modelo Sanitario en Cataluña se está produciendo con una privatización de los recursos sanitarios. Recientemente (2002), el *Departament* ha fundado una oficina especializada para coordinar y organizar el modelo de atención, servicios y recursos destinados la problemática asociada a la inmigración, y a las necesidades de los inmigrantes.

A pesar de esos esfuerzos limitados de coordinación, la complejidad del problema es enorme. La Sanidad catalana atiende actualmente a personas

procedentes de 80 países que hablan 37 lenguas distintas⁽¹⁸⁾, lo cual está significando asumir una extraordinaria complejidad cultural e idiomática que no es fácil encuadrar especialmente por la limitación de los recursos. El sobrecosto adicional que supone una atención equitativa a todos los usuarios ni suele ser bien explicado por los responsables políticos – porque permite réplicas demagógicas –, ni a menudo es bien aceptado por sectores de la ciudadanía autóctona que, dependiendo de su lugar de origen regional o del resto de España y viviendo en Cataluña, a su llegada a los recursos sanitarios o centros de atención son los que más protestan acerca de la diversidad cultural, llegan a pensar que se trata mejor a los usuarios inmigrantes, o que estos alargan las listas de espera, al mismo tiempo son perceptibles situaciones en las que los profesionales o los administrativos utilizan la presión de la demanda de los inmigrantes para excusarse de retrasos o enlentecimientos.

En los distintos dispositivos o servicios de salud problemáticas de presión asistencial, (tiempo de asistencia) incremento de usuarios y problemas estructurales, han creado profesionales con distintos enfoques de atención, algunos con actitudes que se perciben como discriminaciones indirectas o directas y que coexisten al mismo tiempo con colectivos de profesionales que han creado estrategias de conocimiento y atención, generando cambios en distintos servicios de atención a la salud. Esto permite detectar cuales de los dispositivos o complejos asistenciales en relación a la diversidad de culturas tienen más dificultades en la atención. La existencia de una problemática, por un lado de elementos en la atención de la salud que son vividos en parte como discriminatorios por los usuarios inmigrantes debido a un conjunto de dificultades de todo tipo y por otro lado, las condiciones que en estos encuentros se han ido creando dependiendo del grado de conciencia de los profesionales. Algunos manifiestan demandas de recursos al sistema sanitario o social, pidiendo la puesta en marcha de dispositivos para que expliquen a “los otros como se hace aquí”. En esta demanda de un grupo de discusión de profesionales sanitarios se percibe la no implicación de los actores, la disociación entre el discurso y la práctica. La manifestación abierta de prejuicios que desde una perspectiva previa y etnocéntrica en su vida diaria, se refuerza en sus lugares de trabajo debido a las dificultades, el desconocimiento de los “otros” es vivido como destabilizador. Es en esta posición de no reconocer, donde se construyen representaciones sociales del otro. El propio Sistema de Gestores y Coordinadores reconocen su existencia pero estos factores operan en la práctica y es de difícil detección. Parte de esta disfunción pertenece al propio sistema organizativo hospitalario y que lo centramos en la dificultad de interac-

ción-comunicación. Mas allá de la discriminación, el planteamiento es “el papel” que el médico representa para los usuarios, y vamos a tratar de explorar como se coordinan y dirigen sus actividades con el fin de ver elementos que permitan analizar las representaciones de estos, y en que lugar se sitúa actualmente el rol del profesional médico, entendido como capacidad de comunicación-interacción..

Modelo médico, rol del medico, comunicación interacción

Si parte de los factores aludidos forman parte de la discriminación estructural, o de la individual vinculada a factores extra-sanitarios, otra tiene que ver con elementos estructurales del modelo médico y con las culturas organizacionales de las instituciones sanitarias. Recuérdese que en el modelo catalán, la figura del *practitioner* se ubica en una institución, el área básica de salud o centro de salud primaria que reúne médicos generales, ginecólogos, pediatras, personal de enfermería y a un técnico en salud pública. Y estos profesionales nada tienen que ver con sus colegas de los hospitales a los que remiten los enfermos cuando conviene. Por eso hay una notoria diferencia entre los médicos de familia, los pediatras y los médicos o especialistas hospitalarios. Se detecta en el trato o práctica con el usuario, distanciado y condicionado por el modelo hospitalario de atención. A lo largo de estos tres años de investigación, la lejanía de los médicos hospitalarios en relación a los usuarios es una constante, es detectada por los usuarios en general, se da acrecentada y con mas dificultades para los ciudadanos inmigrantes debido a que el conocimiento del sistema implica procesos de adaptación y *agency* que según la lejanía idiomática y cultural se hace más largo en el tiempo. Estos dis-funcionamientos no siempre son perceptibles, o se presentan como una deficiencia o como consecuencia de “la falta de recursos del sistema” para la población en general. Sin embargo, aunque las quejas sean comunes en las derivaciones por los circuitos asistenciales, en los largos tiempos de espera sean inmigrantes o no, el trato que opera en los itinerarios de los usuarios inmigrantes muestran diferencias a tener en cuenta.

La diferencia de los profesionales clínicos tiene relación con las necesidades distintas de las relaciones y la comunicación. Un usuario dirá: “*The family doctor of primary health was nice and explain the facts*”.

No obstante el paciente percibe que la mayoría de doctores que intervinieron en el proceso de su enfermedad no se puede considerar satisfactorio,

mas bien lo contrario. Especialmente antes y después de la operación. El paciente dirá:

«I never met the doctor that operated me. I had the impression they didn't want to see me and the feeling of treat because of what a woman told me when I had test done: that I had do sing a papers he said it was dangerous and I could die»

El paciente se refiere a la hoja de consentimiento que firma el usuario antes de una prueba. Desde este punto de vista si para muchos aborígenes resulta problemático firmar una hoja que al leerla advierte de los peligros de una prueba que “responsabiliza al enfermo de un posible accidente no previsto”, peor resulta para un inmigrante que carece de condiciones para leer el lenguaje de los formularios españoles o catalanes. En realidad, actualmente no hay una explicación verbal previa del consentimiento del usuario sobre posibles alergias u otros accidentes y ha pasado a ser una rutina a la que no se le da ninguna importancia. Las percepciones de los pacientes sujetos a sus miedos, a la enfermedad y lo que pueda pasar es algo que parece no tenerse en cuenta. Para los inmigrantes la hoja de consentimiento no es traducida y la mayoría de las veces los profesionales de enfermería o médicos no disponen de traductores o mediadores dentro de la rutina hospitalaria. Estamos aquí ante un ejemplo de discriminación estructural derivada de la cultura organizativa de las instituciones, y una insatisfacción en relación a la comunicación-interacción.

Las diferencias que se destacan en distintos grados y en la mayoría de pacientes es *la dificultad de esta interacción* con el médico. El segundo ejemplo es el de un usuario que necesitaba un tratamiento, e ilustra la actitud del médico hospitalario ante un enfermo que le crea dificultades en su propia estructura de atención. Por un lado, la dificultad se puede reflejar como impotencia del profesional especialista que se le derivó el paciente de la EAP, medicina de familia, para un tratamiento⁽¹⁹⁾, y que a su vez este especialista estaba sujeto a una derivación hacia otro servicio, el cual actualmente se encontraba cerrado en este asistencial. (Existen, distribuidos circuitos asistenciales por zonas) La dificultad de no poder derivar a este paciente para un tratamiento se transmite como impotencia y descontento del propio profesional o como FREIDSON (1986) sugiere del “asalariado” acerca de lo que se ha conseguido en relación a la praxis hospitalaria. Al mismo tiempo este profesional es crítico con el modelo o sistema sanitario⁽²⁰⁾.

Otro factor es la rigidez en la que se sitúa el especialista. Esta impotencia del especialista puede debatirse en la contradicción de la concepción “del bien del individuo enfermo” o la aplicación de los protocolos o normas Institucionales que se aplican al individuo miembro de una población. En

este caso concreto, la rigidez es la protección del especialista, la argumentación de una deficiencia estructural del sistema sanitario que exime de cualquier acción o estrategia de derivación hacia otros circuitos y que existen como estrategias que el propio sistema ha creado. Las normas protocolarias en este caso sirven para enmascarar las percepciones de los profesionales especialistas en cuanto a estereotipos o construcciones sobre el "otro". Encontramos algunos elementos que sugieren que la práctica profesional médica no es inmune a las percepciones y representaciones que más o menos son las de la ciudadanía en general y que puede afectar en el trato comunicacional con el paciente. En este caso la situación en la que se sitúa el médico hospitalario es en "el criterio médico", de no considerar urgente el tratamiento y que se diferencia de los otros médicos: Actitudes y posiciones en las que coexisten varios elementos y que se podrían argumentar de distintas formas como por ejemplo de falta de "sensibilidad" término que trataremos de analizar posteriormente. Coexisten en este ejemplo actitudes que pueden considerarse discriminatorias, pero a su vez muestran la descoordinación de criterios de profesionales médicos y deficiencia de circuitos, dispositivos o complejos asistenciales. En una solicitud, "la demanda" de la persona usuaria es considerada subjetiva. No obstante la solicitud clínica es una solicitud "profesional", es por referencia a un seguimiento propiamente médico en el que se atiende a la enfermedad. Tratamos de ver como y que lugar ocuparían los especialistas médicos de hospitales y como se relacionaría con los recursos en el marco hospitalario y sus circuitos, su lista de criterios, sus posibilidades de acción dentro del sistema Sanitario, comprender como la medicina contemporánea se inscribe dentro de los dispositivos de la Sanidad Pública, y en que medida se va restringiendo y afectando a sus propios profesionales.

Nos preguntamos si son mecanismos que se nos presentan como movimientos de cambio de un sistema deficitario económicamente, ya que se percibe un sistema sanitario con deficiencias en la atención que bien puede tener relación con el recorte de gastos y crisis económica, cambios que van operando hacia una medicina cada vez más privatizada. O si por el contrario esta despersonalización de los médicos especialistas hospitalarios tiene una relación directa con factores de rol y lugar que ocupan determinadas especializaciones. Estos cambios o movimientos se han puesto en evidencia a partir de los encuentros con la diversidad de culturas que manifiestan un tipo de demandas muy diferentes y en diferentes ámbitos. La percepción de obligaciones y derechos de los trabajadores inmigrantes existe al respecto del cuidado de su salud. Sus percepciones del sistema las manifiestan a través de las entrevistas realizadas, historias de vida y segui-

miento de sus recorridos en distintos servicios sanitarios, este hecho los sitúa al mismo tiempo en sujetos subordinados⁽²¹⁾ y en una percepción de inferioridad de condiciones, a diferencia de los autóctonos que, aunque sean conscientes de estas deficiencias las representaciones del estar sano o enfermo y de la concepción del modelo están inscritas en su propia cultura, y a su vez no reivindican una mejora al respecto a nivel oficial.

La comunicación-interacción que el usuario paciente describe como frialdad y que a veces percibe como discriminación, es la que permite centrar las percepciones de ambos lados. En la relación-comunicación, nos preguntamos si el rol o papel del médico ya no puede ser practicado por los especialistas hospitalarios, su relación con múltiples factores como el poder médico, la distancia entre el docto y el profano⁽²²⁾ y la disfuncionalidad de criterios médicos que se produce en un circuito asistencial entre los distintos profesionales acerca de un mismo usuario y una misma enfermedad no pueden estar sujetos solamente a las normativas o rigidez protocolarias, pues produce usuarios de distintas clases dentro del mismo sistema público. Es decir, de selección en la asistencia sanitaria. Pero en el caso de un paciente con una enfermedad grave existe a su vez la dificultad del especialista en la atención a la angustia del propio enfermo

«Un être malade, gravement malade, dans son corps ou dans sa tete est un être amoindri, fragilisé. Cette situation induit très vite l'émergence de l'irrationnel. Cet irrationnel nous le voyons à l'oeuvre dans les systemes des cultures non occidentales. Et circule beaucoup plus en sourdine, mais non moins efficacement, dans notre propre culture» (BROUSTRA J. 1996 : 37).

El imaginario de la noción de enfermedad se distribuye de distinta forma según las culturas en lo que concierne al terreno de la angustia o fragilidad, no obstante, existe una constante de base que puede ser susceptible de aumentar esta angustia si el usuario o paciente no tiene la opción de la búsqueda de estrategias. Dependiendo de estas, pide o reclama según se interprete desde las diferentes representaciones del docto o del usuario por su tratamiento. Freidson nos habla del control profesionalizado que en nombre del individuo y de la pericia técnica ha sustraído al profano el derecho de evaluar su estrategia: En este caso concreto del usuario, sería el de recibir un tratamiento urgente en el que las posibilidades del sujeto enfermo y su derecho a restaurar su salud están sujetas a la administración de un medicamento y tratamiento posterior. La medicalización de la vida en la que los problemas sociales y políticos se convierten en enfermedades iatrogénicas de dependencia respecto al sistema de organización médica (ILLICH, 1976) pero no permite al inmigrante participar en este sistema, que como ciudadano concibe como

sistema sanitario de representación de la cura de su enfermedad, tiene que tomar su posición de subordinado o profano. No se acepta la búsqueda de sus propias estrategias buscar otro circuito para ser atendido⁽²³⁾, reclamar atención y explicaciones. De hecho analizamos como la posición de paciente subordinado forma parte de las representaciones que el profesional tiene acerca de los usuarios.

El conocimiento de estos usuarios inmigrantes y su práctica en la gestión de su enfermedad o salud han sufrido transformaciones, sus tratamientos antes de emigrar al mundo Occidental eran distintos. En el caso de este usuario, su experiencia anterior y sus representaciones de la salud enfermedad parten de la concepción del cuerpo, el conocimiento o estado de fragilidad es sentido con distintas representaciones, una de ellas es la relación directa que el enfermo tiene con su “curador” o terapeuta y participa en su proceso de curación, no obstante, lo que pide al especialista es la posibilidad de ser tratado urgentemente tal y como han indicado los otros médicos de circuito, en definitiva, lo que está pidiendo entra en las representaciones de la medicina Occidental, a pesar que el no puede entender ni el trato ni la comunicación que el profesional le dispensa y que le sitúa en un estado donde además de la fragilidad y la enfermedad le enfrenta al miedo a su muerte, en preguntarse si esto le sucede por ser inmigrante, en sentirse discriminado, o en una clara posición de infravaloración como sujeto.

Lo que nos interesa profundizar es en la pérdida de capacidad de esta interacción o comunicación del especialista, donde la técnica, su situación o posición en el engranaje dentro de la estructura sanitaria de este modelo ha situado al médico-especialista hospitalario, en *un lugar sin rol*⁽²⁴⁾. Como Parsons señala el acto profesional no es solo una función técnica, sino también social. Principalmente aparte de las representaciones, en este caso es la distancia y la falta de comunicación creada y que en muchos casos los usuarios no van a volver a visitarse. Si tenemos en cuenta que desde una posición de poder puede haber influenciado que las estructuras institucionales, sus pautas protocolarias y económicas pueden condicionar al médico especialista y que este puede ser crítico incluso como trabajador en este sistema médico, intentamos analizar si en general pueden estar dotados de una rigidez en mayor o menor grado dependiendo de los distintos profesionales clínicos. La diferencia entre los médicos de familia y los especialistas es importante, el médico de familia recibe con más o menos frecuencia a los pacientes, intenta hacer un diagnóstico, se establece un conocimiento mutuo. El especialista recibe derivaciones, que con los criterios anteriores va a determinar las pruebas y la búsqueda de la enferme-

dad o diagnóstico, pero a su vez va a remitir el paciente a su referente inicial. En este proceso uno de los factores sería la diferencia entre médicos de EAP y los médicos especialistas que su lugar de inicio es configurado en el marco hospitalario.

Para la Antropología profundizar en las representaciones de los elementos entre lo subjetivo y lo objetivo y concretamente las representaciones que de ello tienen los profesionales en cuanto a aspectos de interacción, es analizar como operan los mecanismos de cambio y hacia donde se dirigen. El médico hospitalario en su formación no ha tenido oportunidad de una continuación donde se tengan en cuenta las experiencias subjetivas. Ni ha sido instruido acerca de una tradición o ruptura de esta. Al referirnos a esta práctica como representación del propio profesional, se infiltra un elemento más a tener en cuenta, la *despersonalización* como médico, si este se encuentra en un lugar situado en la impotencia de acción, derivación rápida de un paciente, en un engranaje, o ante una enfermedad crónica con ningún elemento mágico de cura donde su *rol de médico*, en sus representaciones ha dejado de tener un espacio. Evidentemente, no es generalizable, pero los elementos citados anteriormente en su conjunto están relacionados, lo que hay que ver es que tipo de mecanismos como profesional-médico especialista le quedan en unas estructuras burocratizadas e institucionalizadas. El corporativismo y la asociación continúan siendo mecanismos de protección frente a posibles problemáticas o denuncias. Pero antes de este proceso, se centraría en la pérdida o frustración que han ido desarrollando en su vida profesional como mecanismo de defensa frente al usuario profano, en relación con el dolor y la enfermedad que se le presenta para la cual no siempre operan mecanismos o recursos de respuesta. Esto sería lo que repercute en el rol o papel del profesional médico, desacralizado. El médico visto en un tiempo como el poseedor de operar un milagro que las representaciones profanas aun siguen ostentando en mayor o menor grado, pero empezando a cuestionar en función de la inoperatividad *de este rol que situamos en la comunicación-interacción*.

La hegemonía médica ha generado una visión de poder en nuestras sociedades, (MENÉNDEZ E. L. 1984: 5) en usuarios de distintas culturas todavía es representada como una atención donde se establece una relación de confianza⁽²⁵⁾. En este contexto la relación que se encuentran en el marco de los dispositivos sanitarios dista mucho de sus propias representaciones o expectativas, que a su vez en momentos determinados condicionan o se construyen estereotipos en ambos lados y no propician las formas relacionales primarias de confianza.

Notes

- (1) Ver texto y bibliografía final.
- (2) Community Action Programme to Combat Discrimination 2001-2006 Partners for Health – Phase II A pilot Action to Fight Discrimination against Immigration in Health care Services (VS/2002/0264) B. Line B5-803 European Commission Directorate General Employment and Social Affairs
- (3) Referencia presentación, COMELLES J - MASCARELLA L. - ALLUÉ X. variables culturales, en *Partners for Health II* (2003). Referente a un sistema de salud de cultura organizacional.
- (4) Destacamos la radicalidad del modelo: la universalidad del derecho individual se transporta a la ideología del modelo médico y refuerza la tendencia a ignorar la diversidad cultural.
- (5) WIEWIORKA M. (1994: 153) «Dividing from the social construction of the racism, the prejudices exist in the open or sly form largely of the civil society, have a wide effect to the professional practice without being recognised the existing discrimination in the institutional systems tends to separate the practice of the prejudice, the action and the conscience, or give seen well to this dissociation».
- (6) Ver mas ampliamente en AA.VV. (2003), report *Partners for Health II*, 2003.
- (7) COMELLES J. - BARDAJÍ F. - MASCARELLA L. - ALLUÉ X. (2000).
- (8) Diecisiete comunidades autónomas y Ceuta y Melilla que dependen directamente del Ministerio de Sanidad del Estado. Las comunidades tienen grados diversos pero muy amplios de capacidad legislativa, y no todos establecen las mismas prioridades. En el caso de las migraciones extracomunitarias solo algunas comunidades Cataluña, Madrid, Murcia, Comunidad Valenciana, Andalucía, Canarias y el País Vasco han desplegado esfuerzos significativos debido a la mayor presencia de inmigrantes en las mismas.
- (9) Un médico integrante del grupo LC.
- (10) Claro es que estas restricciones no son privativas de España. La actitud de países como el Reino Unido o Dinamarca en relación al protocolo de Schengen, la asunción por los partidos democráticos en Francia o en España de las retóricas sostenidas por grupos de extrema derecha y el propio ascenso de ésta en muchos países, así como el eco mediático que reciben refuerzan aún más la irracionalidad de las respuestas de la ciudadanía y buscan así adhesión electoral.
- (11) PORTES (1999: 16) dirá que en la sociedad de acogida, la presencia significativa de inmigrantes con rasgos marcados de diferencias culturales tiene efectos profundos de naturaleza cultural y social de la misma. Otros Autores sobre identidad: AMSELLE J. L. (1999); REMOTTI F. (1997).
- (12) El total de extranjeros en toda España es de 1.324.001 Ministerio del Interior. Entre ellos 110.095 de A. Latina y 107.746 del continente africano. 2002-Mai 2003
- (13) En la *Oficina per a la no Discriminació* del Ayuntamiento de Barcelona creada en el año 1998, se atendieron en 2002 448 casos de los cuales 105 de discriminación con inicio de expediente por racismo hacia población inmigrante, actos racistas o discriminaciones directas en el trabajo, pero solo un 1,23% en relación al sector salud.
- (14) En la dirección que señala WIEWIORKA M. (1994) sobre el racismo, los autores sugieren que (PIORET -VOURCH, 1998) “no hay una relación automática entre perjuicios y comportamientos racistas”.
- (15) Datos TSI proporcionados por la Oficina de Cooperación Sanitaria Internacional y Salud Migración, suministrados por la División de Atención al Cliente y cualidad, 2003. Los inmigrantes legalizados consiguen la tarjeta con el alta de afiliación a la seguridad social cuando firman los contratos de trabajo.
- (16) *La Vanguardia*, 15 de julio 2003.
- (17) Actualmente en Catalunya este modelo de atención consta de 345 equipos de atención, la mayoría de los cuales son gestionados por (Scs) “*Servei Català de la Salut*” (Generalitat), otros se gestionan a través del (Ics) “*Institut Català de la Salut*” y otras entidades proveedoras. 16 de ellos, de creación reciente son gestionados por entidades de base asociativa, son los mismos miembros del equipo los que están encargados de gestionar el Área Básica de Salud (*Pla de Salut*, 2003).

- ⁽¹⁸⁾ Cataluña es también la Comunidad que recibe más turistas foráneos del país: 11 Millones al año frente a los 6.5 millones de población local, de la cual un 10% son inmigrantes extranjeros.
- ⁽¹⁹⁾ Paciente derivado para un tratamiento de administración de yodo y posterior tratamiento por cáncer de laringe.
- ⁽²⁰⁾ Según sugiere DODIER N. (1993: 329) «Les règles qui s'appliquent à l'individu, membre indifférencié d'une population, sont confectionnées sur la base des calculs agrégés, recherche d'un équilibre financier des institutions de protection sociale».
- ⁽²¹⁾ Siguiendo el Modelo MMH de MENÉNDEZ E.L. - DI PARDO R. (1996) que estructura su propuesta teórica a partir del análisis de las relaciones de hegemonía y subalternidad que se establecen en tres modelos distintos.
- ⁽²²⁾ Siguiendo los criterios de Poder médico que MENÉNDEZ E.L. (1984) nos sugiere en su MMH.
- ⁽²³⁾ Usuario que a través de un cambio de domicilio pudo cambiar de circuito y ser atendido por otros especialistas.
- ⁽²⁴⁾ Ver Parsons señala como el rol del médico se caracteriza por la preocupación y el interés del enfermo, reconoce la significación social de la salud y enfermedad.
- ⁽²⁵⁾ Una usuaria Pakistaní : «Para nosotros el médico es la persona a la cual podemos explicar lo mas íntimo incluso mas que a algunos integrantes de nuestra familia».

Bibliografía

- AA.VV. (2003), *Partners for health II*, no publicado, *A pilot action to fight discrimination against immigration in Health Care Services*, CIDIS ALISEI, Perugia - Departament d'Antropologia, Filosofia i Treball Social, Universitat Rovira i Virgili, Tarragona. Grup d'investigació: MASCARELLA L. - COMELLES J.M. - ALLUÈ X.
- AA.VV. (2003), *Pla de salut de la generalitat*, Departament de Sanitat i Seguretat Social de Catalunya.
- AJA E. - NADAL M. (2003), *La immigració a Catalunya avui. Anuari 2003*, Fundació Jaume Bofill, Barcelona.
- ALVITE J.P. (ed.) (1995), *Racismo antirracismo e inmigración*, Ed. Garakoa, Tercera Prensa Hirungarren Prentsa S. L., Donostia.
- BROUSTRA J. (1994), *Les maux de l'Autre. La maladie comme objet anthropologique. Actes du Colloque de Bordeaux*, preface par BENOIST J., L'Harmattan, Paris.
- COMELLES J.M. - MARTINEZ A. (1993), *Enfermedad, cultura y sociedad. Un ensayo sobre las relaciones entre la Antropología Social y la Medicina*, Eudema, Madrid.
- COMELLES J.M. (1995), *La sacralización de la práctica hospitalaria. Seminari d'estudis sobre la Ciència, Malaltia i Cultura*, Valencia.
- COMELLES J.M. (1997), *Reforma asistencial y práctica económica. De la crisis del tratamiento moral a la hegemonía del kraepelinismo*, pp. 83-107, en APARICIO BASAURI Víctor, *Orígenes y fundamentos de la Psiquiatría en España*, Ed. Libro del Año, Madrid.
- COMELLES J.M. - MASCARELLA L. - BARDAJI F. - ALLUÈ X. (2000), *La percepción de los colectivos de inmigrantes no comunitarios en los dispositivos de salud en España*, in VULPIANI P. - COMELLES J.M. - VAN DOGEN E. (eds.), *Health for all, all in health. European experiences on health care for migrants*, CIDIS ALISEI, Perugia.
- DODIER N. (1993), *L'expertise médicale*, Ed. Métaillé, Paris.
- FASSIN D. (2000), *Les politiques de l'Etnopsychiatrie*, "L'Homme", n. 153, 2000, pp. 231-250.
- FASSIN D. (2001), *The biopolitics of otherness. Undocumented foreigners and racial discrimination in French public health*, "Anthropology Today", vol.17, n. 1, 2001, pp. 3-7.
- FREIDSON E. (1986), *Professional Powers: A Study of the Institutionalization of Formal Knowledge*, University of Chicago Press, Chicago.

- GELLNER E. (1993), *Cultura, identidad y política. El nacionalismo y los nuevos cambios sociales*, II ed., Gedisa, Barcelona.
- ILLICH I. (1976), *Limits to Medicine, Medical Nemesis: the Expropriation of Health*, Marion Boyars, London.
- LAPLANTINE F. (1999 [1992]), *Antropología de la enfermedad*, Ed. A.B.R.N. Producciones Gráficas, Buenos Aires [ed. orig.: *Anthropologie de la maladie: étude ethnologique des systèmes de représentations étiologiques et thérapeutiques dans la société occidentale contemporaine*, Payot, Paris, 1992].
- MASCARELLA L. - COMELLES J. M. - ALLUÉ X. (2003), *A pilot action to fight discrimination against immigration in Health Care Services*, in AA.VV., *Partners for health II*, no publicado, *A pilot action to fight discrimination against immigration in Health Care Services*, CIDIS ALISEI, Perugia - Departament d'Antropologia, Filosofia i Treball Social, Universitat Rovira i Virgili, Tarragona.
- MENÉNDEZ E. L. (1979), *Cura y control. La apropiación de lo social por la práctica psiquiátrica*, Ed. Nueva Imagen, México.
- MENÉNDEZ E. L. (1984), *Hacia una práctica médica alternativa. Hegemonía y autoatención (gestión) en salud*, "Cuadernos de la Casa Chata", n. 86, CIESAS, México.
- MENÉNDEZ E. L. (1990), *Antropología médica. Orientaciones, desigualdades y transacciones*, CIESAS, México.
- MENÉNDEZ E. L. (2002), *La parte negada de la cultura. Relativismo, diferencias y racismo*, Ediciones Bellaterra, Barcelona.
- MENÉNDEZ E. L. - DI PARDO R. (1996), *De algunos alcoholismos y algunos saberes. Atención primaria y proceso de alcoholización*, CIESAS, México.
- PARSONS T. (1999 [1951]), *El sistema social*, Alianza Editorial, Madrid [ed. orig.: *The Social System*, The Free Press, New York].
- SIXTE G. - PAJARES M. - CACHON L. - EGENBERGER V. (2003), *La discriminación racial. Propuestas para una legislación antidiscriminatoria en España*, Ed. Icaria, Barcelona.
- WIEWIORKA M. (ed.) (1994), *Racisme et xénophobie en Europe*, Ed. La Decouverte, Paris.
- VIGARELLO G. (1993), *Le sain et le malsain*, Editions du Seuil, Paris.
- VULPIANI P. - COMELLES J. M. - VAN DOGEN E. (eds.) (2000), *Health for all, all in health. European experiences on health care for migrants*, CIDIS ALISEI, Perugia.



2.4 ¿Dónde están las diferencias?

Inmigrantes en una consulta de pediatría^(1, 2)

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1. *Equal access for equal needs: Antecedentes*

El objetivo del estudio que aquí se presenta, es el de analizar si existen diferencias en el acceso a la atención pediátrica por parte de hijos de inmigrantes, frente a los autóctonos, en un ABS concreto de la periferia de Barcelona. Y de ser así, cuáles pueden ser los factores socioculturales relacionados con las mismas. Ya en diversas ocasiones, se han realizado estudios epidemiológicos sobre la cuestión de la equidad en la utilización de los servicios de salud. Los resultados no muestran una única tendencia homogénea en la relación entre etnicidad y uso de los servicios de salud: mientras en algunas ocasiones se habla de una mayor admisión de ciertos grupos de inmigrantes en los servicios de salud mental de Países Bajos (UNIKEN VENEMA H. P. - GARRETSEN H. F. L. - VAN DER MAAS P. J. 1995) o en la asistencia a la atención primaria (STRONKS K. - RAVELLI A. C. J. - REIJNEVELD S. A. 2001); otros relatan cómo es menor el periodo de hospitalización en afroamericanos comparado con el de la población blanca en Estados Unidos (CORNELIUS S. J. 1991) o el acceso a médicos especialistas de algunos grupos étnicos (STRONKS K. - RAVELLI A. C. J. - REIJNEVELD S. A. 2001); y en varias ocasiones se llega a la conclusión que no se puede decir que haya un efecto claro del factor étnico, frente a la población mayoritaria (BLAIS R. - MAIGA A. 1999, SMAJE C. - GRAND 1997, KRASNIK A. *et al.* 2002), en lo que se refiere a la media de servicios utilizados durante un año, o bien a la duración del periodo de hospitalización en distintos grupos diagnósticos. Esta heterogeneidad de resultados nos muestra la complejidad del estudio sobre si, en condiciones de igual necesidad, existe un acceso igualitario al sistema de salud para los distintos grupos étnicos (equal access for equal needs). Para comprender esta complejidad cabe detenernos en dos reflexiones, una sobre los conceptos utilizados en este tipo de estudios, otra sobre

las diferencias entre los distintos escenarios en los que se pueden llevar a cabo estas investigaciones: no es lo mismo hablar de unidades de atención primaria, que de especialistas de distintos tipos, urgencias u hospitalizaciones, hablar de servicios de medicina pública o privada, etc.

En primer lugar, cabe señalar que los conceptos de “igual necesidad” y “acceso igualitario” no están exentos de ambigüedad y diferencias en su definición o uso (GODDARD M. - SMITH P. 2001): es fundamental reconocer y tener en cuenta en los estudios que no todos los grupos sociales tienen las mismas necesidades de salud, así como que para evaluar el acceso a un servicio sanitario es necesario tener en cuenta no sólo la utilización del mismo, sino los factores que facilitan o dificultan su accesibilidad. En lo que respecta al concepto de “etnicidad”, no siempre se habla de lo mismo. En los distintos estudios epidemiológicos consultados, muchas veces, se utilizan indistintamente los términos de etnicidad y migraciones, cuando la variable que finalmente, están tomando en cuenta es la de nacionalidad o país de nacimiento; en otros casos, en gran parte ingleses, se habla exclusivamente de etnicidad y ésta se define por auto-adscripción.

¿Dónde se pone entonces la razón de las diferencias entre los grupos? ¿el hecho de migrar? ¿las diferencias culturales? En la mayor parte de los estudios consultados las diferencias étnicas encontradas se explican en gran medida con las variables socio-económicas (COOPER H. 2002), aunque en distintas ocasiones se encuentra que las diferencias siguen siendo significativas después de los ajustes por factores socio-económicos (IGLESIAS E. *et al.* 2003). En otra de las investigaciones (CHANDOLA T. 2001) se llega a concluir que el uso de mediciones de clase social más elaboradas, que puedan valorar por ejemplo las situaciones de autoempleo, explicarían todavía una mayor parte de las diferencias que normalmente se consideran étnicas. Para los casos en los que se considera que los factores socioeconómicos no justifican las diferencias, aparecen entonces una multitud de posibilidades que nunca son profundizadas: problemas de comunicación, discriminación en las derivaciones, uso irregular de los documentos sanitarios, baja educación que conlleva el uso erróneo de los servicios, red social de autocuidado, dificultad de acceso a servicios privados por los costes etc. Resulta llamativo que en los dos estudios epidemiológicos en los que se valora el uso de los servicios pediátricos (COOPER H. - SMAJE C. - ARBER S. 1998, SAXENA S. - ELIAHOO J. - MAJEED A. 2002, ambos realizados en el Reino Unido) se concluye que mientras no se encuentran diferencias relacionadas con el estatus socioeconómico, sí las hay dependiendo del grupo étnico al que se adscriban los padres de los pacientes: algunos grupos étnicos utilizarían más los servicios de aten-

ción primaria y menos los servicios especializados. Como se verá más adelante, no sucede de igual manera en el caso concreto de la investigación aquí presentada.

En este estudio se reconoce la gran importancia de los factores socioeconómicos para la explicación de las diferencias en la equidad en el acceso al sistema de salud, y todavía más para la evaluación de las necesidades de salud. Ahora bien, teniendo en cuenta que el nivel socioeconómico de las personas que asisten al Centro de Salud donde se ubica el estudio, sean o no inmigrantes, es bajo en general, al residir en un municipio donde el 70% de la población tiene unos niveles de renta bajos, entre el 80 y el 55% de la media metropolitana (SERRA J. 2001). No se ha considerado que existan variaciones sustantivas de estrato socioeconómico entre inmigrantes extranjeros y no inmigrantes que son usuarios del mismo⁽³⁾. Nos centraremos, entonces, en la discusión de otro tipo de factores socioculturales que explican las diferencias encontradas, en gran parte vinculados al hecho de migrar y a los cambios que supone. Este es, por tanto, un estudio sobre inmigrantes y no sobre minorías étnicas, y es por ello que se ha tomado en cuenta la variable de nacionalidad y no la adscripción a categorías étnicas.

Como hemos visto al inicio, la heterogeneidad en las situaciones de los trabajos epidemiológicos comparados, de distintos países y sobre servicios sanitarios muy diversos, tampoco permite generalizar tendencias en la relación entre migraciones y/o etnicidad y el acceso al sistema sanitario. La variedad de escenarios conlleva variedad de resultados. La complejidad del sistema biomédico debe ser tenida en cuenta. Las investigaciones muestran grandes diferencias entre las consultas de atención primaria, los especialistas, las urgencias, las hospitalizaciones, rangos de edad atendidos, etc. También hay que tener en cuenta la diversidad de situaciones en las que los sistemas biomédicos se encuentran en distintos países, en especial la existencia o no de un estado del bienestar y las diferencias entre el acceso a servicios públicos y privados de distintos tipos. Sin desdeñar el hecho de que los procesos migratorios y de integración de los grupos minoritarios también varían en los distintos países, y afectan a su acceso al sistema sanitario.

Se hace necesario, entonces, definir primero las particularidades del contexto donde se ha realizado el estudio – unas consultas pediátrica de atención primaria en el área metropolitana de Barcelona – para después señalar dónde no y dónde sí se encontraron diferencias entre los usuarios migrantes y aquellos que no lo son.

2. Contexto de la investigación

Esta investigación se ha realizado en una de las tres consultas de pediatría de un ABS localizado en un municipio de la periferia de Barcelona. Dicho municipio se caracteriza por ser estructuralmente una ciudad de migrantes, su desarrollo desde principios del siglo veinte hasta la década de los setenta inclusive ha estado vinculado a las corrientes migratorias internas. En los últimos años hay una creciente presencia de población de nacionalidad extranjera, que en la actualidad supone un 10,71% del total de la población del mismo. Ahora bien, dentro del municipio, el barrio al que está asignado el ABS donde se ha ubicado este estudio, es uno de los que tienen menor porcentaje de población extranjera: un 4,72%.

Según los datos del Ministerio del Interior, a finales del 2002 eran 1.324.001 los extranjeros con permiso o tarjeta de residencia en el país. De ellos, el 24,81% se encuentra en Catalunya, y más concretamente, el 17,94% en Barcelona, siendo la segunda provincia con mayor concentración de residentes extranjeros después de Madrid. Tanto en el nivel nacional, como en el autonómico tratándose de Catalunya y en el provincial si vamos a Barcelona, la mayoría de los extranjeros regularizados son de origen marroquí, seguidos en segunda posición por los ecuatorianos. Estos datos contrastan con los que nos llegan del anuario estadístico del municipio del estudio donde son los ecuatorianos el grupo principal, constituyendo el 32% de los 26.837 extranjeros allí empadronados, les siguen los marroquíes con, aproximadamente, la mitad de efectivos. Esta aparente contradicción se puede explicar fácilmente analizando la dinámica de las migraciones a la zona: no es hasta 1997 que comienza un aumento considerable en el municipio de las altas de nacionalidad extranjera⁽⁴⁾, cuando ya otras áreas, como los barrios del centro de Barcelona, concentran una buena cantidad de población de origen extranjero. Es en 1998 cuando comienza el crecimiento acelerado de la inmigración ecuatoriana, ubicándose por consiguiente en lugares de la periferia no ocupados en el momento por otros grupos.

Este estudio, por tanto, está ubicado en una zona urbana con una baja densidad migratoria en comparación con otros barrios adyacentes, y en la cual la presencia mayoritaria es de inmigrantes latinoamericanos, especialmente ecuatorianos, que comparten lengua con una buena parte de los usuarios autóctonos del Centro de atención primaria (CAP). Nos encontramos entonces ante una situación menos crítica que la que se presenta en otras ciertas zonas del área metropolitana de Barcelona, donde la alta densidad de inmigrantes y las dificultades en la comunicación relacionadas con las diferencias lingüísticas pueden llegar a ser mucho mayores.

Una segunda característica específica de este estudio es el hecho de realizarse en un CAP⁽⁵⁾. No se debe pasar por alto que, junto con los profesionales de salud mental y los especialistas en medicina tropical, ha sido la atención primaria uno de los ámbitos sanitarios en los que las migraciones despertado más interés (JANSÀ J.M. - BORRELL C. 2002, MARTÍN LASO M.A. 2001), apareciendo múltiples propuestas de acción. Sin ir más lejos, en el municipio donde se ubica el estudio, desde la primavera del 2002 se está llevando a cabo un curso de "Formación de mediadores sociosanitarios". Y más concretamente, en el CAP de la investigación, se ofertan cursos de formación continuada para el personal sanitario, sobre comunicación con pacientes inmigrantes⁽⁶⁾.

En tercer y último lugar esta investigación se ha realizado en consultas de atención pediátrica. Como veremos, el que se trabaje con niños va a dar lugar a diferencias substanciales frente a lo que sucede con inmigrantes adultos. Hay que tener en cuenta que en lo que respecta a los menores la ley sí que reconoce el derecho a una asistencia gratuita en las mismas condiciones que los españoles (LEY ORGÁNICA 4 /2000), derecho que va en consonancia con otras declaraciones universales, así como con la construcción cultural hegemónica de la infancia que considera a los niños y niñas objeto de múltiples cuidados y protección. Por otra parte, al menos en los casos en los que los hijos que nacidos en otros países vienen a reunirse con sus padres, estamos hablando de familias que ya llevan aquí algún tiempo y tienen una cierta estabilidad, como mínimo económica. Y no sólo eso, como para ir a la escuela es obligatoria la presentación del certificado vacunal, deben ser excepcionales los niños que no pasan por los pediatras de atención primaria una vez llegado – siendo diferente lo que les ocurre a los inmigrantes adultos jóvenes, que no acuden al médico hasta que no se sienten enfermos –. No sólo es la obligatoriedad del certificado de vacunación lo que mueve a los padres de los niños/as inmigrantes a ir a las consultas de atención primaria, también ellos valoran y están habituados a controlar la salud de sus hijos. A lo largo de mi estancia en la consulta hubo muchos padres que demandaron "chequeos" en sus primeras visitas; en algunas ocasiones ya habían realizado un control de salud previo a salir de su país, y les traían con más vacunas de las que aquí se exigen; e incluso hubo un caso en el que la madre priorizó la atención médica a la escuela a la que no pensaban llevarlos hasta el curso siguiente.

Es en este contexto – una consulta de pediatría y enfermería pediátrica, de un centro de atención primaria, en un barrio con una relativamente baja densidad de migrantes del área metropolitana de Barcelona – donde estuve realizando mi trabajo de campo durante tres meses. Junto con la obser-

vación participante, llevé a cabo el análisis de los datos del registro de pacientes por día de la pediatra y de las historias clínicas de los pacientes que pasaron por la consulta en esos meses: Fueron total de 487, de los cuales un 16,63% eran hijos de inmigrantes⁽⁷⁾. El 67,90% de los hijos de inmigrantes resultaron ser de origen latinoamericano, mientras que sólo un 17,28% son de origen magrebi. En total se citaron 1244 consultas pediátricas, de las cuales el 13,26% fueron de hijos de inmigrantes.

3. *Dónde NO están las diferencias*

Comienzo la exposición de los resultados por las similitudes encontradas entre los inmigrantes y la población autóctona, dado que a lo largo de estos tres meses han estado tan presentes como las diferencias y han sido, como iremos viendo, igual de relevantes. Considero que el énfasis en las diferencias – en este caso, además, no justificado por los resultados obtenidos – y más concretamente en las diferencias culturales, tiene entre sus riesgos una mirada “exotizante”, y con ello estigmatizadora, de los inmigrantes. Más allá, para el caso de los Países Bajos, hay autores (VAN DIJK R. 1998, VAN DIJK R. - VAN DONGEN E. 2000) que han expuesto cómo el conocimiento cultural que en un momento se propuso como la solución a todos los problemas de los profesionales sanitarios con los inmigrantes, fracasó en su empeño, en gran medida por ofrecerse una imagen de la cultura de los inmigrantes tradicional, exótico, diferente, inflexible e inmutable. Cuatro son los aspectos principales en los que no se encontraron diferencias, y que desarrollamos a continuación: los diagnósticos mayoritarios, los bajos índices de trastornos de la conducta, la asistencia a consultas preventivas y la comunicación en las consultas por enfermedad.

En primer lugar, las enfermedades por lo que más se acude al pediatra de atención primaria son las mismas hablemos de la población en general o de la población migrante: mientras que del total de las 820 consultas con un primer diagnóstico⁽⁸⁾ el 38,86% de los casos corresponden a los tres diagnósticos mayoritarios⁽⁹⁾: infección viral no especificada, nasofaringitis aguda o resfriado común, y amigdalitis aguda. En lo que respecta a usuarios inmigrantes el porcentaje es de un 42,16%. Un mediodía, hablando con los pediatras al final de las consultas sobre su trabajo, me comentaba uno cómo había tenido la esperanza de que con la llegada de los inmigrantes cambiase el tipo de demandas, encontrando casos más estimulantes, distintos, y cómo la realidad no había sido así: los pacientes inmigrantes vienen por los mismos motivos que los autóctonos, la otra

pediatra confirmaba tener la misma impresión. En una ocasión, ante una pirexia de origen desconocido, la madre de la paciente dice que su hija había tenido “fiebre tifoidea” hace algún tiempo en Ecuador, la pediatra lo anota en la historia con dudas y posteriormente lo descarta. Más que con una enfermedad exótica, no encontramos con un malentendido lingüístico: entre lo que para la pediatra significa una tifoidea, y lo que para una madre ecuatoriana significa esta palabra.

No se han encontrado en esta consulta enfermedades relacionadas con las migraciones: ni propias de climas tropicales y excepcionales como la miasis (BELDA HOFHEINZ S *et al.* 2003); ni relacionadas con situaciones de pobreza, hacinamiento e ilegalidad tanto en origen como aquí, ejemplo de este caso sería la tuberculosis (CHIRVECHES PÉREZ E. *et al.* 2001); ni relacionadas con hábitos y/o déficits alimenticios (APARICIO APARICIO M.D. *et al.* 2002, BONET ALCAINA M. *et al.* 2001, PARRILLA RUIZ F. *et al.* 2003, OLIVÁN GONZALVO G. 2000). También es escasa presencia de demandas de atención primaria de inmigrantes por traumatismos, contusiones y heridas, si bien la muestra no es lo suficientemente grande para llegar a conclusiones firmes: existen diversas investigaciones, principalmente en los Estados Unidos, que documentan la relación entre este tipo de demandas pediátricas y los grupos étnicos (MULL D.S. *et al.* 2001), cabría preguntarse si en nuestro entorno se da una situación parecida o no, y qué factores pueden estar detrás de este tipo de asociaciones – si no será uno de tantas diferencias entre grupos étnicos relacionada más con las condiciones socioeconómicas que con el hecho de migrar o que alguna característica específicamente relacionada con la identidad cultural.

Un caso representativo es el de las parasitosis intestinales, datos de las cuales encontramos en seis historias clínicas, de las cuales cuatro son de inmigrantes latinoamericanos. Aparentemente parecería un claro caso de enfermedad distintiva y relacionada con la inmigración. Pero cuando analizamos cada una de las historias encontramos que: 1) en dos de los casos de inmigrantes se realizan análisis de heces que dan como resultado que no se observan parásitos. 2) En un tercer caso de los de inmigrantes, el niño refiere que considera tener parásitos, porque le rechinan los dientes, en el primer control, recién llegados de Ecuador, que se realiza en la consulta, sin que se confirme mediante análisis. 3) El cuarto caso es de un niño nacido aquí y no está relacionado con un viaje al país de sus padres. 4) En los dos casos de autóctonos la presencia de parásitos intestinales es detectada mediante análisis de heces y a partir de allí tratada. 5) Cuando pregunto a la pediatra sobre esta enfermedad, me comenta que ciertos parásitos pueden ser relativamente frecuentes en los niños, y que no ha en-

contrado diferencias en el trato con niños inmigrantes. Parece, por tanto, que en esta consulta no está tan clara la vinculación entre las parasitosis y la migración. No se puede negar que dentro de las preocupaciones de las familias de inmigrantes sí están las posibles enfermedades parasitarias, como queda reflejado en sus demandas, principalmente en las primeras citas programadas, las consecuentes actuaciones y anotaciones en sus historias pediátricas. Teniendo en cuenta que las parasitosis son endémicas en distintos lugares del mundo, resulta comprensible que formen parte del repertorio de enfermedades habituales para algunas familias migrantes. Como además, al igual que de las otras enfermedades comentadas anteriormente, hay estudios que permiten suponer una cierta incidencia en inmigrantes en España⁽¹⁰⁾, puede resultar importante que los pediatras tengan en cuenta su posible aparición, siempre y cuando se valoren en función de su aparición, escasa, y no se utilicen para estigmatizar, por tanto, a una población que, como se demuestra en este estudio, tiene, en sus motivos de consulta de la atención primaria mucho más de común que de exótico.

En segundo lugar, las consultas por problemas de conducta – tanto alimenticia, como de sueño, ansiedad, rendimiento escolar, lenguaje, celos, comportamiento en casa o en el colegio – son bajas tanto para los niños autóctonos como para los inmigrantes. A lo largo de estos tres meses se realizaron 21 consultas en total. De ellas sólo 2 son de niños considerados como inmigrantes, y no precisamente de los prototípicos: ambos tienen un progenitor español y el otro europeo. Este dato contrasta con los datos generales sobre inmigrantes que plantean los potenciales efectos patogénicos del estrés y los duelos de la migración, así como los consecuentes problemas de salud mental (BARTOLI P. - PAQUINI C. - ZÚÑIGA VALLE C. 2001, ACHOTEGUI J. 2000). Problemas que son expresados, en muchas ocasiones, en las consultas de atención primaria, donde pueden llegar a ser la segunda causa de consulta (ESTEBAN Y PEÑA M. M. 2001). Pareciera que mientras que tanto en los países receptores de migrantes como en los de origen – pongamos como ejemplo el caso de Ecuador (CAMPAÑA A. 2001) – el proceso y condiciones migratorias se consideran factores de riesgo para distintas enfermedades mentales en adultos, no sucede lo mismo si hablamos de niños. Se argumenta que su plasticidad y capacidad de adaptación a las nuevas situaciones, les hace sencillo acostumbrarse a vivir en un nuevo sitio. El duelo y los problemas psíquicos en el caso de los niños se consideran vinculados a la permanencia en el lugar de origen una vez que los padres, especialmente la madre, ha migrado. En Ecuador «se sostiene como verdad incuestionable que la ausencia de los padres, (especialmente de la

madre) es la causa de graves desórdenes psicológicos en niños, niñas y del alcoholismo, la drogadicción y los embarazos precoces en los y las adolescentes» (HERRERA G. - MARTÍNEZ A. 2002: 50). Esta visión está generalizada, es compartida tanto por familiares y vecinos de los migrantes, como por maestros, trabajadores sociales, curas, médicos y políticos de Ecuador. También en España se opina de igual manera: la estabilidad que los niños necesitan es la que les dan sus padres. En la consulta de pediatría siempre que se conocía la existencia de hijos menores de edad que seguían en el lugar de origen se instaba a *traerlos pronto*. Es por tanto en lo relacionado con la salud mental donde se encuentra una de las principales variaciones por grupos de edad en la relación entre salud y migraciones⁽¹¹⁾. Como hemos podido ver, esta diferencia se manifiesta en las demandas que se hacen al sistema de salud.

Una tercera similitud se encuentra en la asistencia a consultas preventivas. Al contrario que lo que sugieren distintos estudios realizados con adultos (BARTOLI P. - PAQUINI C. - ZÚÑIGA VALLE C. 2001, ESTEBAN Y PEÑA M.M. 2001) en los que los inmigrantes muestran una muy baja asistencia encaminada a la prevención. Los inmigrantes, que recordamos forman el 16,63% de la población atendida por este equipo, ocupan un 15,17% de las consultas programadas, prácticamente un porcentaje equiparable al de su presencia. Sin dudar de la importancia que para muchas familias de inmigrantes tiene el control de la salud de sus hijos, es necesario apuntar que el hecho de que las nuevas incorporaciones sean principalmente de inmigrantes a los que se hace necesario abrir una historia, hace necesaria una mayor programación de controles del niño sano: Sólo en los días en que no hay mucho trabajo, lo cual puede ser algo más frecuente en estos meses que en el otoño / invierno, se pueden permitir realizar el control en el tiempo de consulta a demanda.

Por último, al ser el uso del castellano en la consulta tan común como el del catalán – no olvidemos que nos encontramos en una zona donde viven muchos inmigrantes e hijos de inmigrantes españoles que se expresan habitualmente en castellano – y dado que la mayoría de los inmigrantes son latinoamericanos, no resulta, la lengua, un impedimento serio de comunicación. Las variaciones en el vocabulario sí han podido ser fuente de algún malentendido, en especial en cuando comenzaron a venir pacientes de origen latinoamericano. Con el aprendizaje que se lleva a cabo al ir haciéndose habitual la presencia de usuarios latinoamericanos, cada vez son menos los malentendidos de este tipo. La pediatra no consideraba tener dificultades a la hora de hacer su trabajo en este tipo de consulta: El hecho de que en estas consultas la comunicación verbal se complementa con una

exploración física⁽¹²⁾, que es la base fundamental del diagnóstico y el consecuente tratamiento, está en la base de ese consenso, como mínimo social⁽¹³⁾, en las consultas a demanda: la pediatra considera que ha podido llevar a cabo su trabajo y el paciente ha obtenido lo que venía a buscar.

4. *Dónde SÍ están las diferencias*

Tal y como hemos ido viendo no nos encontramos en una consulta con una situación crítica: no hay una alta concentración de pacientes inmigrantes y/o problemas lingüísticos. Más bien nos encontramos en una situación en la que los propios profesionales reconocen que hay muchos aspectos en los que no hay diferencias. Sin embargo también consideran que hay aspectos en los que sí que hay diferencias y que los inmigrantes “dan trabajo”. A continuación relato los ámbitos principales donde se han encontrado diferencias en este estudio.

En primer lugar en estos tres meses los pacientes de origen inmigrante han asistido menos que los autóctonos a la consulta de esta pediatra: formando un 16,63% de los pacientes sólo ocupan un 13,26% de las consultas. Esto podría ser una manifestación de que, como plantean BARTOLI P. - PAQUINI C. - ZÚÑIGA VALLE C. 2001, los migrantes tienen un consumo médico más moderado y circunscrito; o bien de que tienen un patrón de demanda de atención pediátrica distinto, que pudiera incluir una preferencia mayor por el uso de urgencias. Ambas alternativas pueden estar relacionadas tanto con las condiciones de vida aquí (problemas de compatibilizar horarios laborales entre otros) como con pautas de demanda que vengán condicionadas por la relación con los servicios médicos que tuvieran en el país de origen.

Una segunda diferencia, que apuntamos brevemente con anterioridad, se debe a los cambios poblacionales que producen las migraciones. El 56,79% de los hijos de inmigrantes se han incorporado a la población de la consulta en el último año, muchos de ellos recién inmigrados, en comparación con el 13,79% de nuevas incorporaciones que ha habido en los pacientes de origen español, de los cuales además la mayoría era recién nacidos. Cada nueva incorporación supone la apertura de una historia clínica y un control del niño sano, para lo que en la mayor parte de ocasiones se programa una visita tanto con la pediatra como con la enfermera. El protocolo de abrir las nuevas historias clínicas, organizar los certificados vacunales, completando las dosis de vacunas necesarias, y realizar los controles del niño sano, lleva tiempo, y en el caso de los hijos de inmigrantes se ha

convertido en un procedimiento habitual. Es principalmente a estas actividades a las que se refieren algunos profesionales al asegurar que los inmigrantes dan “mucho trabajo”.

Es más, con la incorporación de los inmigrantes a las visitas programadas, los equipos de pediatría han tenido que valorar y tomar decisiones respecto en distintos aspectos. Han tenido que valorar los certificados de vacunación de los distintos países de origen de los inmigrantes, y establecer a partir de ellos los criterios de vacunación para esos niños cuando traían estos certificados así como cuando llegan sin ellos. Han tenido que preguntarse sobre la validez de los indicadores de nutrición y crecimiento que utilizan (DE ARANZABAL AGUDO M. 2003), y valorar el uso que pueden hacer de los mismos cuando trabajan con población inmigrante. También aumenta el malestar de los profesionales al ver que ese trabajo realizado muchas veces no tiene continuidad debido a los cambios de domicilio que son frecuentes entre los inmigrantes en los primeros años aquí, pudiendo interpretarlo como “trabajo perdido”.

En tercer lugar, el desconocimiento de algunas normas implícitas y prestaciones del sistema biomédico, puede estar entre las causas de una mayor asistencia de urgencia, y la total ausencia de demandas telefónicas y peticiones de atención a domicilio, características de su demanda que les diferencian de los autóctonos. Prestemos atención al caso de la demanda por *emergencias*, especialmente aquella que se da a partir de las 12.00, es decir fuera ya del horario de cita previa, de manera espontánea. Este tipo de demandas no son del agrado de los profesionales, quienes consideran que en la mayor parte de los casos no se tratan de verdaderas urgencias, por lo que podrían haber ido en horario de cita previa, o bien esperado hasta el día siguiente. Sin embargo, tanto los usuarios de origen extranjero como español realizan este tipo de consulta espontánea. Los profesionales relatan cómo se incrementó en la medida en que ellos no fueron muy estrictos y comenzaron a atender a los pacientes que llegaban fuera de hora de citas, y cómo posteriormente han conseguido “educar” a sus usuarios para que vayan en el horario dispuesto para ello: el de cita previa. A pesar de este proceso de educación hay padres autóctonos que siguen trayendo a sus hijos a partir de las doce del mediodía. En algunos casos, esto sucede por el desacuerdo que existe entre las normas de horario de atención que ponen los pediatras, y las lógicas de los usuarios, vinculadas tanto sus condiciones de vida como a lo que perciben como derecho dentro de un centro que se autodenomina como de atención continuada. Entre los usuarios inmigrantes, en muchas ocasiones, las visitas de *emergencia* son fruto del desconocimiento de las normas de horario de los pediatras,

pudiéndose observar, que, una vez realizada la llamada de atención no vuelve a suceder.

El desconocimiento de algunas características específicas del funcionamiento del sistema sanitario español, va acompañado del conocimiento de un sistema biomédico diferente: el de su país de origen. Conocimiento y expectativas que en algunas ocasiones son origen de malentendidos, como en el caso de los “chequeos”: Al equipo que acompañé en esos tres meses, les llamaba la atención que pidiesen análisis diversos que bajo su punto de vista no eran necesarios, y que se refiriesen a que hacía mucho tiempo que no se “purgaban”. Tengamos en cuenta, por ejemplo, lo que sucede en Ecuador, país del que provienen la mayoría de los hijos de migrantes. Allí, anualmente, se exige en las escuelas junto con el certificado vacunal, unos análisis de orina y coproparasitarios, así como una revisión médica y otra odontológica; asimismo, al menos en las zonas de parasitosis endémica, se realizan desparasitaciones regulares a todos los niños y niñas de las escuelas. De esta manera se podrían interpretar estas demandas específicas de la población migrante por sus hábitos de relación con el sistema sanitario en el país de origen.

En último lugar sí que encuentran diferencias y dificultades a la hora de dar pautas y consejos, de educar sobre la crianza de los niños. En muchas ocasiones la enfermera me habló a cerca de los problemas de comunicación percibidos en su labor de educación para la salud, pongamos por ejemplo el día que me dijo *«no me he enterado de nada de lo que están haciendo con la alimentación del niño, y no creo que ellos se hayan enterado de los alimentos que tienen que incorporar ahora, y eso que he estado un buen rato con ellos, total para nada»*. A la hora de hablar sobre lo que se come, cómo se duerme, la higiene, el ejercicio físico, así como de otras prácticas cotidianas, las peculiaridades que dependen del lugar de origen se entremezclan con las condiciones y cambios que suponen los procesos de inmigración. Factores que están presentes tanto en la vida de los migrantes, como en los razonamientos que los profesionales con que yo trabajé hacían sobre la situación de estos nuevos pacientes, y sus consiguientes adaptaciones de los mensajes educativos: que si en Ecuador no se tiene la costumbre de utilizar aceite de oliva como hacemos aquí; que si con las limitaciones de espacio que tienen en unas viviendas muy compartidas no permiten muchas veces separar los dormitorios de niños y padres, como aquí se considera que se debe hacer; que si los jugos naturales tan comunes y sanos en sus países de origen están siendo reemplazados por zumos comerciales y bebidas gaseosas, costumbre habitual aquí, que no aporta nada positivo al organismo (COMITÉ DE NUTRICIÓN DE LA ASOCIACIÓN ESPAÑOLA DE PEDIATRÍA 2003). En algunos

casos, se procura aprender de las costumbres, en especial de las alimenticias, del otro cuando hay tiempo y disponibilidad por parte del otro para entablar este tipo de conversaciones. En otros muchos se dejan notar las dificultades que estas diferencias en la forma de vida suponen para la educación para la salud ⁽¹⁴⁾.

Hemos podido ver cómo las diferencias entre hijos de inmigrantes y de autóctonos en el acceso a esta consulta de pediatría pueden estar relacionadas con una amplitud de factores socioculturales. Las formas de acercarse a la atención sanitaria están vinculadas a las dinámicas demográficas que supone el proceso migratorio, los conocimientos del sistema biomédico que tenían en su país de origen, el conocimiento que van adquiriendo sobre el sistema sanitario español, y las maneras de gestionar su salud en el país receptor – en las que se entrelazan hábitos previos y unas nuevas condiciones de vida –. Todos ellos son factores socioculturales, factores que nos hablan de la cultura como algo dinámico y situacional. A lo largo de estos tres meses sólo se hizo referencia a una práctica folk de salud, uno de los bebés ecuatorianos llevaba un amuleto contra el mal de ojo – de la misma manera que otros niños españoles llevaban medallas de alguna virgen –. Esta ausencia nos permite ver lo situacional de los conocimientos y prácticas culturales. Al igual que otros pacientes autóctonos, los padres de los niños inmigrantes, saben qué puede curar el sistema biomédico y qué va a mirar como supersticiones. Esta es una de las razones que hace necesaria la investigación desde los conocimientos y prácticas de los inmigrantes, si queremos saber cuáles son, desde su perspectiva, los factores que condicionan su acceso al sistema sanitario y qué otros recursos tienen para cuidar de su salud.

Notes

⁽¹⁾ Este estudio ha sido realizado bajo el auspicio de una beca FPU del Ministerio de educación y cultura vinculada a los proyectos financiados con fondos europeos Partners for Health I y Partners for Health II. Las informaciones recogidas en Ecuador se llevaron a cabo durante una estancia como investigadora asociada a FLACSO - Ecuador.

⁽²⁾ Este estudio no hubiera sido posible sin la colaboración de Xenia, Gloria, Mercè, y todo el equipo del Área básica de salud que me acogió y permitió realizar con ellos el trabajo de campo.

⁽³⁾ En muchas ocasiones nos encontramos con que los padres inmigrantes que asisten a la consulta tienen un mayor grado de formación que los padres autóctonos, y que ha sido con el proceso migratorio como han bajado de estrato social.

⁽⁴⁾ En 2002 las altas de nacionalidad extranjera supusieron el 67,97% del total.

⁽⁵⁾ Para una visión antropológica de un centro de atención primaria en el Estado español véase URIBE J. M. (1996).

⁽⁶⁾ Este interés concuerda con otras iniciativas que se están llevando a cabo en distintas instancias políticas, sanitarias y no gubernamentales (COMELLES J. M. *et al.* 2000, MASCARELLA L. 2002).

⁽⁷⁾ Consideramos hijos de inmigrantes, y por tanto pertenecientes a esta categoría de la muestra, a aquellos pacientes que tienen como mínimo a uno de sus progenitores de origen extranjero. Tomamos este criterio, y no el de lugar de nacimiento del niño/a, para agrupar en esta categoría tanto a los nacidos en el país de origen como a los que ya han nacido en España.

⁽⁸⁾ El número es menor al total de consultas: 1659, dado que excluye todas las consultas que no sean con el pediatra, y dentro de las del pediatra aquellas en las que el paciente no se presenta, las que son programadas, las de seguimiento de una enfermedad ya diagnosticada, y las de peticiones burocráticas.

⁽⁹⁾ Diagnósticos mayoritarios que coinciden con los encontrados en una unidad de urgencias pediátricas de un hospital catalán (ALLUÉ X. 1999).

⁽¹⁰⁾ *Resúmenes del X Congreso de la Sociedad española de enfermedades infecciosas y microbiología clínica (SEIMC) (2002).*

⁽¹¹⁾ Aunque queda fuera de las posibilidades de este artículo, considero importante seguir con la reflexión a cerca de las relaciones entre salud mental, migraciones e infancia. Es necesario complejizar y profundizar en las diferencias encontradas, sobre todo teniendo en cuenta que la salud mental ha sido uno de los principales focos de interés en el estudio de las repercusiones de las migraciones en los procesos de salud, enfermedad y atención.

⁽¹²⁾ El valor indiscutible de la exploración física dentro de la biomedicina, pudiera estar acentuado, en el caso de los niños, por el hecho de que la narración de los síntomas no la realiza el propio paciente sino que proviene de una tercera persona.

⁽¹³⁾ La diferencia entre consenso social y el consenso cultural, es que el primero se refiere al acuerdo dentro del plano de las acciones, en este caso las que tienen que ser llevadas a cabo en la consulta, y el segundo a los significados de esas acciones, que no tienen por qué ser iguales para el pediatra y el usuario. La aplicación de estos términos al ámbito de la atención primaria está tomada de URIBE J.M. 1996: 293.

⁽¹⁴⁾ Una crítica al concepto de estilo de vida dentro del sistema biomédico y de su uso en los consejos, la educación para la salud, médicos, sobre lo que se tiene y no se tiene que hacer, puede encontrarse en MENÉNDEZ E. L. 1998.

Bibliografía

AA.VV. (2002), *Anuari estadístic de la ciutat de L'Hospitalet*, Ajuntament de L'Hospitalet, L'Hospitalet, Barcelona.

AA.VV. (2002), *Anuario estadístico de extranjería*, Ministerio del Interior, Delegación de Gobierno para la Extranjería y la Inmigración, Madrid.

AA.VV. (2002), *Resúmenes del X Congreso de la Sociedad española de enfermedades infecciosas y microbiología clínica (SEIMC)*, "Enfermedades Infecciosas y Microbiología Clínica", vol 20 (supl. 1), 2002, pp. 94-95.

ACHOTEGUI J. (2000), *Los duelos de la migración: una aproximación psicopatológica y psicosocial*, pp. 83-100, en PERDIGUERO E. - COMELLES J.M. (eds.), *Medicina y cultura. Estudios entre la antropología y la medicina*, Edicions Bellaterra, Barcelona.

ALLUÉ X. (1999), *Urgencias. Abierto de 0 a 24 horas. Factores socioculturales en la oferta y la demanda de las urgencias pediátricas*, Mira Editores, Zaragoza.

APARICIO APARICIO M. D. - MUÑOZ GALÁN M. D. - ALARCÓN DÍAZ I. - ORTEGA DOMÍNGUEZ J. A. (2002), *Inmigración, nuevas enfermedades: tetania hipocalcémica nutricional*, "Atención Primaria", vol 30, 2002, p. 662.

- DE ARANZABAL AGUDO, M. (2003), *Inmigración: indicadores de nutrición y crecimiento*, "Anales de Pediatría", vol. 58, 2003, pp. 236-240.
- BARTOLI P. - PAQUINI C. - ZÚÑIGA VALLE C. (2001), *Health-seeking behaviours of immigrants in Umbria. Practices of domestic management of health and illness and recourse to health and social services*, "AM. Rivista della Società italiana di antropologia medica", vol. 11-12, 2001 (*Medical Anthropology and Anthropology*), pp. 255-272.
- BELDA HOFHEINZ S. - GUILLÉN MARTÍN S. - PÉREZ CAMPOS D. - RASERO PONFERRADA M. - RAMOS AMADOR J. T. - SALTO FERNÁNDEZ E. (2003), *Miasis en el cuero cabelludo en niño inmigrante*, "Anales de Pediatría", vol. 59, 2003, pp. 114-116.
- BLAIS R. - MAIGA A. (1999), *Do ethnic groups use health services like the majority of the population? A study from Quebec, Canada*, "Social Science and Medicine", vol. 48, 1999, pp. 1237-1245.
- BONET ALCAINA M. - MARTÍNEZ ROIG A. - PUJALS FERRER J. M. - VALL COMBELLES O. (2001), *Kwashiorkor como síntoma de maltrato y negligencia en Barcelona*, "Anales Españoles de Pediatría", vol. 54, 2001, pp. 405-408.
- CAMPAÑA A. (2001), *Salud mental y migración, conferencia del Cuarto Curso Internacional "Nuevos Paradigmas en Psiquiatría"*, Asociación Latinoamericana de Psiquiatría y Asociación Ecuatoriana de Psiquiatría, Quito.
- CHANDOLA T. (2001), *Ethnic and class differences health in relation to British South Asians: using the new National Statistics Socio-Economic Classification*, "Social Science and Medicine", vol. 52, 2001, pp. 1285-1296.
- CHIRVECHES PÉREZ E. - PELEATO CATALÁN M. D. - CABELLO DÍAZ M. S. - TORNÉ CACHOT J. (2001), *Enfermedad tuberculosa en la comarca de Garraf*, "Atención Primaria", vol. 28, 2001, pp. 508-509.
- COMELLES J. M. - MASCARELLA L. - BARDAJÍ F. - ALLUÉ X. (2000), *Some health care experiences of foreign migrants in Spain*, pp. 144-173, en VULPIANI P. - COMELLES J. M. - VAN DONGEN E. (eds.), *Health for all, all in health. European experiences on health care for migrants*, CIDIS ALISEI, Perugia.
- COMITÉ DE NUTRICIÓN DE LA ASOCIACIÓN ESPAÑOLA DE PEDIATRÍA (2003) *Consumo de zumos de frutas y de bebidas refrescantes por niños y adolescentes en España. Implicaciones para la salud de su mal uso y abuso*, "Anales de Pediatría", vol. 58, 2003, pp. 584-593.
- COOPER H. (2002), *Investigating socio-economic explanations for gender and ethnic inequalities in health*, "Social Science and Medicine", vol. 54, 2002, pp. 693-706.
- COOPER H. - SMAJE C. - ARBER S. (1998), *Use of health services by children and young people according to ethnicity and social class: secondary analysis of a national survey*, "British Medical Journal", vol. 317, 1998, pp. 1047-1051.
- CORNELIUS L.J. (1991), *Access to medical care for black Americans with an episode of illness*, "Journal of the American Medical Association", vol. 83, 1991, pp. 617-626.
- ESTEBAN Y PEÑA M.M. (2001), *Motivos de consulta y características demográficas de una comunidad de inmigrantes "sin papeles" en el distrito de Usera-Villaverde (Madrid)*, "Atención Primaria", vol. 27, 2001, pp. 25-28.
- FERNÁNDEZ-RUFETE J. (2002), *Capitalismo global, Estado e inmigración. La lógica de los espacios derogados y los procesos de salud / enfermedad / atención*, en Aa. Vv., *Cultura y Política, Actas del IX Congreso de Antropología*, Institut Català d'Antropologia, Barcelona.
- GODDARD M. - SMITH P. (2001), *Equity of access to health care services: Theory and evidence from the UK*, "Social Science and Medicine", vol. 53, 2001, pp. 1149-1162.
- IGLESIAS E. - ROBERTSON E. - JOHANSSON S-E. - ENGFELDT P. - SUNDQUIST J. (2003), *Women, international migration and self-reported health. A population-based study of women of reproductive age*, "Social Science and Medicine", vol. 56, 2003, pp. 111-124.
- HERRERA G. - MARTÍNEZ A. (2002), *Género y migración en la región del sur. Informe final revisado*, FLACSO-Ecuador, Quito.
- JANSÀ J. M. - BORRELL C. (2002), *Inmigración, desigualdades y atención primaria: situación actual y prioridades*, "Atención Primaria", vol. 29, 2002, pp. 466-468.

- KRASNIK A. - NORREDAM M. - SORENSEN T.M. - MICHAELSEN J.J. - NEILSEN A. S. & N. (2002), *Effect of ethnic background on Danish hospital utilisation patterns*, "Social Science and Medicine", vol. 55, 2002, pp. 1207-1211.
- LEY ORGÁNICA 4/2000, de 11 de enero, sobre Derechos y Libertades de los Extranjeros en España y su Integración Social, en su redacción dada por la Ley Orgánica 8/2000, de 22 de diciembre.
- MARTÍN LASO M. A. (2001), *El paciente inmigrante en atención primaria. ¿Estamos preparados?*, "Atención Primaria", vol. 28, 2001, pp. 21-22.
- MASCARELLA L. (2002), *Cultura, poder y salud*, en AA. VV., *Cultura y Política, Actas del IX Congreso de Antropología*, Institut Català d'Antropologia, Barcelona.
- MENÉNDEZ E. L. (1998), *Estilos de vida, riesgos y construcción social. Conceptos similares y significados diferentes*, "Estudios Sociológicos", vol. XVI, 1998, n. 46, pp. 37-67. México.
- MULL D. S. - AGRAN P. F. - WINN D. G. - ANDERSON C. L. (2001), *Injury in children of low-income Mexican, Mexican American and non-Hispanic white mothers in the USA: a focused ethnography*, "Social Science and Medicine", vol. 52, 2001, pp. 1081-1091.
- OLIVÁN GONZALVO G. (2000), *Evaluación del estado de salud y nutrición de los adolescentes inmigrantes ilegales de origen magrebí*, "Anales Españoles de Pediatría", vol. 53, 2000, pp. 17-20.
- PARRILLA RUIZ F. - CÁRDENAS CRUZ D. P. - VARGAS ORTEGA D. A. - CÁRDENAS CRUZ A. (2003), *El ayuno en Ramadán y una unidad de urgencias*, "Atención Primaria", vol. 32, 2003, pp. 145-146.
- SAXENA S. - ELIAHOO J. - MAJEED A. (2002), *Socioeconomic and ethnic group differences in self reported health status and use of health services by children and young people in England: cross sectional study*, "British Medical Journal", vol. 325, 2002, pp. 520.
- SMAJE C. - GRAND J. (1997), *Equity and the use of health services in the British NHS*, "Social Science and Medicine", vol. 45, 1997, pp. 485-496.
- SERRA J. (2001), *L'Hospitalet a l'àrea de Barcelona, 1925-2000: de la perifèria al centre*, "Quaderns d'Estudi" (Centre d'Estudis d'Hospitalet), vol. 17, 2001, pp. 31-48.
- STRONKS K. - RAVELLI A. C. J. - REIJNEVELD S. A. (2001), *Immigrants in the Netherlands: Equal access for equal needs?* "Journal of Epidemiological Community Health", vol. 55, 2001, pp. 701-707.
- UNIKEN VENEMA H. P. - GARRETSSEN H. F. L. - VAN DER MAAS P. J. (1995), *Health of migrants and migrant health policy. The Netherlands as an example*, "Social Science and Medicine", vol. 41, 1995, pp. 809-818.
- URIBE J. M. (1996), *Educación y curar. El diálogo cultural en atención primaria*, Ministerio de Cultura, Madrid.
- VAN DIJK R. (1998), *Culture as a excuse: the failures of health care to migrants in Netherlands*, pp. 243-251, in VAN DER GEEST S. - RIENKS A. (eds.), *The art of medical anthropology. Readings*, Het Spinhuis, Amsterdam.
- VAN DIJK R. - VAN DONGEN E. (2000), *Migrants and health care in the Netherlands*, pp. 47-68, in VULPIANI P. - COMELLES J. M. - VAN DONGEN E. (eds.) *Health for all, all in health. European experiences on health care for migrants*, CIDIS ALISEI, Perugia.

2.5 *Umbilicals and baths, aby food and strollers: embodying hybrid cultures.*

Child care strategies and practices among African mothers in Perugia (Umbria)

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«Our cosmogonic experience had its beginnings in the heat of the maternal body, along the edge of our warmed skin, when the inaugural horizon of a homeland first began obscurely to be lived. Against the affective background of that heat [...] we acquired our mouth, sucking milk, and as a mouth we emerged in the gluttonous pleasure of nutrition. Under the caress of the maternal hand the surface of our body came to be described and defined, just as by the image of the maternal face we trained to eminence the capacity to concentrate our gaze and reveal through the fog of the world the first wavy figure [...]. Our first practicable space opened up for us within that space which our mother, cradling us, gave us and took from us in equal spans, sweetening it with the soft iterations of a lullaby: a model space of security, of which we were saved the initiative and in which the going in both directions was followed by a return which always erased it again, while the first domestic voice helped with its melopoeia to make this thrifty becoming acceptable to us. From this space and from this motion, as sure as the orbit of a planet, we acquired our first cultural – and not just biological – possibility of human sleep [...]. Finally, through our mother we also acquired tears and pain [...], when the hard pedagogy of the separations began and we began to try out the harsh norms of human initiative that make time irreversible» (DE MARTINO E. 2002²: 620-621) .

Project Background

The study of which this paper provides a partial report⁽¹⁾, is articulated in two directions: on the one hand the elaboration of social and personal data relative to foreign families with children from 0 to 3 years, regularly registered in the Commune of Perugia, and particularly users of municipal infant day-care centres (*nidi* or “nests”). On the other, an ethnographic study of childcare practices of immigrant mothers from the Maghreb and West-central Africa, the home regions of most immigrant mothers resident in Perugia.

Immigration has imposed itself as an unavoidable terrain of research, solicited by the density of changes that it has introduced in the Umbria region, by the importance that it is assuming (or should assume) for local governments, by the complex configurations of local multi-culturality, which has brought the problem of deciphering others to “our own back yard”⁽²⁾. Our focus on maternity and early childhood derives from the fact that Italy is now joining the ranks of countries with a substantial presence of “children of immigration” – children born to immigrant parents or who arrive in their new country at an early age. In 2001 in Perugia these children are 12% of the resident population under 3, with an increase of 3,1% from 1999. This phenomenon, however, was not unexpected⁽³⁾. Already in 1993 the Region of Umbria, thanks to the impassioned initiative of a civil servant, who attributed to anthropology an essential role in public education, commissioned us to conduct an intercultural training program for staff of municipal infant day-care centres as well as a pilot project for a Centre in which Italian and foreign mothers and children could meet and share meaningful experiences. We have thus had the opportunity of establishing a long term relationship with the early childhood education services which has continued for ten years now⁽⁴⁾, constituting a privileged observatory on processes of parenthood development and contacts and conflicts of an intercultural nature. We have been concerned for the most part with *research-training*⁽⁵⁾ activities in educational anthropology, which have led us to cultivate an intensive collaboration with social and pedagogical psychologists⁽⁶⁾.

In the present study the objectives are of an exclusively cognitive nature, to begin a more systematic analysis on the dynamics of adaptation, negotiation, and re-naturalization, which immigrant mothers of small children find themselves elaborating in the private sphere and in their relationships with public services in health and education.

The foreign women in our study live their pregnancies and childbirths in a medicalized context. They consult with paediatricians in raising their children, make use of – if they succeed in gaining access to them – municipal day-care services, and tend to follow “western” models of child care largely shaped by the health care system and child care industry. The health careers activated by the births are generally considered crucial in the parents’ own social integration, in that they are generally induced to revise their migratory plan towards greater stability⁽⁷⁾ and to enter into closer relationships with the institutions of the host society. The school system and health and social services play a decisive role in the immigrants’ insertion in the local context. Their evaluation is substantially positive, especially when compared to levels of discomfort connected to work, living

conditions, and often problematic daily interactions with natives. Such services are generally recognized as better and more accessible than those in their country of provenance while negative considerations, when made explicit, are usually very similar to those often expressed by Italians. Criticisms directed at the organization of the health care system, for example, largely concern the bureaucracy or doctors' insufficient availability, while negative comments on day-care focus on costs and difficulty of access. It must be underlined, however, that foreigners in conditions of need or marginality rarely manifest to staff or to members of the research team, needs or possible dissatisfactions of a non-material or psycho-cultural nature. In the infant day-care centres, for example, they try to negotiate schedules and hours, but they rarely present requests tied to child rearing models or the care of their children and, even when inquiries are limited to asking mothers what differences they note or what care practices they might not share, they generally prefer to say that there are no differences and that everything is going fine.

Nonetheless, the first stages of the life cycle, on a closer examination, turn out to be a field of complex cultural strategies for the mothers who, though often in conditions of isolation, carry out intensive syncretic elaborations and actively mediate between differing conceptions of childhood and stages of growth. Although, contrary to native mothers and contrary to what staff members of the municipal day-care centres (at least those most sensitive among them) would prefer, they do not feel the need to talk about the doubts and anxieties they face, the solutions they adopt from time to time, the knowledge and resources they draw on, and why, on the one hand, they don't consider all of this to be a proper object of negotiation with professional staff or why, on the other hand, they are absorbed in the effort to orient themselves in their new situation. Precisely for this reason it is important that occasions be created, in the micro-contexts of child rearing services, to provide support for mothering through the sharing of experience and discussion among mothers. And studies like this one can also be useful to overcoming the facile dichotomy of integration/non-integration and recognizing in the practices of immigrant women the production of meaning vital for the foundation of a sustainable future.

Some notes on our methodology

The mothers in our study were first identified as active or waitlisted users of infant day-care centres and then indicated by our collaborators who

played a role of cultural mediation. We did not concern ourselves with the application of selection criteria aimed at ensuring homogeneity with respect, for example, to a more specific area of provenance. While on the one hand we were dissuaded from doing this by the difficulties involved, given the fragmentation of the foreign presence in the day-care centres we studied, we were also aware, on the other hand, that nationality – especially in sub-Saharan Africa – is not sufficient to mark the boundaries of a common sense of belonging and that construction of a homogenous sample of women would require the introduction of too many other variables. What the women in our study have in common (apart from the generic provenance from the Maghreb or West-central Africa) is, therefore, their condition as mothers who are raising children in a context of immigration.

A further unavoidable limitation of the study stems from the fact that, among the women with whom we made contact, the mothers who accepted to collaborate were the least marginal: the ones with the most available free time and the most flexible working hours; the ones who had better instruments for understanding the objectives of the investigation; or the ones who were less diffident and less uncomfortable in contacts with foreign women.

Our ethnographic findings are based on semi-structured interviews so as to allow interviewees to develop their own discursive itineraries and to construct the narrative nuclei that they considered most important in their story of immigration and maternity. We also made use of direct observation in contexts of daily living⁽⁸⁾ or during rituals (weddings or religious ceremonies) in order to overcome the mediation of words or the silences underlying the obviousness of the practices, even though this involved difficulties in being accepted in the private sphere. The interviews and observations were centred on thematic fields regarding: the organization of the baby's daily routine and corresponding rituals connected to food, sleep, washing; bodily techniques, manipulation and modes of baby carrying; nursing; the stages held to be important in the acquisition of infant autonomy (the detachment of the umbilical cord, weaning, walking, toilet training); the management of health/illness.

The nine mothers from West-central Africa come from Cameroon, Ivory Coast, Nigeria, and Benin. Three of them have been in Perugia for 3 to 6 years and came here to follow their husbands or fiancés. Two emigrated to look for work, four to study, and their time of residence in Perugia has been longer (from 7 to 12 years). The youngest, who came here to join her husband, is 21 years old. The others range in age from 25 to 35. They are

all married to a co-national, except two who married an African of a different nationality; in both cases the couples met in Perugia. Four women have only one child, four have a second one (but one of these was pregnant again) and one has two other children. All the mothers have high school diplomas or university degrees except one who has a middle school diploma. At the time of the study four had low level jobs (caretaker, cook), two were unemployed, or were looking for work, with the exception of one, who was self-employed. In addition, all but one of their husbands were low level dependent employees.

The immigration plans of the women are for the most part indefinite; only one woman plans on remaining here until her daughter reaches the age of majority and completes her education, at which point the mother will return to the Ivory Coast, leaving her daughter the choice of where she wants to establish herself or, if she should choose to remain in Italy, to go back and forth regularly between Africa and Italy. The youngest, also from the Ivory Coast, hopes to leave Italy as soon as possible, in five years, after having earned enough to go back home “with her head held high”. At the time of our meetings she was thinking about the possibility of taking her daughter back to her country and returning here with her husband to work, but then she decided against the separation.

Homemaking Industriousness. From maternal care to the embodiment of culture

The concept of life cycle, traditionally used with reference to folklore as an organizing scheme for lore and practices connected to critical moments of passage⁽⁹⁾, seems to us to be useful – especially in reference to pregnancy, parturition and birth, and early childhood – in analyzing some of the most important effects produced by medicalization in its unceasing advance into the realm of healthcare, beginning, in fact, with the capillary diffusion of obstetrics and pediatrics. We first developed this line of research in a historical perspective (BARTOLI P. - FALTERI P. 1987) studying the encounter/clash between folk medicine and official medicine as it took place in the Italian context up to recent times, but it also holds important implications for the analysis of the present and of the modalities with which women today re-elaborate lore and practices whose transmission from generation to generation has been hindered or interrupted.

It has been a long time since the feminine genealogy of care could be described as linear, but there is no doubt that the initial stages of the life

cycle are to be considered a question of gender. Francine Saillant (SAILLANT F. 1999) proposed a gendered repositioning of research on health and illness by way of an *anthropologie des soins* (anthropology of care) that recognizes the central role played by women everywhere in the domestic production of health, thus correcting the neutral perspective with which the cultural dynamics connected to the pluralistic recourse to therapeutic careers are examined. This is an approach, moreover, which should overcome the *care/cure* dichotomy implicit in most Anglo-American medical anthropology, which risks reducing and fragmenting the object of study by defining it in reference to professional circles rather than the whole complex of the experience and management of health and illness.

But the maternal care that we are talking about here goes beyond the proper horizon of health. Indeed, its primary function is an anthropo-poietic one, which reduces the initial indeterminacy of the human condition – open to many as of yet unrealized possibilities – implying a project for the production of “partial”⁽¹⁰⁾ individuals. Maternal care is and produces *habitus* (BOURDIEU P. 1972); it constitutes not only the driving force in the construction of maternity and infant subjectivity but also the primary terrain of the embodiment of culture.

In *La fine del mondo* (“The End of the World”) from which we have taken our epigraph, Ernesto DE MARTINO (2002²) spoke about *la laboriosità appaesatrice* (“homemaking industriousness”) which allows us to acquire the *datità del mondo* or the “givenness of the world”, understood as that familiar backdrop which – precisely because it has been rendered domestic and practicable – can become the *patria accogliente dell'esserci* (the “welcoming homeland of being there”). It is through the domestication of the world that we are able to constitute ourselves “as a centre of operability [...] a centre of fidelity to past securities, converted into comfortable habits, and a centre of initiative for constituting, here and now, the pre-eminent security of which we are in need” (DE MARTINO E. 2002: 656). This is the “primary ground of cultural life” on the basis of which we are able to conceive other utilizable horizons and other life projects. The domestication and the acquisition of givenness are not addressed only or even primarily toward the outside; they are addressed above all to the body. It is not an accident that de Martino entitled his reflections on these themes *Tecniche del corpo* (“body techniques”) even though their implications are much denser than those imagined by Mauss: beyond mere ability, the embodiment of culture produces the possibility of being in and acting on the world⁽¹¹⁾.

The feminine work of child rearing – daily, intimate, socially almost invisible – constructs, therefore, bodies and individuals. In rapidly changing

contexts, mothers, especially with their first child, deeply feel the responsibility of this task, which otherwise would appear obvious to them, and they are aware in some way or other that those minute operative and relational practices are the theatre of a hegemonic contest waged between the medical system, the educational system, and the childhood industry. They realize that they are being asked to choose and to rely, to be autonomous and to follow the heterogeneous indications suggested by professionals and service staff, by pediatric and pedagogic advice, or by the marketplace.

For immigrant mothers the perception of change is more clear cut and conscious; they know that child care requires mediation, substitution, interpretation, decision, and that this dense elaboration – to be rendered as economical as possible – is necessary to the further domestication of the new environment, no longer just for themselves or the couple, but in order for her and them to be able to raise their child who was born here. Perhaps it is because this labour is so evident that they do not complain about it to service staff – when they are users of day care – and tend to keep it to themselves, as an integral part of their own existential and cultural itinerary. They do not think of turning to day-care staff, as professional figures, to resolve problems that are part of their child rearing responsibilities and thus of the most intimately domestic sphere. They do turn systematically, however, to the medical system – to their paediatrician or the hospital emergency room – for illnesses and check ups, albeit in different ways and patterns depending on their personal choices.

The cultural *bricolage* of immigrant mothers is for the most part a solitary affair. There are visits from their mothers or their mothers-in-law, from their sisters or sisters-in-law, when the baby is born. Sometimes there are relationships with African friends who are mothers or with elderly Italian neighbours who sometimes compensate for the absence of women relatives with childrearing experience⁽¹²⁾. There are the children's fathers, who everyone acknowledges are more present – work schedules permitting – than they would be in their country of origin. But the work connected to the process of embodiment, the production of health, and the choice of practices to adopt, is all substantially in their hands.

The moving boundaries between Tradition and Modernity

The women in our sample spontaneously draw boundaries between “tradition” and “modernity”. To the first they attributed what is seen as a corpus

of local practices transmitted along female lines, that goes back to one's own mother or – if she is already no longer a *traditionalist* – to other female figures in one's family (a grandmother who lives in the country), or to an impersonal and generic group custom defined in terms of belonging (“*what we do*”, “*our culture*”) and another place (“*Africa*”, “*down there*”). Modernity, on the other hand, is the term of reference for attitudes and modalities of care attributed to cosmopolitan medicine and to urban living, where the feminine condition has changed: women work, they have fewer children, nursing doesn't last as long, paediatricians are consulted for check ups.

For the most part our mothers declare themselves to be “*on the modern side*”, with the single exception of V. (Ivory Coast), the youngest, who does not define herself in these terms, because her thoughts are all directed to her home country and returning there. This *modern* orientation is not, however, considered by the interviewees to be a consequence of their migration experience. On the contrary, they are anxious to point out that their culture of provenance has changed and is part of the contemporary world. «*Our times* – says C. (Benin) – *are already modern*». Yet C. has her own strong idea of tradition and is the only interviewee who wants to talk about local practices, showing impatience when our discussion doesn't turn to them immediately. She has hung a string of pearls around her daughter's hips, which are supposed to serve to shape her back, to make it more “*curved*” and less “*smooth*” than a boy's. She does not attribute to the necklace a propitiatory function for fertility, but sees it as a way of modelling the body and a symbol of gender; one should be able to tell just by touching the body that it is feminine. C. adds that only certain types of pearls are used and, when asked to explain, says: «*it's always been that way that you only put certain types of pearls on the back. That's all there is to it*». Tradition cannot be explained because that would mean it might be subject to discussion.

Thus Cn. (Cameroon), who cites in support of her modernity the fact that she prefers to carry her baby in a sling or a baby carriage rather than a piece of cloth, recounts nevertheless that she would have preferred – in accordance with tradition – to bury her baby's umbilical cord in her home country, by giving it to her mother-in-law⁽¹³⁾. But the elder woman, who is a nurse, refused to take it and told her to throw it away. Cn. couldn't bring herself to part with it and, taking advantage of the fact that her mother-in-law had departed before the cord detached, she buried it in the garden of her house in Perugia: «*to not just throw it away like that, so I dug up a little earth and put it under there with my hands*». What this involved then was a hasty gesture with no solemnity but still perceived as vital and necessary; although she would have preferred that it be the soil of Cameroon to wel-

come the detached cord, in the end the earth is the same everywhere. And maybe it was a way of “localizing” her child⁽¹⁴⁾.

Many of the practices the mothers mention for their effectiveness are now only faint memories. They come to mind only because our discussion solicits the memory and a relationship with the culture of provenance beyond what may be really practicable. Cn., when she complains that her son was late to start walking, says that she’s sure that in Cameroon he would have overcome the problem:

«I started walking at seven (months), seven and a half. There is a ritual in our country to make children start walking. If I was there, I would have done it right away [...] they give you some special massages, with special bones, then the baby starts walking very soon».

But even though she asks for help in remembering from a friend who is present at the interview, the memory remains vague. In any case, it wouldn’t have been of any use, because she would have wanted or been able to reconstruct the ritual outside of the African context.

Even with regard to recipes (foods prepared for the baby, broths for the puerpera, herb infusions, decoctions) the women speak generically of operations that evoke a collective female industriousness – pound, crush, mince, chop, mix, boil – rather than describe or explain.

What seems to be lacking is not so much the right ingredients or the skills to use them, but the backdrop of relationships in which to situate the preparation of the recipes. All of the interviewees agree, in fact, on a difference that translates into an absence. In Africa, during the baby’s first months of life, new mothers go to live with their own mothers or in any case they have the support of the women in their families; they don’t have to do anything but “*eat and nurse*”, think about their own well-being and that of their newborn baby.

In Italy, African women – like all women immigrants from countries in which the process of medicalization has not been completed – find themselves in an environment where the social importance attributed to the first stages of the life cycle has been turned on its head. They are struck, in fact, by the disproportion between the care that one can receive here during pregnancy and the isolation in which one is left during the puerperal period⁽¹⁵⁾. The only reference point, which in any event regards the health of the baby and not the well-being of the mother, is the woman paediatrician (all of the mothers interviewed by us have, in fact, chosen a woman):

«You’re better off going to the paediatrician, if not, what can you do? You can’t be sure, you can’t see... the baby’s weight, the length, the growing

organism, the ears, the equipment. The whole thing, at least this kind of check-up. You go to the paediatrician, even if [the baby] is doing fine, because there are little things you need to know, to see» (A).

The objectifying gaze of the physician, made penetrating by technology (the *equipment*) reaches where the eyes of the mother cannot. There remains, nevertheless, the awareness that is the mother's duty to mediate with the paediatrician, to put her own competence into play in interpreting the baby's state of health, so as to then illustrate effectively any problems that may arise.

«First I explain and then the paediatrician will tell me what I have to buy. When the baby is sick I call her and explain everything to her» (V). «You have to look for the information and then ask for advice from the paediatrician. That's the way it works; you're the one that gathers the information» (M).

But the mediation is not always easy, not so much because of language problems – the interviewees from West central Africa, unlike those from the Maghreb, speak fluent Italian – but because the cultural frames of reference are not the same. Although it is considered obvious that the home country's medicine, whether empirical or magical⁽¹⁶⁾, is neither known nor practicable, perplexity arises in regard to treatments that do not fit the opposition between official knowledge and traditional knowledge, but are attributed to a “domestic” medicine (SAILLANT F. 1999) that draws on products also available in the Italian market. This is the case of remedies (such as castor oil, or vaguely defined infusions or syrups) that have the function – beyond strengthening bones or preventing worms – more generally described as “*cleaning*”, “*cleaning out*”, “*washing*” the baby's body internally⁽¹⁷⁾. The mothers would like to administer them regularly, as is their custom, beginning with the third month, but the paediatrician believing them harmful, prohibit them and admonish the mothers: «*If the baby comes down with something the responsibility is yours*». The physicians believe that anti-helminthic and purifying products may be useful in Africa, where hygiene is not widespread, but dangerous here, where it is. And even the mothers admit: «*it's cleaner here*», «*in my country there's a little more dirty*». But transference of the opposition dirty/clean from the inside of the body to the outside environment is not always convincing and some mothers consider it unacceptable that the paediatrician should interfere with their management of their children's health with such rigid prohibitions.

Nevertheless, taken as a whole, what emerges from the practices and words of the women in our study is not only the felt absence of a support system or the tendency to delegate responsibility to the paediatrician, but the labour of cultural elaboration that they are engaged in for themselves

and their children. Our attention has been focused primarily on what they consider to be unrenouncable and interchangeable, on what, therefore, they don't believe to have lost but that they put into action, and that becomes, therefore, the driving force of recontextualization and resemanticization⁽¹⁸⁾.

From this point of view, the most significant sphere of experience is their handling of their children, because it appears to be an integral part of a naturalized theory of childhood, of the body, and of care, which is functional to their immigrant condition.

Their childcare practices – such as baths and massages, the ways they carry and contain the baby – are fundamental forms of cultural modelling. Here, in a context of immigration, they also become ways of constructing a body able to domesticate a world perceived as constantly unstable.

As soon as they are home from the hospital the mothers bathe the baby, regardless of the advice of the obstetrician or the paediatrician, without waiting for the detachment of the umbilical cord. C. says: «*When the obstetrician came to show me how to bathe the baby, I laughed; behind her back though, because it's not polite*». The home visit had come too late; the first bath had already been given. Contact with water is considered to be too important. It is not a question of purification; rather it is thought necessary that the newborn be reintroduced to the natural element where he passed his intra-uterine life and to the fluid confines to which he was accustomed in his mother's womb, because this will bring him pleasure and relaxation as well as awareness of his own body (a body that "hurts" from its change of state).

The bath and the massage are part of the daily routine, once or twice a day. Beyond their being necessary for the pleasure of the baby and the care of his skin, which otherwise turns dull and whitish, they have a function thought to be literally molding. Usually the massage is performed with products generally found in stores but shea butter and various oils, purchased in stores run by Africans or sent from home, are also used, depending on the season. Mothers from the Ivory Coast have their families send them local "sponges," made of netting; these are an indispensable personal care item, used starting from the earliest days of infancy for the work of cleansing and reconfiguring the body.

But the infant body, before it is modelled, must first be constructed: it is subjected to a passive physical training, complementary to the massage, to invigorate, *loosen* and straighten the limbs, promoting early autonomy of movement. Legs and arms are pushed behind the back, the baby is held up by the feet. The white babies, not subjected to these practices, are per-

ceived as more fragile, more flaccid and more rigid at the same time, and even one's own child, if not manipulated sufficiently, risks failing to acquire the strength, compactness, and elasticity that his body should have. It is a body that his mother's hands have rendered more flexible and more aware of its own extremities, a "localized" body that can handle the challenge of instability.

Notes

⁽¹⁾ The study is been conducted for the CNR (National Research Council) within the framework of a project which also includes a research team in Milan and one in Rome. On the national level the project is coordinated by Tullia Musatti (CNR), while I am responsible for coordinating the research team in Perugia, composed of Fiorella Giacalone and Roberta Pompili, with the collaboration of Loredana Vanacore Falco for relations with the women from West-central Africa and Asmaa Lafi for those with women from the Maghreb.

⁽²⁾ The *Istituto di etnologia e antropologia culturale della Università degli studi di Perugia (today Sezione antropologica del Dipartimento Uomo & Territorio)* has been involved in immigration research for many years, both in the case of Umbrian emigrants to distant countries and migrants from the country to the city, and in the last ten years in the case of intense foreign immigration to Umbria. Tullio SEPPILLI, who from the beginning of his research career has cultivated an interest in processes of acculturation and syncretism, has considered migratory flows from the point of view of medical and food anthropology (2000a, 2000b, 2002). Paolo BARTOLI, Caterina PASQUINI and César ZÚNIGA VALLE have conducted a multifaceted study on "Health Itineraries of Immigrants in Umbria: practices of household management of health/illness and recourse to health and social services" (2001).

⁽³⁾ For an informative overview of immigration flows in Umbria, see MARINI 2000; CIPRIANI *et al.* 2001; MONTESPERELLI - CARLONE 2003.

⁽⁴⁾ Among the publications which document my direction of the work are: FALTERI P. 1997a, 2001a; FALTERI P. - MUSATTI T. 2001.

⁽⁵⁾ This term refers to forms of research which are conducted not *for* but *with* staff members: the social use of such research consists not only in the indications for intervention which emerge from the information-gathering process, but above all in the development of reflective skills on the part of staff members of health and social services. For a methodological framework tied to a choice of working methods, see BARTOLI P. - FALTERI P. 1994.

⁽⁶⁾ Our Milanese and Roman partners in the CNR study are, in fact, social psychologists and pedagogists. As a result of their research experience within immigration, they have moved progressively towards an ethnographic and anthropological approach.

⁽⁷⁾ Not to be underestimated, nevertheless, is the fact that, in some cases, infants are entrusted to the family of origin back in the mother country because of the economic and organizational difficulties of daily life faced by their parents, and particularly by working mothers, in Italy. In such cases, problems of a material nature are accompanied by a desire that the child spend the initial stages of growing up in the family and in the context of provenance, learning the mother tongue, the religion, and nutritional and dietary practices, so as to avoid irreversible cultural breaks, even though this means risking a break in the mother-child relationship. At this point not much is known about these traumatic separations in terms of numbers and personal experiences; they are beginning to become known through the accounts of mothers and mediating women: BALSAMO *et al.* 2002; CHINOSI L. 2002.

⁽⁸⁾ In one case Roberta Pompili arranged for one of the mothers to come to her house to help her in the care of her own one-year-old child. The relationship in this case was thus reversed: it was not

the researcher who became a participant in the other woman's experience but the other woman who entered into Roberta's daily routine to share in moments of child care with the (uninformed) consent of the child.

⁽⁹⁾ For a brief historical overview of life cycle research in Italy, particularly on de Martino's initial interest during his research in Lucania in the 1950s (DE MARTINO E. 1996), see FALTERI P. 1996.

⁽¹⁰⁾ Francesco Remotti (REMOTTI F. 1999) uses the term *anthropo-poiesi* for processes in the construction of given forms of humanity – always therefore specific and particular – through ritualized and naturalized practices, which manipulate and shape the body in order to make individuals coherent with a shared social ideal

⁽¹¹⁾ De Martino himself uses the term *embodiment* when he speaks of the act of walking as an automatic operation that implicitly embraces the "personal and human history of knowing how to walk": in this sense – he says – "we never walk alone". "That lengthy not knowing, that relative forgetting, that *embodying* of teachings in operative abilities that can be carried out in the relatively unconscious [...] is in integral part of that constantly renewed liberation from givenness that constitutes the emergence of being there" (DE MARTINO E. 2002: 617).

⁽¹²⁾ A. (Cameroon) has, in fact, relied on the experiences of elderly women, considering herself fortunate to have had for some time the benefit of advice from her grandmother, who came to stay with her in Perugia after her baby was born, and from a neighbour, whom she calls her "Italian grandmother". "They - says A. - have a different way of doing things than young women have. When you're on your own you're afraid to do certain things. But they gave me strength". For the dense meaning that the word *neighbourhood* can have in contemporary society, see APPADURAI 1996.

⁽¹³⁾ It is well known that, prior to the medicalization of parturition/birth, the stump of the umbilical cord has had great symbolic importance everywhere and has been the object of rituals in which it is burned, dried and conserved or, as in this case, buried, as generally happens in West central Africa.

⁽¹⁴⁾ Here, we are referring to the "production of locality", according to APPADURAI A. 1996.

⁽¹⁵⁾ In Italy this reversal is as recent as the medicalization of parturition/birth. For some thirty years now the puerperal period has become practically irrelevant, no longer addressed by either profane or technical knowledge. The cases in which it has been the object of attention from medicine are both rare and interesting: FALTERI P. 1997.

⁽¹⁶⁾ This is how C. (Benin) expresses herself with regard to magical practices of preventive medicine, about which she talks profusely: «What's different in my country are certain types of talismans that are prepared for protection from illness, because with us everything is mystical, no?».

⁽¹⁷⁾ The same function with regard to the respiratory system is attributed to a «traditional honey that clears out the chest [...] cleans out the mucous» (C.).

⁽¹⁸⁾ For a model analysis of processes of meaning production among immigrants, see SIGNORELLI A. 2000.

Bibliography

APPADURAI Arjun (1996), *Modernity at Large. Cultural Dimensions of Globalization*, University of Minnesota Press, Minneapolis - London.

BALSAMO Elena - COLMEGNA don Virginio FAVARO Graziella - GIACALONE Fiorella - PAVESI Amalia - SAMANIEGO Monica (2002), *Mille modi di crescere. Bambini immigrati e modi di cura*, Franco Angeli, Milano.

BARTOLI Paolo - FALTERI Paola (1987), *La medicina popolare in Umbria dalla fine dell'800 ad oggi: permanenze e trasformazioni*, pp. 167-208, in PASTORE A. - SORCINELLI P. (eds.), *Sanità e società. Emilia Romagna, Toscana, Marche, Umbria, Lazio. Secoli XVI-XX*, Casamassima, Udine.

BARTOLI Paolo - FALTERI Paola (1994), *Usage social de l'anthropologie. Pour un éloge de la formation*, "Ethnologie Française", tome 24, n. 3, juillet-septembre 1994 (issue on Italia. *Regards d'anthropologues italiens*, LOUX Françoise - PAPA Cristina eds.), pp. 531-548.

- BARTOLI Paolo - PASQUINI Caterina - ZÚNIGA VALLE César (2001), *Health-seeking Behaviours of Immigrants in Umbria*, "AM. Rivista della Società italiana di antropologia medica", ottobre 2001, n. 11-12, pp. 255-271.
- BOURDIEU Pierre (1972), *Esquisse d'une théorie de la pratique*, Droz, Genève.
- CHINOSI Lia (2002), *Sguardi di mamme. Modalità di crescita dell'infanzia straniera*, introduction by Silvia VEGETTI FINZI, Franco Angeli, Milano.
- DE MARTINO Ernesto (1996), *L'opera a cui lavoro. Apparato critico e documentario alla Spedizione etnologica in Lucania*, edited by GALLINI Clara, Argo, Lecce.
- DE MARTINO Ernesto (2002² [1977]), *La fine del mondo. Contributo all'analisi delle apocalissi culturali*, edited by Clara GALLINI, introduction by Clara GALLINI and Marcello MASSENZIO, Einaudi, Torino.
- ERNY Pierre (1999 [1972]), *Les premiers pas dans la vie de l'enfant d'Afrique noire. Naissance et première enfance*, L'Harmattan, Paris.
- FALTERI Paola (1996), *Il nano Pipino che nacque vecchio e morì bambino. Intorno al ciclo della vita e ai riti di passaggio nella ricerca demoantropologica*, pp. 216-264, in SPERA Enzo - MAGNELLI Francesco (eds.), *Un laboratorio tra i castagni. Teoria e metodi della ricerca demoantropologica*, Arnaud, Firenze - Gramma, Perugia.
- FALTERI Paola (1997a), *Contatti, "Bambini e Bambine in Umbria"*, anno XIII, n. 2, febbraio 1997 (issue on *Servizi multietnici, culture in comunicazione*).
- FALTERI Paola (1997b), *La quarantena è una cosa sacra. Puerperio, ciclo della vita e mutamento culturale*, pp. 1-15, in PECORELLI Sergio - AVISANI Rosaria (eds.) (1997), *Puerpera, puerperio, assistenza (Brescia, 11 ottobre 1997)*, Spedali Civili - Università degli studi, Brescia.
- FALTERI Paola (2001a), *Multidimensionalità dell'esperienza infantile e approcci valutativi*, pp. 27-31; *Scelte metodologiche: il percorso di monitoraggio della qualità e gli strumenti di rilevazione*, pp. 43-51; *Scelte metodologiche: la dimensione della qualità percepita dagli utenti*, pp. 52-60; *I servizi integrativi al nido: la qualità percepita*, pp. 157-170; *I servizi di sostegno alla genitorialità*, pp. 171-206; *I servizi educativi e ricreativi per il tempo libero: la qualità percepita dai genitori dei ragazzi utenti*, pp. 293-304, in CIPOLLONE Laura (ed.), *Il monitoraggio della qualità dei servizi per l'infanzia e l'adolescenza. Indicatori e strumenti*, Junior, Bergamo.
- FALTERI Paola - MUSATTI Tullia (2001), *Cura dell'infanzia e uso dei servizi nelle famiglie con bambini da 0 a 3 anni. Una ricerca a Città di Castello e Gubbio*, Assessorato alle Politiche Sociali, Regione dell'Umbria, Perugia, (Quaderni del Centro per l'Infanzia e l'Età Evolutiva).
- GIACALONE Fiorella (ed.) (2002), *Marocchini tra due culture. Un'indagine etnografica sull'immigrazione*, Franco Angeli, Milano.
- MARINI Rolando (2000), *Convivenza interetnica e politiche pubbliche locali. Il caso dell'Umbria in prospettiva comparata*, Irres - Istituto regionale di ricerche economiche e sociali, Perugia.
- MONTESPERELLI Paolo - CARLONE Ugo (2003), *Primo rapporto sull'infanzia, l'adolescenza e le famiglie in Umbria*, Regione dell'Umbria-Assessorato alle Politiche Sociali.
- REMOTTI Francesco (ed.) (1999), *Forme di umanità. Progetti incompleti e cantieri sempre aperti*, Paravia, Torino.
- SAILLANT Francine (1999), *Femmes, soins domestiques et espace thérapeutique*, "Anthropologie et Sociétés", vol. 23, n. 2, 1999, pp. 15-40.
- SEPPILLI Tullio (2000a), *Immigrants in Europe and Health Services Strategies. An Introductory Outline*, pp. 31-43, in VULPIANI Pietro - COMELLES J.M. - VAN DONGEN Els (eds.), *Health for all, all in health. European experiences on health care for migrants*, CIDIS ALISEI, Perugia.
- SEPPILLI Tullio (2000b), *Le nuove immigrazioni e i problemi di strategia dei servizi sanitari europei: un quadro introduttivo*, "AM. Rivista della Società italiana di antropologia medica", n. 9-10, ottobre 2000, pp. 35-58.
- SEPPILLI Tullio (2002), *Migrazioni e processi di acculturazione alimentare*, pp. 35-53, in DIPARTIMENTO DI STUDI STORICO-SOCIALI E FILOSOFICI, UNIVERSITÀ DEGLI STUDI DI SIENA (ed.) (2002), *Culture e mutamento sociale. Per Carla Bianco: studi e testimonianze*, Le Balze, Siena.
- SIGNORELLI, Amalia (2000), *Le molteplici singolarità di un processo di massa. Alcune riflessioni sullo studio antropologico delle migrazioni*, "Etnoantropologia", n. 8-9, 2000, pp. 285-293.

2.6 *"Feeding bodies, nurturing identities".*

The significance of food for the well-being of Peruvian migrants in Chile

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Introduction: Food and Migration

Products such as sugar, spices, chocolate, tea and tobacco brought once to Europe from exotic places are concrete evidence of the historical role food played in the development of European empires and reveal the double character of food as indicative of "roots and routes". This continues to be the case at present for more recent and global migrations⁽¹⁾.

Food patterns are linked to cultural roots as long as they operate as markers of a localized material culture. (At the same time are routes)-confusing, as pointed out by Döring; «testifying on the contact zones and "routes" which their produces and consumers have gone through» (DÖRING T. - HEIDE M. - MUHLEISEN S. 2003: 7). In fact the displacement and transformation of food patterns resulting in people's migration rarely erase previous food traditions. By looking at the vestiges of old culinary traditions within the existing ones, it may be possible to trace back the paths of people's migrations.

Looking at Peruvian migrant's selection and manufacturing of food from the perspective of their previous and current whereabouts reveals the extremely rich culinary history of Peruvian food. It dates back to the Incas and pre-Incas times and was later influenced by the Spanish colonizers. Throughout its historical development as a nation, Peru has incorporated food practices; tastes, recipes, cooking techniques of the different migrations and *mestizajes*⁽²⁾. This is indeed a history that continues "to be cooked" along new *transnational* journeys, as Peruvian migrants spread throughout the world. This paper deals with a small portion of that history, one that is taking place among the Peruvian northern coastal immigrants in Santiago de Chile⁽³⁾.

The traditional cuisine brought to Chile by Peruvians is one of the most successful contributions of this migration to Chile, an exception to the generally hostile climate towards Peruvian migration in the country. Peruvian restaurants have multiplied and are very popular as a result of Chilean enjoyment of the flavour of Peruvian food. Peruvian ingredients are currently being imported to Chile and sold in almost every market (e.g. Yuca, Rocoto, purple maize, cancha [dried, fried maize], Inca-Cola, among many other products). Chilean families that have hired Peruvian domestic workers have also benefited from the cooking skills and cuisine from Peru. Even more significant is the place food has (holds) among the migrants community itself. As shown in this paper food comprises a central material and symbolic resource utilized by the migrant community to cope and resist the adverse climate of the Chilean society and maintain their well being.

Food is seen in this study as a field of resistance rather than of transformation by looking at the use of traditional food by the migrants to overcome the mental and physical disruption of the oppressive social environment of the hosting society. This paper examines how, through activities such as cooking, gathering around food, eating and sharing food, conversing and recalling memories of food, migrants' contested identities are revitalized and ill health cared for. The findings of this article were gathered through a participatory observation carried out among a community of Peruvian migrants living in downtown Santiago, during the spring of the year 2002.

Although I did not focus on food initially, after beginning my observation of this community, the importance of how the community members' lives were structured around food became apparent. It appeared as though general concerns about their well-being, as well about health and illness in particular were often expressed in the language of food, through talking and recalling memories of meals, cooking and eating traditional food. Food seemed to be the "centrepiece" around which the migrants' collective lives were articulated and as such, proved to be a path into the subject of migration and health, which I was principally investigating.

This paper is organized into three sections. The first section presents a conceptual approach to understanding the relation of food practices, identity and health. It also gives background of this migration to Chile and a picture of the living conditions Peruvian migrants are exposed to in Chile. The second section refers to the micro context within which these ethnographic observations were carried out; the shared housing unit, placing emphasis on the different elements that made this place a "home away from home". The third section delves into the meanings and practices that

make food a source to keep and restore the bodily balance and to foster migrants national identity. The conclusions are then presented.

I. Food, Identity and Health

Food patterns as conveying cultural meanings have been extensively studied by anthropologists. Claude Lévi-Strauss set the grounds of a structural analysis of food, continued later by Mary Douglas. Both authors focused on a wide realm of phenomenon by examining the rules and principles guiding what is considered food, good food, bad food, how food should be cooked and eaten (e.g. its temperature, the combination of ingredients, consistency etc.), prescriptions regarding when, what and how food should be eaten, by whom, as well as of its prohibitions or food taboos⁽⁴⁾.

Food patterns are not only indicative of structural oppositions, they result from the interaction of any given community with its milieu. Consequently, food binds identities to localities. This last notion has been put into question to the extent that these same localities and homes are displaced as people move around the globe.

However, food not only anchors identities to localities. Whether it is "here" or "there" food continues drawing the community boundaries. It is indeed by food choices and food sharing that people establish the limits of "us" and "them". Thus, the study of food and eating patterns may be indicative of how groups and identities are defined; since in the most different contexts, food lies at the center of rituals of belonging through which these various identities are marked and celebrated.

This study focuses on relationship between food, identity and health by looking at the case of Peruvian migrants in Chile. The point of departure is the displacement of food practices resulting from migration and evolves around its material and symbolic dimensions, in close relation with the societal context where these practices find their meanings and uses.

Food as material culture and its connection with health, is studied by examining migrants' conceptions and principles according to which they judge food to be good, edible and healthy. For migrants "a good food" is one which works in compliance with those preconceived principles. Consequently, food materializes in migrants' bodies, re-establishing the equilibrium altered by illness. Far from being arbitrary rules, these principles are remnants of an ancient conception of health kept alive by this community throughout their lineage.

Food serves as a cultural memory and as such it is linked to identity. Accordingly, attention is paid here to times when gathering around food or engaging in food related conversations, migrants bring in their own memories and share with other members of the community their different regional culinary traditions. At this moment, a sense of collective identity is produced just as the idea of a “national culinary tradition” is envisioned.

Sidney Mintz, has questioned the very existence of a “national cuisine”; a discussion of relevance for the case studied here. According to this author, ‘cuisines’ should be thought of primarily in regional, not in national terms. By drawing a parallel between cuisine and language the author argues that « local cuisines predates the political construction of a state just as do local dialects the standardization of a national language», and claims that «national cuisine, like a national language, is in some sense a political artifact on its way to becoming a tourist artifact» (MINTZ S. 2003: 26). However, Mintz concede the existence of national cuisine as “a textual reality” conditioning it to an immaterial reality; «as long as national cuisine is understood as having a textual reality as opposed to a concrete reality – something people talk about, imagine but do not literally eat » (*op. cit.*).

Likewise, in the case studied here, food operates as text (as spoken, imagined, described, evoked, and remembered). As a reality in such level, food produces a subjective effect on migrants’ identity. It is argued here that similarly performing as language through which Peruvian migrants communicate a familiar sensorial experience, food channels a positive relation with their native land and a sense of belonging to a national identity.

In the next section, the background of this migration will be introduced to better grasp the context where the above discussion is grounded.

Migration to Chile in the Nineties

The economic prosperity and the newly inaugurated democracy attracted a wave of migrants from several Latin American countries to Chile.

The first wave of regional migrants arrived in Chile in the beginning of the 1990’s. The majority were professionals from Ecuador, Peru and Cuba and entered existing economic niches, including the Health Sector⁽⁵⁾. Yet, during the second half of the 1990’s Chile witnessed the arrival of a new type of migrants.

Less educated than the former group, the second wave of migrants was mostly women and blue-collar workers that filled the available jobs in the

lowest economic strata of the labour market. Willing to work for lower salaries and longer hours than their Chilean counterparts, this group found jobs in the construction sector and in the domestic service. The number of Peruvian among the whole group increased noticeably. Currently, Peruvians are the second largest group of migrants in Chile. It is calculated that they number 39.084 whereas the Argentineans, the largest foreign group, number 50. 448, while the total population of foreigners in Chile adds up to 195.320 people (Census 2002).

The speed and scale of the recent Peruvian migration to Chile shapes its distinctive features and suggest differences between the several groups that have simultaneously arrived in Chile. Yet, public opinion tends to exaggerate the expected size of this migration. In particular, the media projects many distorted images of migrants thus channelling among the Chileans feelings of "being invaded" and exacerbating their xenophobic attitudes.

Among the different foreign groups Peruvian migrants are the most discriminated against. As workers, they are segregated in the labour market. In spite of their work capacity and training they have very limited access to job opportunities. Peruvians suffer from verbal and physical violence particularly on behalf of working class Chileans who blame them for problems such as unemployment and low salaries. Peruvians are treated badly in shops and insulted when using public transportation or services. Likewise, their children are often the target of scorn when attending Chilean schools.

Yet the roots of this phenomenon should be historically situated. As a result of the Pacific war of the XIX century among Chile and the Peruvian-Bolivian coalition, part of their (whose?) territories were annexed to Chile⁽⁶⁾. Such events fuel the current feeling of "superiority" by Chileans over their neighbours. This attitude has grown stronger with the knowledge that Peruvians fled their country for the better economic prospects in Chile,. However, at the core of the discrimination against Peruvians is a racial ideology widespread among Chilean population. For example, Chileans think of themselves as being of a whiter colour than Peruvians, and therefore superior. In consequence, Peruvians are seen as inferior, backward presumably more "Indian" than the average "mestizo" Chilean population.

After this general reference to the context of this migration, information will be given next to the micro-context in which Peruvians live as migrants in Chile, and to the various factors threatening their well being.

Migrants in Chile: far from Heaven

Economic migrants in Chile often feel forced to limit their personal expenditures severely in order to save remittance money from their very modest salaries⁽⁷⁾. They do so by devoting all their time and energy to work which has detrimental consequences for health. Migrants save money by living in crowded, unhealthy and insecure places. They are often exposed to street violence and fall prey to discrimination and insults. Burdened by economic problems and the emotional distress of having left their families behind, migrants experience loneliness and nostalgia.

Increased consumption of alcohol and unprotected sex are a common practice among migrants and are closely associated with their living circumstances, all of which adds extra risks to their mental and physical health. Illegal migrants avoid searching for medical care at public clinics out of fear of being reported to the immigration police. Even though it is not available in reality, their lack of papers puts a limit to their access to public care, restricting it to few primary care clinics. However, even if they have access to health care, migrants tend to postpone medical check-ups and medical treatment. Financial, practical and cultural barriers are particularly prevalent in mental and reproductive health issues, often preventing them from seeking professional medical care. In sum, to make their economic endeavours worthwhile, migrants often sacrifice their personal well-being by living in harmful conditions and by exposing themselves to various health risks.

Yet, an inside look into the life of Peruvian migrant's community in Santiago reveals the role of food as a cultural resource they make use of to face the adversity of their life in Chile. As it will be shown, the preparing and consumption of their traditional food helps migrants "to make a home away from home". Before delving into the uses and meanings embedded in food consumption; references to the community where these observations were carried out will be made next.

II. Talking, cooking and eating at home with the migrants

The migrants' shared housing unit

The migrants' shared housing unit was located on the second floor of building in Bandera street, downtown Santiago, only five blocks away from the *Plaza de Armas*, the main meeting place of the Peruvian migrant community in Santiago.

The building began to host migrants since 1998. However, in March of 2003, the authorities forced the building's owner to shut down the place due to the poor and unsafe conditions in which the building was kept. Although most of its permanent residents moved out to neighbouring houses they continued to live in similar conditions. Thus, the environment observed in the migrant housing unit, which is described hereafter, can be considered as representative of the conditions which migrants are often exposed to in Chile.

In total the shared housing unit had 20 rooms and the whole floor was inhabited by approximately 50 people — a number which increased on the weekends with temporary residents, friends and acquaintances who dropped by for a visit. By improvising beds or squeezing into the existing ones, residents hosted all those migrants who needed temporary shelter. This group came from the cities of Chimbote, Trujillo, Barranca and Lima, as did the majority of Peruvian migrants who have settled in Santiago.

The strategy of sharing a house and even sharing a room is common among migrants⁽⁸⁾, splitting the price of otherwise, unaffordable rents. In fact this type of housing arrangements is profitable to property owners, who often charge migrants high rents for poor housing in devalued buildings. This particular example of migrant housing is not an exception. In a space the size of a gymnasium, flimsy dividers made of triplex were used to create twenty small rooms. Two toilets, two showers that only provided cold water and two make-shift kitchen areas made up the shared facilities. However for migrants, the building's strategic location in the city centre compensated to some extent for its poor state.

In general, the housing area was kept in very bad and insecure conditions. Pipes were constantly leaking water, and electricity shortages were frequent due to the overloaded electrical system threatening the migrants' lives and damaging their appliances. This migrant housing area resembled a sort of small-scale shantytown, a kind of precarious neighbourhood hidden behind an anonymous door of a run down building in downtown Santiago. Although the building was in extremely poor condition, insecure and expensive⁽⁹⁾, it served as their temporary home. This was the ethnographic site chosen for my fieldwork, and this community the one with whom I shared the living space⁽¹⁰⁾.

The next section describes the events and relations that made up a substantial part of the collective life of this community.

A home away from home

The shared housing unit can be considered a home for this migrants' community. A physical and social space where cultural codes are shared, holding its members in a social and emotional web; a constructed *transnational* place. Its inhabitants had the experience of "being here and there" simultaneously and continually. It was there where migrants' cultural identity was produced and celebrated and migrants' well-being maintained through meaningful interactions and culturally distinctive practices.

In this place migrants lived, met, talked, rested, slept, ate, and exchanged information on jobs, bargains, and strategies for dealing with the foreign system. It functioned as a place where illegal migrants could hide from the police and feel secure. It was a place to listen to their favourite traditional music played loudly disrupting the sleep of more than one, and whenever possible to eat traditional food and reminisce about home.

It was a place to love and fight, to celebrate and mourn, to share worries and concerns, to complain about the hardship of their lives, to share joys and pains, to get and give advice, to tell stories from home and to gossip, to sell and buy, to borrow and lend goods and money to share resources and treatments, to face illness and to restore health.

It was there where migrants spent their most meaningful time away from Peru, because only another migrant could fully understand the sadness and loneliness of being away from home, especially during culturally important holidays such as Christmas and Mothers' day, as well as being absent on birthdays, deaths and/or sicknesses of beloved ones. It was there where the sadness and nostalgia of being away from home was futilely drawn in alcohol by men less often by women who would gather there to drink for an entire weekend, disrupting the precarious balance of the relations with their partners and neighbours.

At the core, migrants' housing temporarily suspended the oppressive relations that migrants were subjected to in the broader Chilean society, but certainly did not erase other conflictive and sometimes violence ridden relations among their members. In fact the housing unit was not free from robberies, nor from loud and violent quarrels among neighbours and couples. More than once the police had to be called upon to stop a violent incident.

In this place married women and men lived together (ambiguous at this point if they are married together or married to other people but living together), setting up temporary relationships to help each other cope with

the distance and unbearable loneliness of being away from their spouse and families. In living arrangements that may well coexist with an intended faithfulness and priority given to each one's *compromiso*⁽¹¹⁾ in Peru. In this new context the task of cooking tended to be initially assigned to women in line with the gender order of the traditional Peruvian patriarchal family. Furthermore, often relationships among migrants started up and consolidated through a woman cooking for a man. However, such arrangements soon changed as a result of women carrying out paid work, causing tensions regarding the traditional sexual division of labour and forcing men to also take part in the cooking.

As observed, a redistribution of the traditional gender order took place so that feeding each other among couples tended to be seen increasingly as a mutual obligation. In situations where food sharing was not based on family relations negotiations had to be carried out among men and women and the different resources and tasks involved (e.g shopping, cooking, washing up) were assigned independently of gender. Men eventually participated in cooking.

In sum, the transformation of the foreign world into their own Peruvian space took place in the shared housing unit being observed. Food was central among the different elements used by migrants to make of this inhospitable place a home⁽¹²⁾. Migrants gathered around food. They enjoyed the freedom to cook and eat in their own Peruvian way. By sharing food, migrants built and confirmed social relations. However, other social relations such as the traditional division of labour were transformed.

Food sharing made up a substantial part of the practices and rituals performed in the close community, corroborating their sense of belonging to a collective.

Food helped to create and enact the social world which supported migrants' well-being, resulting in the restoration of the ability of the community members to act outside in the foreign world. The ways in which food protected migrants' well being, will be explained in detail in the next section.

III. Food the material source to restore the body's balance.

Good food, bad food

In general, Peruvian migrants often complained about having to eat frozen food, or food that was cooked a long time ago and stored for days.

They complained that food consumption in Chile is restricted to indoor venues as opposed to street eating venues such as the street vendors so common in Peru which provide freshly cooked food. They also complained that Chilean people eat very little and rush through eating junk or tasteless and insipid food. The migrants felt that the seafood available for consumption in the Chilean markets is not fresh; for example, fish is frozen and transported to the city days after being caught. Rather than debating on the veracity of such statements, I would like to reflect on what seems to underlie migrants' opinions; ultimately it was the clash of ideas and principles of what is good and healthy food.

Let us analyse one central element: temperature. As it is possible to observe in the account above, temperature seems to be an important criterion applied to food and health by migrants. Along with it underlies a coherent conception of health. It is actually a vestige of the Hippocratic Medicine brought by the Spaniards to Latin America where some of its principles, such as temperature are still prevalent among the population. For example, a good meal should be one which is warm and recently cooked, and it should never be eaten the day after it was cooked, not only due to the loss of its nutritional qualities but also because it might harm one's health. Reheating food may cause it to ferment, a process that continues in people's stomach resulting in illness⁽¹³⁾. In addition a wrong combination of food's temperature in a meal may alter its quality. For example, according to popular perceptions, eating something too cold after having eaten something hot will have a negative effect on either the stomach or the throat. The qualities of being hot and cold are extended to physical processes (such as pregnancy or menstruation) and also to emotional states. For example, in the case of a nervous breakdown the body is considered to be in a hot state. During this episode, the body of person affected accumulates heat, heat that should be expelled. The person needs to *desfogar* or "let off steam" by throwing things around, breaking things, screaming or crying. After having calmed down, drinking cold water with lemon juice is advisable.

This happened to Olga, a forty two year old live-in domestic workers who spends every weekend with her relatives in their shared room at the migrants' house. Olga usually called home from a nearby call centre at Plaza de Armas, as she did that Saturday, when I was there. Having received the bad news that her mother was seriously sick in Peru, she began to tremble. Her sister and niece who were there with her brought her back to the room where she had a nervous attack. Olga was allowed to cry, soon after she was given lemon juice in cold water to drink. The treatment and support hel-

ped her to feel better. The choice of food given to Olga, in this case a cold liquid does not come arbitrarily. It is ruled by the temperature principles, present in physical process and emotional states. The body under a nervous attack produces heat and needs an intake of cold infusions to regain its balance. More examples can be given for food and drinks selection and the operation of such principles⁽¹⁴⁾. The importance of this is stressed in order to highlight the underlying logic which may lead to revealing the relationship between health and illness. Certainly migrant's food choices are indicative of a knowledge transmitted through generations and applied every time migrants recognize in each other the signs of sickness. If eaten in the traditional way, food has a healing effect when ill. Let us now move to some other food-related aspects.

Food as a symbolic source nurturing migrants' cultural identity

Talking about food

Even though the actual act of eating is central, talking about food seemed at times to be even more important to the migrants than what they actually ate or cooked. Furthermore, as observed, the ability to cook traditional Peruvian dishes was often limited by the availability and affordability of obtaining the necessary ingredients in Chile. However for migrants, eating "real Peruvian food" in Chile seems to be impossible; whenever they used similar Chilean ingredients as opposed to the authentic Peruvian ingredients, the migrants often commented that: "*Peruvian dishes cooked with Chilean ingredients never taste the same*".

As it was said, the importance of it became more evident to me while sharing the living space with the migrants. It was the length and frequency with which people engaged in food-related conversations and the vivid character of their descriptions which lead me to suspect that there was something else which was being talked about when conversing about food; something which transcended food but which is at the same time intimately linked to the migrants' bodies, self and identity.

It was interesting to note that while talking about Peruvian food, there was no internal clash; neither regional antagonism nor class or gender hierarchies; women and men participated equally in the discussion, as well as people from the sierra and from the coast. Each participant was free to add comments to the collective picture using their own culinary experience and subjective preference as well as memories of the meals, recipes or

fruits they used to eat and dishes they used to cook back home. Each element would be celebrated and included without opposition. It was as if each one was allowed to bring into this evocative scenario their regional specialities and these memories were taken with pleasure into each one's repertoire. In addition, accounts of the variety, size, colour, taste and nutritional value of the food produced in Peru were often presented as proof of the richness of their homeland: of the goodness of the Peruvian nature and abundance of its diverse landscape.

It seems that what migrants actually evoked through this collective remembrance is a primordial element of their cultural identity assembled in the palatable texture of their traditional food. As a result of this exercise it would nurture a positive relationship to their common native soil, as described in the next account; "*Vivir al lado del mar es mas sabroso...*" ("living near by the seaside is more delicious") were the lyrics sung by one of the migrants in between courses during a meal shared at the migrants housing, in remembrance of the delicious fish they used to eat in their coastal hometown in Peru. Migrants also commented that in Peru even with just a little money, a fresh, big fish can be purchased, "*the fish are so delicious, fresh... as if they just jumped out of the sea*".

In contrast, comments in regard to Chilean food lead inevitably to the undisputable conclusion of the superiority of the Peruvian food. The dynamics of the food related conversations reveals how feelings regarding their national identity are channelled. Conversations around food were frequently held while talking about Peru. Memories of Peruvian cuisine were connected with a feeling of nostalgia and longing for being back in Peru. Conversations about food always occurred while sharing a meal with the migrants.

This also happened while shopping for food products, when two or more people engaged in such activities. Whereas with me, a Chilean citizen, these conversations took on another fashion, they tended to be more descriptive of the size, colour, and taste of vegetables and fruit, and quality of the meat used in Peru since it was implicitly assumed that I was not familiar with it. In summary, among migrants themselves, these conversations were dominated by memories but with me or other non Peruvian people present they were descriptive emphasizing its characteristics.

In my opinion, such comparisons helped the migrants to reposition themselves in their unbalanced relation with their host country. The interpretation I propose here is that remembering, recalling and appraising Peruvian food and Peru's natural resources allows migrants to strengthen their common cultural identity and reconcile themselves with a country which

has been steadily "expelling their people" ⁽¹⁵⁾. By placing an emphasis on what the Peruvian natural environment gives them, Peruvian migrants acknowledge belonging to a country that despite its many problems (unemployment, corruption, political instability, and violence) remains faithful to its people and can provide for its population. As Demetrio, who used to be a fisherman in Chimbote often said: "*en Peru nadie se muere de hambre*" ("in Peru nobody dies of hunger"). In contrast, the harshness of Chilean society is expressed through the small size of the Chilean natural products and in its colourlessness and tastelessness food. Chile is seen a country which gives them jobs but does not feed them.

Concluding remarks

From the observations made within the shared housing unit it was possible to interpret that the migrants' collective life was structured around food. In this paper I explored whether activities such as conversing, cooking and eating can be seen as a means through which migrants communicate, confirm and ultimately take part in a shared national identity. This cluster of activities forms a material and symbolic source of resistance to the multiple forms of oppression Peruvian migrants experience in the Chilean society.

It was shown how by appraising their national food, migrants reconcile themselves with their home country which has, in some way, expelled them. In sum, it was shown how the cooking of traditional food is used by migrants to maintain their health and well-being. Furthermore, the practices underlying migrants' food choices display traces of a coherent conception of health and ways to treat illness. This stems from a more ancestral knowledge, nowadays labelled as a popular medical system. I asserted that far from been arbitrary, these principles are based in an intrinsic logic and comprise a cultural resource for this migrant community.

Food choices also reveal the extent to which, through this transnational migration, an extension of previous mobile livelihood practices in Peru can be seen (such as internal rural-urban migration). Ultimately, changes in food and eating patterns demonstrate whether migrants' acculturation into the more modern and westernised urban setting of Santiago is taking place. In addition, changes that result from migrant women engaging in the labour market trigger changes in the traditional sexual division of labour. As observed, migrant men are increasingly taking part in cooking. Such changes may also be reinforced by the less rigid gender order prevalent in the Chilean society.

As has been demonstrated, by examining practices and meanings around food it is possible to look at the connections between material culture, identity and health. Examining the conditions in which food is prepared provides an opportunity to look at the wider political and social context in which the subjects are positioned. As shown, where migrants' identity and well-being is threatened, having control of the conditions in which food is cooked turns out to be of a vital importance. This reveals a broader role of food preparation and consumption regarding self-determination. Such control allows migrants to use food as a means to achieve cultural cohesion and to maintain their psychological and physical welfare.

Notes

- ⁽¹⁾ DÖRING T.- HEIDE M.- MUHLEISEN S. (eds) (2003).
- ⁽²⁾ Such groups are included Chinese, European, African and Japanese immigrants.
- ⁽³⁾ Certainly, the selection of ingredients, its combinations and the cooking techniques are all codes containing traces of the paths followed by people in their previous journeys as well as those of their past generations. The ingredients currently used by Peruvian migrants in cooking are reminiscent of the cooking traditions from the sierra (such as the use of maize, yucca and potatoes), as well as of the coastal areas evident in the abundant use of fish and seafood. It is also very common to use the animal viscera as well as parts of the animals discarded by Chileans such as fish heads, particularly due to its cheap price. This seems to be a tradition inherited from slavery; since slaves were forced to develop tasteful meals out of animal leftovers discarded by their masters.
- ⁽⁴⁾ For a comprehensive review see COUNIHAN C.-VAN ESTERIK P. (1997)
- ⁽⁵⁾ The recognition of their professional titles in Chile was possible due to existing bilateral agreements subscribed to by the governments during the past century. According to recent statistics from the Ministry of Health, more than 50% of the professional personnel working in the Public Primary Health Care Sector (medical doctors, nurses and midwives) are of foreign stock from other Latin American countries.
- ⁽⁶⁾ The Chilean northern cities of Arica and Antofagasta were once Peruvian and Bolivian territories respectively. Controversies around this issue continues until today troubling the countries relations
- ⁽⁷⁾ Remittance money needs to be successively changed from Chilean pesos (CHP) into US dollars (US\$) and from US dollars to Peruvian soles, paying taxes and commissions with each transaction. The size of migrants' remittances depends heavily on the exchange rate. While the value of the US dollar has been steadily increasing, salaries in Chile have remained stable (minimum wage in Chile is CHP 110.000 pesos = US\$146 dollars-a-month, the exchange rate at the time was of 755 CHP per 1 US\$). For migrants, the monetary value of the salary earned in Chile is decreasing. Good times are gone, as migrants often say. In the past migrants enjoyed better salaries in the Chilean labour market and a more favourable exchange rates between the Chilean peso and the US dollar (for example in 1997 when the exchange rate was 500 CHP per 1 US\$).
- ⁽⁸⁾ Living in overcrowded accommodation of devaluated building seems to be common among migrants in different context, as described for the case of Senegalese migrants in Italy (RICCIO B. 2002).
- ⁽⁹⁾ A monthly rent for a room not bigger than 18 square meters was approximately US 65 dollars, and approximately US 45 dollars for a smaller room of 12 mts². Electricity and water were paid separately.

⁽¹⁰⁾ I rented a room in the house and lived there several days a week over a period of four months (September to December of the year 2002). Doing participatory observation meant joining migrants' normal activities and routines e.g. shopping, cooking, eating meals there, going out dancing, as well as more meaningful ones such as calling home. Migrants were aware of my identity and goals and had agreed on my presence among them

⁽¹¹⁾ Term used to refer to the socially recognized and accepted marriage, irrespective of its legal status.

⁽¹²⁾ Music was also a central element.

⁽¹³⁾ As I observed, no matter how little money migrants had or how uncertain they were about their next day's meal they never kept food leftovers to be eaten the next day. Leftover were always thrown away.

⁽¹⁴⁾ In several cases identified among the migrants community temperature principles rules what should be eaten, and done or not done to maintain health and prevent illness, and are carefully applied. As said, they are based on the Hippocratic category of the different humors and temperatures present in the human body. E.g. being in a warm environment and moving too rapidly to a cold one may harm people's health, causing facial paralysis. Postpartum is a "hot" and particularly sensitive state. It is specially during the 20 days after giving birth that women should restrain from drinking and touching cold water or from exposing themselves to cold temperature, or they run the risk to get the culturally bound syndrome called "sobrepardo", which results when the cold temperature reaches the womb.

⁽¹⁵⁾ It is estimated that more than 2 and half million of people make up the so called "Peruvian Diaspora". Along the last two decades, Peruvian citizens have been steadily leaving Peru, migrating to various countries in Europe, USA and Japan. In Latin America Peruvian migrants have mostly migrated to countries such as Argentina, and Venezuela and only lately to Chile.

Bibliography

ARAÚJO Kathy - LEGUA Maria Claudia - OSSANDON Loreto (2002), *Migrantes andinas en Chile: el caso de la migración peruana*, Fundación Instituto de la Mujer, Santiago de Chile.

COUNIHAN Carole - VAN ESTERIK Penny (1997), *Food and Culture. A Reader*, Routledge, New York - London.

CSORDAS Thomas (1994), *Embodiment and Experience. The existential ground of culture and self*, Cambridge University Press, Cambridge.

DORING Tobias - HEIDE Markus - MUHLEISEN Susanne (eds.) (2003), *Eating Culture. The Poetics and Politics of Food*, "American Studies" (A Monograph Series), vol. 106, 2003.

LIN PANG Ching (2003), *Beyond' Authenticity': Reinterpreting Chinese Immigrant Food in Belgium*, in DORING Tobias - HEIDE Markus - MUHLEISEN Susanne (eds.), *Eating Culture. The Poetics and Politics of Food*, "American Studies" (A Monograph Series), vol. 106, 2003.

RICCIO Bruno (2002), *Toubab and Vu Cumpra. Italian perceptions of Senegalese transmigrants and the Senegalese Afro-Muslim critique of Italian society*, pp. 175-196, in GRILLO Ralph - PRATT Jeff (eds.), *The Politics of Recognizing Difference. Multiculturalism Italian-style*, Ashgate Publishing Limited, Aldershot (UK).



2.7 Social representations of the hiv-aids complex amongst Spanish gypsies

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The Spanish Gipsy Community

When we talk about the Gipsy community, we are referring to a large group – the number of Spanish Gypsies varies significantly according to the different authors, ranging from between 800,000 people to over 1,000,000 – that doubtless forms the oldest and first historically recognized ethnic minority in Spain. In order to understand and explain why Spanish Gypsies today occupy a culturally, economically and politically subordinate position in the Spanish state, the contextual references, in historical, political and economic terms cannot be avoided. This subordinate position, in turn, conditions their perceptions and practices regarding health and illness, as well as HIV-AIDS, as will be seen throughout the present article (*).

The first historical references to Gypsies go back to the 15th century, the time at which information is recorded about the arrival of small groups of nomad Gypsies to our country, as also occurred in other European countries. The writings which analyze this historical period and successive ones (SÁNCHEZ ORTEGA M. H. 1986, SAN ROMAN T. 1986) explain in a precise manner the different ways in which the Spanish dominant culture has situated the Gipsy minority on the outskirts of main society⁽¹⁾. In these works it can be observed, throughout five centuries of Spanish Gypsies and Payos⁽²⁾ living together, how a whole set of conflictive relationships developed, marked by a deep inequality between the majority and the ethnic minority. Although summarizing large historical periods in a few lines inevitably implies a large degree of simplification, it can be said that Spanish Gypsies have been submitted to two contradictory tendencies during their presence in this country, tendencies which both have in common the incapacity of the main society to understand the importance of their integration as full-right citizens, without this necessarily implying their assimilation. These two tendencies can be observed on the political level through the different

polities that the Spanish monarchs dictated concerning the Gypsies (SÁNCHEZ ORTEGA M. H. 1986).

On the one hand, during the periods of expansion of the Spanish economy, the integration of the Gypsies is firmly asked for, as long as they abandon the distinctive elements of their identity, which are not only cultural (dress, language) but also constitute their most traditional ways of life (nomadism, specific professional activities). During these periods, it can be glimpsed how the State attempts to constitute not only a controllable citizenship (which explains the insistence that they abandon their nomadic way of life), but also a culturally homogeneous one. In those times many Gypsies did integrate, although the stereotype was already firmly established, and in spite of many laws that favored their settlement, for example in rural areas, they met strong opposition on behalf of the Payos. It must be underlined that in these integration movements Gypsies were only allowed to occupy the lowest positions in the social scale. Nevertheless, during these periods many Gypsies fully incorporated the mainstream social life, although in most cases by finding specific economic niches; they were situated in the social margins, but were allowed a certain autonomy and control over their survival.

On the other hand, during the periods of economic depression, the Gypsies were expelled out of these margins, which were occupied by the lowest social class of the Payo society (SAN ROMÁN T. 1986); their level of survival fell, and it became necessary for them to search for new niches in the social margins. The great impact that the industrialization processes in Spain exerted on the Gypsies must also be highlighted, since they led to the disappearance of practically all their traditional trades. Due to all this, it can be sustained that the Gypsy group is a subordinate one, submitted in a dominant way to the hegemonic society, which owns the capacity to situate it through its own history and according to its own processes of development; in this case, ethnicity is the criterion which defines the subaltern position. Through these processes, and like any subordinate group, the Spanish Gypsy community developed specific resistance mechanisms, which although they did not lead to a change in their position inside the network of unequal relationships, at least enabled them to survive for 500 years, with more or less good fortune. I believe that some of the most defining characteristics of the Gypsy culture – family relationships, speed, intra-family solidarity, sharpness, etc. – are part of this resistance culture.

At the present time, the Spanish Gypsy community is characterized by its almost total sedentarism, by its internal diversity (geographical but mainly in terms of social structure), and for maintaining some of the traits that

best served it, through the centuries, for its social reproduction. Among them, the kinship organization – based on patrilineal lineages, territorially dispersed and spatially organized in big family groups, a great importance being given to matrimonial alliances that increase the power of the lineages⁽³⁾ – has played and is still playing an essential role as a survival mechanism. It is this large kinship group, living together in a close geographical area, which, from my point of view, constitutes a sort of Gypsy “survival mattress”. It represents an important point of support in difficult circumstances and can be mobilized for help when one of its members is in a hard situation. This aspect is particularly relevant, as shall be seen hereafter, when health and illness problems are at stake. The organization around age and gender, as principles which articulate positions of authority and “respect”, also make up the characteristics of “being Gypsy”, without, of course, constituting an exclusive trait of this group. In particular, the marked androcentrism of the Gypsy gender relationships is not so distant from the androcentrism that prevails in the Payo gender relationships.

In nearly all investigations about Spanish Gypsies, the necessity to recall that this community shows, at the present time, a great internal differentiation is underlined. In our investigation work, we found that the vectors which best describe this intra-ethnic diversity are differentiation by social stratum, and by geographical area (Castilian Gypsies, Andalusian, Galician Gypsies, etc.), with the difference that when we talk about the Gypsy community, the social strata cannot be compared to those that exist in the Payo community. What we call Gypsy high class (these persons, still few in number, who in the last generation have had access to university studies, because their parents’ generation had been able to obtain a stable employment paid according to Payo standards) would correspond to the Payo middle class, and so on for the other classes. This means that when we are talking about Gypsies it is necessary to go down one level in the general social stratification, this situation being the result, as I have mentioned, of the unequal historical relationships between the majority and the Gypsy minority. The Gypsy middle and low classes – to which the great majority of Gypsy families belong – are separated by a very thin line, which is easily crossed because of the economic ups and downs I have previously mentioned. Families, which in a situation of economic stability have a medium level of living with professional activities such as sales in markets, work in construction, or agricultural labor, may rapidly fall into the deepest marginality in a moment of general economic recession. Equally, it is in these moments that family support and help mechanisms are activated, as well as a possible professional diversification of the group. To this regard, and

although it is not the object of the present article, it is interesting to point out that the traditional social stratification by classes is made more complex when it meets the existence of unequal ethnical differences, as in the case studied here.

As for the geographical setting of Gypsies, it is important for two aspects. The first one has to do with the auto-identification of subgroups that the Gypsies themselves establish, these sub-groups being endowed with specific characteristics of an identitary type (Andalusian Gypsies are..., Castilians do not...), which in most cases refer to behaviors considered as distant or close to the ideal "being Gypsy". And the second aspect is directly related to the higher or lower possibility of integration of the Gypsies into the main society, and thus to a stronger or weaker stigmatization process. For instance, it is easier to be an Andalusian Gypsy than a Galician Gypsy, since some defining elements of the Andalusian culture are permeated with Gypsy elements. When analyzing an identitarian process, dialectical relationships between majority and minority cultures have to be taken into account. Hence, considering that a geographically defined Gypsy sub-group possesses more Gypsy characteristics (meaning a higher observance of Gypsy traditions, and thus a higher conservatism), we must take into consideration the fact that possibly the Payo society with which the group is living also presents a higher conservatism. For example, it is not only that Castilian Gypsies are more conservative, but also that the Castilian society is more conservative in general.

Social and health conditions

We do not have much bibliography at our disposal about the specific health problems that affect the Spanish Gypsy population, although there are writings that inform us about living conditions of the majority of Gypsies⁽⁴⁾. The theoretical perspective adopted in this investigation connects health and illness problems to the historically constituted forms of social reproduction. In other words, this perspective characterizes health-illness-care processes as fundamentally *social* ones, as it considers that inequalities and differences in health aspects cannot be explained in a detailed way without relating them to the social inequalities and differences built up through long historical processes. This vision is quite distant from the dominant biomedical perspective, which by linking illness to a momentary situation in a personal life, prevents from showing the coherence, links and continuities between the subject who suffers an illness as a social subject and the

social surrounding, and thus a pathogenic evolution that, beyond the solely personal dimension, may be understood as a social one. The case studied here is very pertinent, since the Gipsy ethnic minority has suffered such a long process of social exclusion, and there is no doubt that the analysis of health and illness processes in this community may present a high explanatory capacity that reflects social inequalities.

It is therefore not surprising – as it is indicated in some writings – that the Gipsy population should have a lower life expectancy than the Payo one, and not only in absolute terms, but also in relative terms by social stratum; or that the ageing process should be more premature in the Gipsy population, and the vital time sequence should be adapted to this fact, so that consequently Gipsy ages are defined by other parameters than the Payo ones – a Gipsy is adult at 18 and old at 45. Nor is it surprising that, given the living conditions in shantytowns – where a great number of Gypsies have lived and are still living – infectious diseases should be a daily problem. These facts are the mere result of exclusion and marginalisation, and therefore need, in order to be eradicated, something more than changes in the individual health behaviors and practices, although these are also necessary in many cases. The data presented here tends to show that illness, in the Gipsy case, owes much of its specificity to the condition of poorness that accompanies most Gypsies throughout their lives, which therefore implies that a “radical prevention”⁽⁵⁾ would require the elimination of the poorness and inequality of conditions in which the daily life of an important sector of the Gipsy community takes place. It has been pointed out very often that the strife for decent housing – for Gypsies, although not only for them – and for a job that may enable integration, without assimilation, is a question of personal and collective dignity. I want to add, furthermore, that it is a question of health.

Hiv-Aids and the Gipsy community

It is useful at this step to indicate briefly why a research study on Gypsies and Hiv-Aids was undertaken. In the first place, and taking into account the strong connotation of Aids as a disease laden with symbolic meaning and social prejudice against its carriers⁽⁶⁾, it is necessary to recall that *Aids is not a Gipsy disease, although some Gypsies are infected by this virus*. The epidemiological pattern of Aids among the Gipsy population follows the same parameters as in the Payo population: the great majority of persons were infected through the sharing of needles in the context of parenteral drug

use. This Spanish epidemiological pattern is quite different from the ones that prevail in other occidental and African countries.

Therefore, as some Gypsies fell into drug use, especially those in a situation of strong marginality and social exclusion, and shared needles in their drug use practices, they were affected by the AIDS virus, and much more in the past years than at present. Indeed, as shall be seen thereafter, the large number of deaths and the harm reduction programs reduced little by little the impact of AIDS through this contagion route, among Gypsies as well as among Payos. The main objective of our research, launched at the request of *Secretariado General Gitano*, was to obtain a knowledge of the representations that the Gypsy community holds about AIDS and to explain them, and also to find out if certain characteristics of the Gypsy community could help, or on the contrary could impede, an adequate prevention regarding this disease. It is therefore a theoretical project, but one which also implies a practical engagement towards a better prevention of AIDS in Spain⁽⁷⁾.

Representations of the HIV-AIDS complex

As E. Menéndez and T. Seppilli, among others, have shown in many occasions, health-disease-care processes constitute consistent – but not closed – complexes, which articulate knowledge, representations and practices that enable social subjects and/or groups to face and fight suffering. In this way, specific conceptions about the etiology of a disease conform certain practices concerning care and treatment. These practices are consistent, although not exclusive, in the sense that several medical systems can be activated in order to explain a disease as well as for attention and treatment, according to the opportunities and/or possibilities available for the person, as a social subject, to get access to knowledge and to institutional or non institutional systems of prevention and treatment.

From this point of view, my interest was mainly to understand, and if possible to explain, the common and different aspects of the Spanish Gypsies' knowledge of the HIV-AIDS complex, constantly considering that this knowledge has to be related to the images and projections about HIV-AIDS that developed in the *Payo* society, since the social formulation of HIV-AIDS stems from the majority's hegemony and especially from that of the bio-medical sector.

The problem is therefore to explain, on one hand, the intra-ethnic variations and constancies, and on the other hand their links with the general representations of HIV-AIDS⁽⁸⁾.

Definitions of HIV-AIDS

Definitions of HIV-AIDS can be grouped in three descriptive forms, which constitute three main conceptions of the complex that are rather quite different.

In the first definition, we find a medicalized discourse, and a concrete reference is made to a disease underlined as *infectious and contagious*, transmitted by a *virus*. Mention is made of *antibodies*, different phases are distinguished, the difference between being sero-positive – having antibodies – and having declared AIDS is known, and references are made to the existence or non existence of defenses, as well as to the idea of opportunistic diseases in the declared AIDS syndrome. The following sentences could summarize this conception:

“Well, AIDS goes by phases, the first, second, third and fourth or terminal phase. When I found out, it was already too late (her husband who died of AIDS) was practically already in the fourth, terminal phase. You can have the virus in your blood. When you catch the virus, you have it, and then the different phases develop, and you can catch certain infectious diseases. This is when you’re already in the disease’s phases, because if you’ve only got the virus they can give you a treatment and this can check it. Then when the bug spreads, this doesn’t mean you’re going to die, because if you don’t catch any infection you don’t die. I don’t think anybody really dies of AIDS, it’s because of the infections that it brings, in the lungs, tuberculosis, in the kidneys. AIDS infects you but you can still live with a person who is a carrier of AIDS, and if you treat him on time it can be stopped. I know of a case in ..., who since this person was going to pass away, you can’t imagine how many died in the meanwhile, and this person is well, in the fourth phase. This person doesn’t smoke, nor drink, nor use drugs, and is on Retrovir... Cancer is death although it’s not contagious. AIDS is more dangerous because you can pass it on to people, but you die before with cancer. Cancer is more efficient for death” (Middle-class woman, husband died of AIDS).

“Hiv, well to my daughter they could have changed her blood and she would have been a normal kid, a healthy girl. But when she was four they found out she had positive antigens, that’s AIDS already. With AIDS you catch other diseases, for example my daughter has funguses in the mouth or in the gullet, they call them candidiasis. It grows into your mouth and prevents you from eating, or swallowing, but this all comes from AIDS. AIDS can be solved if you live a normal life and take your medicine. Within a few years it will be like any chronic disease. The doctors told me, it’s going to be like as if you had a chronic hepatitis or chronic asthma. It’ll be like any other disease.” (Low-class woman, sero-positive, infected by drug using husband, daughter with AIDS).

“Well I’ve had antibodies for 16 years, I’m sero-positive and my level of defenses is 651, my viral charge is undetectable. At the beginning I thought that antibodies and AIDS were the same thing. I mean, you said “AIDS” and you were going to die. Now I know that the antibodies are there, they’re blocked and I’ve been like this for 16 years. The antibodies, I’m in the A2

stage. Sero-positive persons are sero-positive, but in the terminal phase you have A, B, C, and then A1, 2, 3, 4 and the same for B. But in the C4 phase there's no... it's the worse, the terminal phase, maybe you've got two days left or a week at the most. I'm in the A2 stage, although my pancreas is bad." (Low-class man, sero-positive, ex drug user).

As can be deduced from the previous statements, in this conception not only the bio-medical definition of the disease has been assumed in a rather precise manner, but also its development, the distinction between being sero-positive and AIDS, the existence of opportunistic diseases related to AIDS, and which are those that kill, the possibility of a normalized life with others, the existence of antiretroviral treatments that turn the infection chronic, and the necessity to maintain healthy practices in everyday life. The image of AIDS as death is thus broken. But above all, HIV-AIDS is considered an infectious disease, for which attention and care is required, as in practically any other disease. And mainly, all types of social metaphors are avoided.

The persons who have this type of conception, of which the previous discourses are examples that appear recurrently, present the following characteristics. In the case of women, and independent of the social strata they belong to, the terminological precision regarding the infection is determined by their role as direct caretakers. Even in the case of the sero-positive woman, all the statements about HIV-AIDS are made concerning her daughter's disease. This example is very significant, because in her relationship with AIDS the woman refers to herself solely as her daughter's caretaker, and only talks about her personal situation (being sero-positive) to underline that she can't think too much about it nor worry too much because this would prevent her from taking good care of her child.

In the case of women, therefore, whether they belong to the middle or to the low class, it is the personalized care of a person with AIDS – as a wife, a mother, an aunt, or a sister – which determines the important competence they acquire regarding knowledge about the disease. This situation seems logical, if we consider on the other hand that as caretakers, they are the ones that have had most direct contacts with the doctors who attended or are attending their family members. In this case, the possible lack of economic and/or cultural capital is compensated for by the specialization that their social role leads to (social capital).

In the case of men the situation is somewhat different. The specialization in medical language stems from the personal and individualized experience of the disease. It is when they find out they are AIDS carriers or patients that they acquire knowledge about the infection. But it must be un-

derlined, as it will be shown later, that in most cases, men, moreover, mention the loss of prestige and the social consequences of being an HIV carrier. For the infected male Gypsy, the disease, although it is described in medical terms, is very directly related to its social consequences. The centrality of the man in an androcentric system explains on one hand the possibility of feeling that one is the individual subject of the disease, which thus needs care (that others will provide), phenomenon that does not occur with women. And on the other hand it also explains that the man should feel he is the main subject affected by the social consequences associated with the disease – for instance he shall not easily establish contacts for matrimonial alliances for his sons and/or daughters, or in case he's a bachelor, he will not be able to get married. This situation is one that favors the *concealment* of the disease, in the case of sero-positive men.

The second main conception of HIV-AIDS still considers it as an infectious and contagious disease, but the specialized knowledge is blurred and some metaphors begin to appear when describing it. The term virus is not used but is replaced by the word *bug*, the different phases of the disease are not distinguished unless in a metaphoric way, and a popular discourse, related to the theory of internal consumption and of germs, is superimposed upon the medicalized narrative about AIDS. This can be observed in the following statements:

"AIDS is a bug... for instance you have the bug, you inject first..., and then the one that injects after you catches AIDS ... or antibodies... or the virus or whatever it may be. You know this is *death*. You know it's *something that's going to kill you* little by little, with time it's going to eat you up." (Low-class man, closeness to AIDS through sero-positive prison mates).

"The thing is that the bug *eats you up* little by little... you have it inside your body and gradually it consumes your blood until time passes... and if you don't take your medicine you die quick." (Low-class man, brother died of AIDS).

"They say *he has something bad, or the bug, he has the bug*. But you don't call this disease AIDS. It's the bug that gets inside and starts eating you up from inside... that's how they told us in the class we took... and those who already have the bug, well they end up like skeletons. I saw it in a movie... it's sad to see them." (Middle-class woman, no nearness to HIV-AIDS).

In this conception, the association of AIDS with death is clearer; it is something that will come sooner or later, and can only be delayed. The skeleton and the internal consumption metaphors are very important. The logic established between the cause (the bug) and its action is very obvious: if you have a bug inside, this bug eats you up from inside and the result becomes visible on the outside. Among men, it must be underlined how

they put an emphasis on the slowness of the process, as an element of cruelty added to the consumption process. In this conception, no difference is established between sero-positivity and AIDS. It is all part of an undetermined set, although there are still some references to a pathogenic agent, the bug. AIDS is considered as a disease where the bug enters from outside, contrary to others for which a bug is also mentioned – mainly cancer. You ask for it, and hence you could avoid it. The blaming of the subject for having certain behaviors is implicit in this conception. But nevertheless there is still place for a certain distinction concerning the routes of contagion: by injection, by sexual intercourse.

Those who sustain this type of conception are: middle and low class women with infected distant family members and/or neighbors, who thus have never been thrust in the situation of the direct caretaker, but still have references of not too distant personal contacts; or women whose knowledge about HIV-AIDS comes from attending short classes where they were told about the disease, or from the information they got from the media, that exert an impact that must be taken into consideration. In these cases, it can be seen that although a more official and medicalized language is used – “they told us”, “they said”, “we saw a movie” – this language is adapted and mixed with terms that are closer to their own socio-cultural conceptions. In many cases these terms are associated with the germ theory – the word germ is sometimes used instead of virus or bug – and this is important because of its link with ideas concerning forms of contagion and preventive measures necessary to avoid infection.

Low and middle class men who are in a situation of direct closeness with infected persons – close family members, cell mates – but who themselves are not infected, are those who hold this type of conception most often. This situation would correspond to that of the care-taking women in the first category, but in this case, and due to the differences in social roles – they are not direct caretakers – and although they may have very close relationships that are affected, their discourse is an intermediate one between popular socio-cultural forms and bio-medical knowledge. In the case of these men, closeness gives a more precise shade to knowledge but does not generate a true specialized one. In the same way, among women, routes of contagion and preventive measures are tied in a conception marked by the idea of diffuse contagion – by air, through the mouth, by injection, through sexual intercourse but without specifying more details, etc. – in which medically proved routes of contagion for HIV-AIDS are mixed with other ideas that belong to popular culture, and not only to the Gipsy one. We must keep in mind that *in this conception, as well as in the other two, and*

given the androcentric orientation of the Gypsy culture, men of all socio-economic strata only consider themselves as subjects who can be infected and never as possible contaminating subjects. And this is very important because it constitutes the basis of the prevention measures they take, especially regarding sexual relationships: they may use a condom in sexual intercourse with unknown women, so as not to be infected, but do not use it with their own wife because they are sure they will not be infected by her.

The third main conception of HIV-AIDS is one that directly relates the disease to social aspects. In this conception, the characteristics of the disease as infectious and contagious are diluted, and all the language refers to social relationships, to risk groups, and finally to everything that condensates evil, in terms of social evil. Knowledge is articulated by attitudes of moral valuation of the disease and the discourse is built on total and absolute externality: AIDS is the disease of others, of “bad” others, not as sick persons but as representatives of a “bad life”. This is how it is told:

“Wow, how scary! This is the worse there is. People know, I mean, if you catch this you die, it’s the *drug addicts’* disease, druggies have it because they shoot up, of course, they shoot up and they catch AIDS”. (Middle class woman, no contact with HIV-AIDS or drugs).

“Then there was this other case of a boy who died of AIDS also, and you know, people knew, because this boy was a drug addict, his father is too, *they’re not well accepted*, and the brother’s also a drug addict and now he has AIDS, and the wife also, she’s on drugs, *she’s Payo*”. (Middle class woman, no contact with HIV-AIDS, brother with past contact with drugs and now in the cult).

“AIDS is like a *punishment for doing what shouldn’t be done*. It isn’t spoken; nobody talks about it. It’s what happens to drug addicts, I think, or to people who’ve been with a drug addict. What I do know is that it can’t be cured. I don’t have anything, I’m touching wood, thank God”. (Middle class woman, no contact with HIV-AIDS).

“Here, among us, it spread very little, I don’t know, it’s as if it doesn’t exist among us. *AIDS among Gypsies sounds weird, it sounds ugly, it sounds like... how should I put it? Disgusting, it’s a bit strong to say a thing like that*. It sounds bad – when the interviewer asks for a comparison with cancer – both are bad, because both mean death, but cancer would be better than AIDS ... from cancer you also die but there’s not contagion, which is a *shame*. It’s a shame because it means you’ve been on drugs or with women. But *cancer is a disease*, and it just comes because it comes. I prefer dying from cancer than from AIDS” (Middle class man, bachelor, distance from HIV- AIDS and drugs).

“The diseases that worry me most are cancer and AIDS, because you die and because they affect more people. I’m personally more worried about AIDS than about cancer, it frightens me more, because it destroys you in an *uglier way*, if you catch it it’s not because of... it’s because of *bad things, like drugs, or,*

well, sex too. I think it has more to do with people who go to funny places." (Middle class man, bachelor, distance from HIV-AIDS and drugs).

"Yes, people are frightened about AIDS, but the thing is that since *we're not druggies* and nor do we... this disease, the people that have it are *homosexuals*, and since we don't have them here, it's something that's not going to affect us. I'm not a druggie, my kids aren't druggies, and we're not fags either, then this disease isn't going to affect us". (Middle class man, married, distance from HIV-AIDS and drugs).

Persons with this third type of conception are mainly middle class men and women, with a marked distance from actual cases of HIV-AIDS, and also distant from cases of drug use; hence they reproduce the most socialized discourse on AIDS: the one that was built with the first medical accounts, in which it was related to specific risk groups, drug users, homosexuals, and promiscuous persons, and which at the time normalized HIV-AIDS by linking the disease with socially rejected groups. In this sense it represents the discourse of normality – of Gipsy as much as Payo normality. This conception enables them to make a moral valuation of other people's life; those who move around weird places, who have a different sexual life, and especially those who are blemished by a thing like drugs. Slight differences are not admitted for these men and women, and it is not actual subjects they consider guilty, but whole sub-groups. Routes of contagion are those that have to do with life styles that are morally valuated as negative. Because of this, it is a dangerous conception, since it prevents making risk practices visible in a non-moral way. The pathogenic agent of HIV-AIDS is "bad life", which is always other people's life: druggies, bums, fags. We are often told that AIDS is a "punishment", which implies that it is just, as a "purgatory" for a "bad life". This is why, for people with this conception, images of surprise appear when cases of sero-positive or AIDS-affected persons' wives are mentioned: they are innocent and unexplainable victims.

This conception is held, as in the case of the Payo majority, by social groups that are in a position of dominant centrality within the Gipsy group. It therefore bathes the images of all sub-groups. It isn't spoken of it bringing "shame", because it is related to social evil, to the most condemnable forms of life from the viewpoint of social normality. Thus when it is talked about, it serves to express fear in a rhetorical way, although the subject rapidly moves this fear aside by affirming that he himself cannot get infected. Since AIDS is built upon externality with regards to oneself or to one's near relations, it reaffirms one's own moral quality. It enables one to draw a line between oneself and other non-normalized forms of life. But because this sub-group is the one that builds Gipsy normality, it is in this

case that AIDS is most often linked to Payo life. It is the same discourse as the one held by the majority society, except that it works the other way around. If in one case the correlation Gipsy / drugs / AIDS is established, in the other case the correlation is Payo /moral degradation: homosexuals, prostitutes / AIDS. Unfortunately, this stereotyped conception, on both sides, is the one that dominates and that we should try to change, underlying once more that HIV-AIDS is only an infectious and contagious disease.

Among the mediators, the elite, and the Payo professionals who work with Gypsies, an interesting situation arises, which shows their liminal position between two worlds. They know the main aspects of the HIV-AIDS complex, this knowledge being acquired through the training they received, through their own economic, social or cultural capital, or through specialized professional knowledge. In all of these three cases, the most medicalized discourse on AIDS is efficiently used. Nevertheless, afterwards, Gypsies are talked of as others, distant and strange. They are all attributed the most socialized conception on AIDS, the third conception: "they don't talk, they don't know, they hide it", without trying to understand the differences and the internal logics of the variations. They reproduce, in a certain way, the stereotype of main society. But mostly, and more important, they incorporate in their own conception some images of this third set of representations about HIV-AIDS in a non conscious manner, and in this sense they end up associating traditional Gipsy prevention practices – all the set of practices concerned with avoiding infectious and contagious diseases – with forms of ignorance and lack of knowledge, and therefore spend much of their efforts in trying to destroy them.

Finally, many Gipsy men and women indicate the existence of suburban ghettos as the main cause of the group's lack of protection in the face of diseases and AIDS, establishing a direct link between forms of social reproduction of inequalities with health and disease processes in general, and with HIV-AIDS in particular. From this Gipsy viewpoint, which is also our theoretical and methodological starting point, the emphasis is set upon structural conditions as the main risk factor for HIV-AIDS. It is underlined that these structural conditions foreshadow and conform certain life styles in which individual practices acquire their meaning, and therefore cannot be studied separately. If we consider the development of the HIV-AIDS pandemic in the world from a historical perspective, with its conversion into a chronic disease and a clear epidemiological decrease in occidental countries, when at the same time it shows a brutal increase with a very high

probability of death in poor countries, we can only conclude, as many Gipsy women and men indicate, that *poverty and pauperization constitute one of the main contagion agents of HIV-AIDS*. This last point of view agrees with the *emic* and the *etic* perspectives.

Conclusion

Although the Gipsy community has these different representations about the main routes of HIV-AIDS contagion, its members apply a whole series of preventive measures, when they are close to an infected person or an AIDS patient, that refer to the existence of the idea of diffuse contagion, related to the popular practices aimed at avoiding infections by germs. Indeed, in presence of an AIDS patient, the near kin uses all the prevention practices that are part of the popular and scientific culture regarding infectious and contagious diseases, which is in fact the characteristic of some of the opportunistic diseases of AIDS. When the ill member of the family lives in the home, the objects he uses for eating and for hygiene are set apart, and cleaned separately; moreover, visits are avoided, especially of children, and when the patient is already in a phase of declared AIDS. The patients do not consider these measures as humiliating, and in many cases they themselves apply these measures so as to protect their family. On the contrary, the loss of respect and social position brought about by the knowledge that someone has AIDS is underlined by Gipsy men as the main source of suffering. Social isolation is directly related to the domination of the most socialized conception of HIV-AIDS, in which contagion is associated with socially "reprobated" forms of life, and which imposes a set of practices that, instead of being really efficient in terms of prevention, constitute moral practices of conformation of a determined normality in which AIDS patients cannot be integrated.

This paper has had as its goal to show the variety within the gipsy Spanish community, and in conjunction with this, the several representations of one complex problem like the HIV-AIDS inside this community, all of which try to break the most common stereotypes about the uniqueness of the "gipsy world".

Notes

(*) The material presented here is the result of a research led by a team of investigators formed by Rosario Otegui, Amelia Sáiz, Arancha Meñaca, F. García Selgas and Antonio A. García. This research was made possible thanks to the support of the Fundación para la Investigación del Sida en España (FIPSE), which financed the field work carried out during the year 2001.

(1) For those who are discovering the Gypsy world, the historical works by M. Helena SÁNCHEZ ORTEGA (1977, 1986) are absolutely essential; this author reconstituted very carefully and in a most detailed manner the complexity of inter-ethnic relationships in Spain and the different periods where it can systematically be observed how the government polities have situated the Gypsies in social exclusion, even in the cases where shy openings enabled brief periods of integration. A. GÓMEZ ALFARO (1999) also provides interesting documentation about the advantages and drawbacks of the deportations to America in the 18th century. On the other hand, Teresa SAN ROMÁN (1976, 1986, 1990, 1994) is without any doubt the social scientist that has best studied Spanish Gypsies, allying in her works the details of ethnographic descriptions with a theoretic reflection about the complexity of inter-ethnic relationships that are bathed in inequality, as in the case referred to here. In her different works, which cover more than twenty years of Spanish Gypsy history, it can be observed how the changes in the main society have enabled, or on the contrary hindered, the integration of Gypsies as full-right citizens. Nevertheless, as she explains, the second class citizenship granted to the Gypsies has only permitted, in most cases, the Gypsy people to “adopt, or be forced to adopt in all places marginal solutions that are fundamentally “*liquenistas*” (parasitical)” (1986, p. 206).

(2) “Payo” is the term used by Gypsies to designate members of the non-Gypsy population. It is a usual term among Gypsies, but conveys a certain depreciative tinge, when used by a Gypsy. This is why, some times during my field work, and especially with Gypsies from Castilla León, I also found the term “paisano” (compatriot) used for non-Gypsies. For reasons of language economy, and knowing that the term “Gypsy” also has a certain pejorative connotation when used among non-Gypsies, I will make use of the two terms: “Payo” for members of the Spanish non-Gypsy majority and “Gypsy” for members of the ethnic minority.

(3) For more details see SAN ROMÁN T. (1976) and following, GAY AND BLASCO P. (1999), GAMELLA J. F. (1996), ARDEVOL E. (1986).

(4) GIEMS (1976), GAMELLA J. F. (1996), SAN ROMÁN T. (1986), MONTES J. (1986), CEBRIÁN (1992), FRESNO G. (1993).

(5) I am using the term in the same sense as MENÉNDEZ E. L. (1998).

(6) For larger information concerning the different ways in which Social Anthropologists have investigated AIDS and the over-stigmatization processes that are implied when associating AIDS with certain social groups, see R. OTEGUI (2003) (to be published).

(7) This project will end after a second phase of field work, in which I shall collect specific information about what it means to live with AIDS in the Gypsy community. I must indicate that although this was not the main objective of the first part of the research, a certain number of our informants were HIV carriers. The ethnographic material was collected in Madrid, Valencia, Galicia, Andalusia, Navarra and Castilla León.

(8) In order to explain the heterogeneity regarding ideas about AIDS, the three variables that we found were most significant were: closeness/distance to HIV-AIDS, gender, and socio-economic stratum. The precision must be made that a distinction is established between what we name general social construction of HIV-AIDS, in which images and concepts are associated with the historically constituted forms of general discourse about HIV-AIDS – for example with reference to “risk groups” –, and what we call the medical construction of the disease, in which bio-medical terms are used and controlled for its description. This does not imply that I am not conscious of the important role played by the bio-medical discourse in the social construction of AIDS. In this sense, and although the present investigation is concerned with the Gypsy group, it must be underlined once more that *Gypsies, when they use the social construction of HIV-AIDS, do it in a manner very similar to that of Payo majority members of equal characteristics, as will be shown in more detail hereafter.*

Bibliography

- ARDÉVOL E. (1986), *Vigencias y cambio en la cultura de los Gitanos*, pp. 61-108, in SAN ROMÁN T. (ed.), *Entre la marginación y el racismo. Reflexiones sobre la vida de los Gitanos*, Alianza Editorial, Madrid.
- ARDÉVOL E. (1986), *Antropología urbana de los Gitanos de Granada: un estudio desde la antropología aplicada al trabajo social*, Concejalía de Servicios Sociales, Ayuntamiento, Granada.
- ASOCIACIÓN NACIONAL PRESENCIA GITANA (1980), *Sanidad, higiene y seguridad social*, "Documentación Social", n. 41, 1980, pp. 111-128.
- BORROW G. (1998), *Los zingales: los Gitanos en España*, Signatura Ediciones de Andalucía, s.l.
- BRUMMELHUIS H. T. - HERDT G. (eds.) (1996), *Culture and sexual risk. Anthropological perspectives on AIDS*, Gordon and Breach Publishers, Amsterdam.
- Femmes Tsiganes* (1997), "Études Tsiganes", vol. 10, n. 2, 1997 (monographical issue).
- FRANKENBERG R. (1994), *The impact of Hiv-Aids on concepts relating to risk and culture within British community epidemiology: candidates or targets for prevention*, "Social Science and Medicine", vol. 38, n. 10, 1994, pp. 1325-1335.
- FRESNO G. (1993), *La situation sociale de la communauté gitane d'Espagne*, "Ethnies", n. 8, 1993, pp. 70-78.
- GAY Y BLASCO P. (1997), *Être une vraie femme gitane: la politique du couple marié et la situation des femmes chez les Gitans castillans à Jarana (Madrid)*, "Études Tsiganes", vol. 10, n. 2, 1997 (Femmes Tsiganes, monographical issue), pp. 29-46.
- GAY Y BLASCO P. (1999), *Gypsies in Madrid: sex, gender and the performance of identity*, Berg, Oxford (Mediterranea Series).
- GAY Y BLASCO P. (2000), *The politics of evangelism: masculinity and religion conversion among Gitanos*, "Romani Studies", n. 10, 2000, pp. 1-22.
- GAMELLA J. F. (ed.) (1999), *Los Gitanos andaluces*, "Demófilo. Revista de cultura tradicional de Andalucía", n. 30, 1999.
- GAMELLA J. F. (2000), *Mujeres gitanas. Matrimonio y género en la cultura gitana de Andalucía*, Consejería de Asuntos Sociales de la Junta de Andalucía.
- GIEMS Equipo (1976), *Los Gitanos al encuentro de la ciudad: del Chalaneo al peonaje*, "Cuadernos para el Diálogo", Madrid.
- GILMAN S. L. (1988), *Disease and representation: Images of illness from madness to AIDS*, Cornell University Press, Ithaca.
- GLICK N. - CRYSTAL S. - LEWELLEN D. (1994), *Risky business: the cultural construction of AIDS risk groups*, "Social Science and Medicine", n. 38, 1994, pp. 1337-1346.
- GRIMBERG M. - MARGULLIS S. - WALLACE S. (1997), *Construcción social y hegemonía. Representaciones médicas sobre el SIDA. Un abordaje antropológico*, in KORNBLOT A. (ed.), *SIDA y sociedad*, Espacios, Buenos Aires.
- GÓMEZ ALFARO A. (1999), *Veto español a la presencia de Gitanos en el Nuevo mundo*, "Deportaciones de Gitanos", Centre de Recherches Tsiganes, Ed. Presencia Gitana.
- GRMEK M. (1992), *Historia del SIDA, Siglo XXI*, México.
- GRUNDFEST B. (1993), *AIDS action-research with women in Kinshasa, Zaire*, "Social Science and Medicine", n. 37, 1993, pp. 1401-1413.
- GRUNDFEST B. (1996), *Culture, sex research and AIDS prevention in Africa*, in BRUMMELHUIS H. T. - HERDT G. (eds.), *Culture and sexual risk. Anthropological perspectives on AIDS*, Gordon and Breach Publishers, Amsterdam.
- HERDT G. - LINDEMBAUN S. (eds.) (1992), *The time of AIDS: social analysis, theory and method*, Sage Publications, Newbury Park.
- LEBLON B. (1987), *Los Gitanos de España: el precio y el valor de la diferencia*, Gedisa, Barcelona.
- LAGUNAS ARIAS D. (1999), *Resolviendo la salud. Los Gitanos catalanes*, "Gazeta de Antropología", n. 15 (revista electrónica).

- MENÉNDEZ E. L. (1998), *Estilos de vida, riesgos y construcción social. Conceptos similares y significados diferentes*, "Estudios Sociológicos", n. 46, 1998, pp. 37-66.
- MONTOYA MONTOYA J.M. (1980), *Sanidad: la otra cara de la verdad*, "Documentación Social", n. 41, 1980, pp. 211-216.
- MONTURIOL JALÓN F. - SILVA RIVERA A. DE (2000), *Los usos de las drogas y su impacto en la cultura (el caso gitano)*, Asociación Secretariado General Gitano, Madrid.
- OTEGUI R. (1991), *Antropología social y educación para la salud: el uso del preservativo en la prostitución*, "Jano", n. 40, 1991, pp. 62-65.
- OTEGUI R. (1999), *La construcción social de las masculinidades*, "Revista Política y Sociedad", n. 32, 1999, pp. 150-160.
- OTEGUI R. (2001), *Social Anthropology and AIDS*, "AM. Rivista della Società italiana di antropologia medica", n. 11-12, 2001 (*Medical Anthropology and Anthropology*), pp. 113-131.
- PARKER R. G. (1996), *The social construction of sexual risk, or how to have (sex) research in an epidemic*, in BRUMMELHUIS H. T. - HERDT G. (eds.), *Culture and sexual risk. Anthropological perspectives on Aids*, Gordon and Breach Publishers, Amsterdam.
- PASQUALINO C. (1998), *Dire le chant: les Gitans flamencos d'Andalousie*, CNRS Editions - Editions de la Maison des Sciences de l'Homme de Paris, Paris.
- PEREIRO C. et al. (1996), *Consumo de drogas e infección VIH/SIDA en individuos de etnia gitana. I Jornadas Europeas sobre la atención a las drogodependencias y el VIH/SIDA en la población gitana*.
- RODRÍGUEZ HERNÁNDEZ I. (1999), *La situación de la comunidad gitana española en la relación a los fenómenos de uso de drogas y VIH/SIDA*, ASGG, II Jornadas sobre drogas y minorías.
- SAN ROMÁN ESPINOSA T. (1976), *Vécinas Gitanos*, Akal, Madrid.
- SAN ROMÁN ESPINOSA T. (1984), *Gitanos de Madrid y Barcelona. Ensayos sobre aculturación y etnicidad*, Universidad Autónoma de Barcelona - Bellaterra, Barcelona.
- SAN ROMÁN ESPINOSA T. (ed.) (1986), *Entre la marginación y el racismo. Reflexiones sobre la vida de los Gitanos*, Alianza Editorial, Madrid.
- SAN ROMÁN ESPINOSA T. (1996), *Los muros de la separación. Ensayo sobre alterofobia y filantropía*, Tecnos, Madrid.
- SAN ROMÁN ESPINOSA T. (1997), *La diferencia inquietante: viejas y nuevas estrategias culturales de los Gitanos*, Siglo XXI de España Editores, Madrid.
- SANCHEZ ORTEGA M. H. (1978), *Los Gitanos. Historia de una represión*, "Historia 16", n. 22, 1978, pp. 67-78.
- SANCHEZ ORTEGA M. H. (1986), *Evolución y contexto histórico de los Gitanos españoles*, pp. 13-60, in SAN ROMÁN ESPINOSA T. (ed.) (1986), *Entre la marginación y el racismo. Reflexiones sobre la vida de los Gitanos*, Alianza Editorial, Madrid.
- SANCHEZ ORTEGA M. H. (1994), *Los Gitanos españoles desde su salida de la India hasta los primeros conflictos en la Península*, "Espacio, Tiempo y Forma. Historia Moderna", n. 7, tomo 2, 1994, pp. 319-353.
- VÁZQUEZ J. M. (1980), *Los Gitanos hoy: visión de conjunto*, "Documentación Social", n. 41, 1980, pp. 157-165.



2.8 *Ogun, the car god, and the others.*

Localized practices of power and the perception of health among Nigerian women in prostitution in Italy

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Premise

This article is the fruit of a training-research project (1997-1999) conducted within the framework of an *Unità di strada (Street Unit)*⁽¹⁾, and focuses on the theme of identity and conceptions of the body, sexuality, and health among immigrant prostitutes.

Street prostitution acquired social visibility in Italy in the early 1990s, when a considerable number of women immigrants from Eastern European countries began to occupy the streets of our country. Ensuing years have seen an increase in the street presence of women from different ethnic groups, with a large component of women from Nigeria and Albania. The only research so far that has attempted to measure the phenomenon (CAMPANI G. *et al.* 2000) has estimated the number of women prostitutes operating throughout the country to be between 18.800 and 25.100.

In the face of the ethnic, linguistic, and cultural diversity also characteristic of immigrant prostitutes operating in the area around Perugia, research has focused increasingly on the group of Nigerian women. This choice has been determined by the relatively large size of the group (representing some 5.000-6.000 women nationwide, or 30% of the total of immigrant prostitutes), but also by my own special interest about their hypothetical different condition of "temporary enslavement" that seem sealed, in many cases, by magic rituals.

Globalization, debt bondage and Nigerian prostitutes

While the mass media have recently informed the Italian public about the common use of coercive practices in the sexual exploitation of immigrant prostitutes, there is also well-documented evidence of diversity in the strategies used by individuals and criminal organizations in the recruitment of Albanian women (and Eastern European women in general), on the one hand, and African women, and particularly Nigerian women, on the other (CAMPANI G. *et al.* 2000). This documentation shows how the Nigerian prostitutes, in addition to being subjected to direct forms of violence and abuse, seem also to be bound by a shared pact sanctioned by magico-religious rituals whose violation can lead to harmful and even fatal consequences for themselves and their families in Africa. The condition of many Nigerian prostitutes has been compared with "debt bondage" (ARLACCHI P. 1999). Generally speaking, once they have paid off the debt incurred to pay for their arrival in Italy, the women are able to reacquire their autonomy, even though it often happens that the people who purchased them attempt, through various forms of harassment, to maintain control over the girls for a longer period.

Several investigators have stressed how, in some countries the impact of colonialism and expansion of the market economy has transformed traditional forms of subjugation into debt bondage (FALOLA T. - LOVEJOY P. 1994). Debt bondage is the central issue of several studies of bondage now being conducted in Western countries (ARLACCHI P. 1999, BALES K. 2000).

Many Nigerian women have recounted how, during various ceremonies, pubic hairs, locks of hair, blood or pieces of fingernails are removed and placed together in a container – often a pair of underpants – and conserved by the shaman. The women generally accept such rituals – which effectively are transformed into rites of initiation to prostitution – as an integral part of the possibility of immigrating to Europe without money of their own.

Participation in a ritual as cultural practice also can constitute a strong moment of identity formation. Women who wish to cut the bond and leave forced prostitution behind generally do not feel protected by Western social workers, who do not offer suitable alternatives to support them.

Appadurai (APPADURAI A. 2001) has insisted on the importance of cultural practices with respect to the production of "local" subjects, or social actors who learn to belong to a situated community of relatives, neighbors, friends, and enemies. Such practices are also *practices of power* because they sanction and codify relationships of hierarchy and domination.

Globalization has acted as a powerful resonator for localized practices of power – tied to local subjects – amplifying their effects and diversifying their aims.

Nigerian women's initiation to prostitution comes about through rituals inscribed in a horizon of shared meanings that displace or re-place their sense of belonging and reconstruct moral and economic ties. The magico-religious ritual can be interpreted as the seal on an instrument of commercial exchange and power. As with other transactions, the traffic in Nigerian prostitutes is inseparable from a "moral" traffic in human and superhuman powers.

At the same time, forms of recourse to religion and magic have been on the upswing in Africa, now undergoing the great economic and social transformations brought on by globalization, because religion and magic take on – on the level of fantasy – the fundamental function of conferring power and guaranteeing some form of control over a world perceived as rapidly changing (COMAROFF J. - COMAROFF J. 1993).

Colonial discourse and voodoo

The effects of ritual loom over the lives of Nigerian women, can constitute a pervasive reality in their collective consciousness. Social workers tell of women who have shown signs of psychic disturbance. In other cases, episodes of adversity, such as street incidents in which women have figured as victims, the incidents have been interpreted by the women themselves as products of witchcraft.

Nigerian prostitutes – especially initially and often in part due to their scarce knowledge of the Italian language – are very untrusting and reluctant to talk about aspects of their daily lives, even more so when it comes to the question "magic ritual". They generally talk about it with staff only when they have filed complaints against their protectors, limiting themselves to recounting only certain, by now well-known aspects of the ritual.

At the beginning of my research it was above all in the literature addressed to social workers and other professional figures involved in the world of prostitution that I found explicit references to what is defined as a voodoo ritual.

Later on, the importance of the magic dimension for my women informants began to become more obvious, starting with a few episodes dating back to December 1998. At that time, many Nigerian women asked re-

peatedly and specifically to have their blood tested. Although they seemed to be well informed about HIV, the women gave the impression that their requests were motivated by reasons that went beyond the risks of contracting disease. Two Nigerian women declared openly that they were worried about the possibility that the health workers would appropriate their blood.

In another episode, a prostitute spoke of the Nigerian women as *wicked women, with dirty blood, victims of voodoo spells, especially the women that have scars on their face and bellies.*

In the encyclopedia edited by Di Nola (DI NOLA A. M. 1976) the terms *vudu, vodun, voodoo* are variants in transcription of the African term with which, in Fon languages, in Dahomey and Togo, one designates a god, a spirit, an object charged with numinous powers. The term is used to indicate the religion of Haiti, composed of a mixture of African traditions and Catholicism.

Although the prostitutes themselves always use the term voodoo, it is clear that they cannot be referring to the Afro-Catholic religion of the Caribbean island.

We are faced with a misunderstanding – and not only a linguistic one – which is highly significant.

The diffusion of the idea, among social workers and other staff, that the women are victims of the “black magic,” voodoo, derives from a particular Euro-American colonial consciousness, subject of studies in a wide range of literature (MUDIMBE V. Y. 1988, LOOMBA A. 2000, GUHA R. - SPIVAK G. C. 2002).

Though generally speaking, this consciousness places blacks and Africa in a position of otherness and ignorance, more specifically the association blacks/wicked magic/voodoo is tied to white colonialist fears with respect to the first black Republic in the world.

In 1791 Saint-Domingue was the epicenter of the struggle by black slaves for the abolition of slavery and the slave trade. The revolt of black Jacobins was so shocking as to represent a constant threat to colonialism and racism.

Colonial discourse contributed to the reduction of that type of experience to a series of stereotypes tied to religion and magic. American film has also drawn extensively on Haitian religious culture, exasperating some of its more magic aspects.

The spread of a colonialist stereotype that reduces all African magico-religious facts to the same model produces a new syncretism. In the encounter with the other, the Western stereotype is confirmed, to the point that it is

the other, as the women tell it, who becomes convinced that voodoo is the Italian translation of juju, or magic.

We are witnessing, on the one hand, a process of unconscious reduction of complexity, and on the other, a syncretic assumption of the terms of the other – whose original meanings are different – to define aspects of one's own identity.

Others have arrived at this same syncretism. For example, the *Madame*, the ex-prostitute that manages the smuggling of women into Italy and who participates in the rituals of subjugation performed on the women, was called for a certain period by social service staff and in the literature on prostitution, *maman*, re-utilizing a term formerly used to indicate the voodoo priestess.

By the same token, in communication, and especially in asymmetrical power relationships, discrepancies in discourse between form and content can be read as a space open to interpretation of the conflict; the unsaid can conceal an attitude of avoidance and resistance with respect to the gaze of the other.

Ogun the car god, and the other

Most of the Nigerian women come from the southern part of the country and they belong mostly to the Edo, Yoruba, and Igbo ethnic groups. More specifically, many women come from the Edo State, and Benin City and Lagos are the central clearing stations for women emigrants. The region of West Africa served as a great human reservoir for the Atlantic slave trade, which in the Americas led to processes of acculturation and the production of religious practices such as the voodoo in Haiti.

The analogies between the traditional Yoruba religion in Nigeria and voodoo religion have been well documented (MÉTRAUX A. 1971) and we can notice analogies between the initiation rituals in such cults of possession and the rituals described by the prostitutes. The woman is initiated to the cult of possession of a divinity who will watch over her behavior, especially during the period in which the adept of the cult (the shaman) will take care of her "soul," represented by the bodily substances that have been exported during the ritual.

The rituals, generally conducted the first time in Africa and in the presence of a woman intermediary from the criminal organization, may be repeated in Italy for the purpose of reinforcing the woman's condition of subjugation.

An informant told of being convinced that *her things* had been sent back to Africa by the shaman, so that she would be a victim of witchcraft. The woman, although stating she did not believe in magic, had repeatedly asked the “madame” for the return of *her things*, without obtaining any result. Despite this, she did not seem particularly worried about the consequences that the witchcraft would have for her, and she even filed a complaint against her protectress. The woman stated that she was “serene”, especially because she had already paid back the sum of money stipulated in her contract.

The women’s native region has always been a place of intense cultural exchange and there is no lack of important divinities belonging to all of the various traditional religions (BARNES S.T. 1997).

This is the case of Ogun, originally the god of metal – and therefore also of all those who work with metal, such as warriors, hunters, or blacksmiths – and of war.

As the god of metals, Ogun has played an important role in the technological advances that have made metal working a fundamental aspect of the spread of civilization. In many African cities, he has become the divinity who protects those who work with automobiles: many taxi drivers, for example, dedicate a little altar to him in their cars.

Ogun, along with other important gods like Shango – god of fire, lightning, and fertility – is one of the traditional divinities invoked by shamans as guarantors of the contract to which the prostitutes are subjected.

The threats and violence incurred by the women have to do with the ire of the gods and their manifestations. Ogun wounds them with knives and cutting weapons, sends cars to run into them on the streets; Shango sets fire to their parents’ houses or makes the women sterile.

Machines for Making Money

In his book analyzing the cosmologies of sub-Saharan Africa, *Iron, gender and power: Rituals of Transformation in African Society*, Herbert (HERBERT E. W. 1993) has examined the relationship between power, gender, and technology. These cosmologies are read as constructions of a gendered world in which female reproductive activity – source of a dangerous power to be controlled – becomes analogy/homology of the reproductive and creative power of the smelter. The blacksmith smelts, in fact, raw metals to forge utensils in furnaces, which in sub-Saharan Africa – Herbert demonstrates –

often resemble parts of the female anatomy. The male monopoly of technology and the reduction of the female body to an instrument or utensil are themes dealt with in the anthropology of gender.

The street women work with their bodies; bodies that have been alienated from them and transformed into *machines for making money* (as one prostitute stated to a journalist who interviewed her) (KENNEDY I. - NICOTRI P. 1999).

In the Nigerian *lukudi* (magic for making money) described by Matory (MATORY L. J. 1993), the maximum alienation of the female body is effected. Parts of the victims' bodies are exported and are used to evoke magic spells capable of producing money.

According to Matory (MATORY L.J. 1993), the female body and its generative powers are metonymies of social relations and metaphors for the integrity of the social body. The *likudi* tell us something about the new capitalism, the infamy of its technology, its alienation and its fragmenting effects on the social body and on the human body itself.

In the West, illegal female immigrants make their alienated bodies available to occasional consumers of *kunt*, *mouth*, and *ass*, thus activating a magic capable of producing money.

Ogun is certainly one of the divinities who best represent the contemporary world, interpreting the anxieties and fears of many Africans, and he can be adopted with different meanings by both the torturers and the victims of the slave trade.

The woman threatened by the Madame with being hit by a car sent by Ogun if she were to violate her contract (by going to the police or hiding money), herself transformed into a machine, sees modernity (represented by money and by machines) as both a death threat and as an opportunity for social and economic advancement (not coincidentally many Nigerian women refer to their clients on the street as machines, thus giving back to them the level of alienation they themselves experience).

Note

⁽¹⁾ The "Unità di strada Cabiria", organized by Arci Solidarietà Ora d'Aria di Perugia, is a project for the prevention and reduction of sexually transmitted diseases among immigrant prostitutes. The activities of the Unit are now part of the much larger "Project Free Woman 2000. Perugian Network Against the Slave Trade," sponsored by the City of Perugia as part of the fight against the smuggling and commercial trade of human beings for purposes of sexual exploitation.

Bibliography

- ARLACCHI P. (1999), *Schiavi. Il nuovo traffico di esseri umani*, Rizzoli, Milano.
- APPADURAI A. (2001[1996]), *Modernità in polvere*, traduz. dall'inglese di Pietro VERENI, Meltemi, Roma [orig. ed.: *Modernity at large: Cultural dimension of Globalization*, University of Minnesota Press, Minneapolis - London, 1996].
- BALES Kevin (2000 [1999]), *I nuovi schiavi: la merce umana nell'economia globale*, traduz. dall'inglese di Maria NADOTTI, Feltrinelli, Milano [orig. ediz.: *Disposable People. New Slavery in Global Economy*, University of California Press, Berkley - Los Angeles, 1999].
- BARNES Sandra T. (1997), *Africa's Ogun. Old World and New*, Indiana University Press, Bloomington - Indianapolis.
- BRADBURY R. E. (1964), *The Benin Kingdom and the Edo-speaking peoples of South-Western Nigeria / The Benin Kingdom: the Ishan; the Northern Edo; the Urhobo and Isoko of the Niger Delta*, International African Institute, London.
- CAGLIERO R. - RONZON F. (eds.) (2002), *Spettri di Haiti. Dal colonialismo francese all'imperialismo americano*, Ombre Corte, Verona.
- CAMPANI G. - CARCHEDI F. - MOTTURA G. - PICCOLINI A. (eds.) (2000), *I colori della notte. Migrazioni, sfruttamento sessuale, esperienze di intervento sociale*, Franco Angeli, Milano.
- COMAROFF J. - COMAROFF J. (1993), *Modernity and Its Malcontents: Ritual and Power in Postcolonial Africa*, The University of Chicago Press, Chicago-London.
- DI NOLA A. M. (ed.) (1976), *Vodu*, vol. VI, coll. 201-231, in *Enciclopedia delle religioni*, 6 voll., Vallecchi, Firenze, 1970-1976.
- FALOLA T. - LOVEJOY P. (ed.) (1994), *Pawnship in Africa. Historical perspectives on debt bondage*, Westview Press, San Francisco - Oxford.
- FORDE Daryll (1951), *The Yoruba-Speaking Peoples of South-Western Nigeria. Ethnographic Survey of Africa, Western Africa*, part 4, Oxford University Press for the International African Institute, London.
- GUHA R. - SPIVAK G.Ch. (eds.) (2002 [1988]), *Subaltern Studies. Modernità e (post)colonialismo*, ediz. italiana a cura di Sandro MEZZADRA, Ombre Corte, Verona [traduz. italiana parziale di *Selected Subaltern Studies*, Oxford University Press, Delhi, 1988].
- HERBERT Eugenia W., (1993), *Iron, Gender and Power: Rituals of Transformation in African Society*, Indiana University Press, Bloomington - Indianapolis.
- KENNEDY I. - NICOTRI P. (1999), *Lucciole nere. Le prostitute nigeriane si raccontano*, Kaos Edizioni, Milano.
- LOOMBA Ania (2000 [1998]), *Colonialismo/postcolonialismo*, Meltemi, Roma [orig. ed.: *Colonialism / Post Colonialism. The New Critical Idiom*, Routledge, London - New York, 1998].
- MATORY Lorand J. (1993), *Government by seduction: History and the Tropes of "mounting" in Oyo-Yoruba Religion*, pp. 58-85, in COMAROFF J. - COMAROFF J. (1993), *Modernity and Its Malcontents: Ritual and Power in Postcolonial Africa*, The University of Chicago Press, Chicago - London.
- MEYER B. (1995), "Delivered From the Powers of Darkness": Confessions of Satanic Riches in Christian Ghana, "Africa", vol. 65, n. 2, 1995, pp. 236-255
- MÉTRAUX Alfred (1971 [1958]), *Il vodu haitiano*, traduz. dal francese di Adriano SPATOLA, Einaudi, Torino [orig. ed.: *Le Vaudou haitien*, Gallimard, Paris, 1958].
- MUDIMBE V.Y. (1988), *The invention of Africa: Gnosis, Philosophy, and the Order of Knowledge*, Indiana University Press, Bloomington.
- VAN DIJK R. (2001), "Voodoo" on the Doorstep: Young Nigerian Prostitutes and Magic Policing in the Netherlands, "Africa", vol. 71, n. 4, 2001, pp. 559-585.



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 - Libri
 - DE MARTINO Ernesto (1948), *Il mondo magico*, Einaudi, Torino.
 - DE MARTINO Ernesto (1973 [1948]), *Il mondo magico*, III ediz., introduzione di Cesare CASES, Boringhieri, Torino [I ediz.: Einaudi, Torino, 1948].
 - DE NINO Antonio (1879-1897), *Usi e costumi abruzzesi*, 6 voll., Barbera, Firenze.
 - DE NINO Antonio (1891), *Usi e costumi abruzzesi*, 6 voll., vol. V. *Malattie e rimedii*, Barbera, Firenze.
 - DE NINO Antonio (1965 [1879-1897]), *Usi e costumi abruzzesi*, ristampa anastatica della I ediz., 6 voll., Leo S. Olschki Editore, Firenze [I ediz.: Barbera, Firenze, 1879-1897].
 - NATHAN Tobie (1990 [1986]), *La follia degli altri. Saggi di etnopsichiatria*, traduz. dal francese e cura di Mariella PANDOLFI, Ponte alle Grazie, s.l. [ediz. orig.: *La folie des autres. Traité d'ethnopsychiatrie clinique*, Dunod, Paris, 1986].
 - FRIGESSI CASTELNUOVO Delia - RISSO Michele (1982), *A mezza parete. Emigrazione, nostalgia, malattia mentale*, Einaudi, Torino.
 - CORIN Ellen E. - BIBEAU Gilles - MARTIN Jean-Claude - LAPLANTE Robert (1990), *Comprendre pour soigner autrement. Répère pour régionaliser les services de santé mentale*, Les Presses de l'Université de Montréal, Montréal.
 - BASTANZI Giambattista (1888), *Le superstizioni delle Alpi Venete, con una lettera aperta al prof. Paolo Mantegazza*, Tipografia Luigi Zoppelli, Treviso / in particolare: *Superstizioni agricole*, pp. 141-146; *Superstizioni mediche (Superstizioni relative ai rimedii alle malattie e alle virtù curative di certe persone)*, pp. 163-189.

□ Opere collettive

- DE MARTINO Ernesto (curatore) (1962), *Magia e civiltà*, Garzanti, Milano.
- GALLI Pier Francesco (curatore) (1973), *Psicoterapia e scienze umane. Atti dell'VIII Congresso internazionale di psicoterapia (Milano, 25-29 agosto 1970)*, Feltrinelli, Milano.
- *Enciclopedia delle religioni* (1970-1976), 6 voll., Vallecchi, Firenze.
- MAUSS Marcel (1965 [1950]), *Teoria generale della magia e altri saggi*, avvertenza di Georges GURVITCH, introduzione di Claude LÉVI-STRAUSS (*Introduzione all'opera di Marcel Mauss*), traduz. dal francese di Franco ZANNINO, presentazione dell'edizione italiana di Ernesto DE MARTINO, Einaudi, Torino.

□ Contributi individuali entro opere collettive o entro collettanee di lavori del medesimo autore

- GOOD Byron - DELVECCHIO GOOD Mary-Jo (1981), *The meaning of symptoms: a cultural hermeneutic model for clinical practice*, pp. 165-196, in EISENBERG Leon - KLEINMAN Arthur (curatori), *The relevance of social science for medicine*, Reidel Publishing Company, Dordrecht.
- BELLUCCI Giuseppe (1912), *Sugli amuleti*, pp. 121-127, in SOCIETÀ DI ETNOGRAFIA ITALIANA, *Atti del Primo congresso di etnografia italiana. Roma, 19-24 ottobre 1911*, Unione Tipografica Cooperativa, Perugia.
- DI NOLA Alfonso M. (1972), *Malattia e guarigione*, coll. 2-15, 2 tavv. f.t., in *Enciclopedia delle religioni*, 6 voll., vol. IV, Vallecchi, Firenze.
- TAMBIAH Stanley Jeyaraja (1985), *A Thai cult of healing through meditation*, pp. 87-122, in TAMBIAH Stanley Jeyaraja, *Culture, thought, and social action. An anthropological perspective*, Harvard University Press, Cambridge (Massachusetts) - London [ediz. orig. del saggio: *The cosmological and performative significance of a Thai cult of healing through meditation*, "Culture, Medicine and Psychiatry", vol. I, 1977, pp. 97-132].

□ Opere collettive in periodici

- LÜTZENKIRCHEN Guglielmo (curatore) (1991), *Psichiatria, magia, medicina popolare. Atti del Convegno (Ferentino, 14-16 novembre 1991). Sezione demo-antropologica. I*, "Storia e Medicina Popolare", vol. IX, fasc. 2-3, maggio-dicembre 1991, pp. 58-213.

□ Contributi individuali entro opere collettive in periodici

- PRINCE Raymon (1982), *Shamans and endorphins: hypotheses for a synthesis*, pp. 409-423, in PRINCE Raymond (curatore), *Shamans and endorphins*, "Ethos. Journal of the Society for Psychological Anthropology", vol. 10, n. 4, inverno 1982.

□ Articoli in periodici

- DE MARTINO Ernesto (1956), *Crisi della presenza e reintegrazione religiosa*, "Aut-Aut", n. 31, 1956, pp. 17-38.
- DE MARTINO Ernesto (1949), *Intorno a una storia dal mondo popolare subalterno*, "Società", vol. V, n. 3, settembre 1949, pp. 411-435.
- BELLUCCI Giuseppe (1910), *La placenta nelle tradizioni italiane e nell'etnografia*, "Archivio per l'Antropologia e la Etnologia", vol. XL, fasc. 3-4, 1910, pp. 316-352.

- DE MARTINO Ernesto (1942-1946), *Percezione extrasensoriale e magismo etnologico*, "Studi e Materiali di Storia delle Religioni", vol. XVIII, 1942, pp. 1-19, vol. XIX-XX, 1943-1946, pp. 31-84.
- MENÉNDEZ Eduardo L. (1985), *Aproximación crítica al desarrollo de la antropología médica en América Latina*, "Nueva Antropología", vol. VII, n. 28, ottobre 1985, pp. 11-27.

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