DELLE RISPOSTE AD ALCUNI CONSULTI

Sù la Natura di varie Infermità, e la maniera
di ben curarle

DI

ALESSANDRO PASCOLI

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Primario di Medicina nella Sapienza di Roma

PARTE PRIMA.

ALLA
SANTITÀ DI NOSTRO SIGNORE
CLEMENTE XII.

*Si aggiugne una breve, e diſtinta notizia del male epidemico inſorto
nel Ghetto degli Ebrei, ne i Rioni, e nelle Campagne di Roma
l'anno corrente 1736, e del mal contagioſo occorſo
l'anno ſteſſo ne i Buoi dello Stato Eccleſiaſtico,
e principalmente nell' Agro Romano.*

IN ROMA, Preſſo a Rocco Bernabò, MDCCXXXVI.
CON LICENZA DE' SUPERIORI.

Bibliot. Collegij Perusini Soc Jesu Ex Dono Authoris

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AM

RIVISTA DELLA SOCIETÀ ITALIANA DI ANTROPOLOGIA MEDICA

Medical Anthropology, Welfare State and Political Engagement

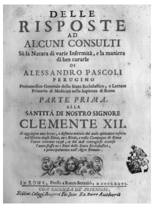
II. *Care and Management of Illness and Distress*

edited by
Pino Schirripa - Sylvie Fainzang - Els van Dongen - Josep María Comelles

19-20
ottobre 2005

Fondazione Angelo Celli per una Cultura della Salute - Perugia

ARGO



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Frontespizio del volume di Alessandro Pascoli, *Delle risposte ad alcuni consulti su la natura di varie infermità, e la maniera di ben curarle*, 2 voll., parte prima [vol. I], presso a Rocco Bernabò, in Roma, 1736 [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 imitazion 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 / *Nuovo metodo per introdursi ad imitazion de' geometri con ordine, chiarezza, e brevita nelle piu sottili questioni di filosofia metafisiche, logiche, morali e fisiche*, 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 solemni studiorum renovatione in Templo Archygymnasii 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 virtu 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 afflictae 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 infermita, 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 aggiravasi 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

Indice

n. 19-20, ottobre 2005

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4. *On patients and therapists in mental health care / Pacientes y terapeutas en el cuidado de la salud mental / Pazienti e terapeuti nella cura della salute mentale*

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 available 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, October 2003, 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 ynderstandings 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 second volume of the Perugia *Proceedings*, after the *Editorial* by the Editors, contains the works attributed by them to the second of the two thematic areas (*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 turn broken down into four subareas, **1.** *Old and new biomedical technologies / Viejas y nuevas tecnologías biomedicales / Vecchie e nuove tecnologie biomediche*, **2.** *Biomedicine and Alternative medicine / Biomedicina y medicinas alternativas / Biomedicina e medicine complementari*, **3.** *Patients' narratives, power and distress / Narraciones de los pacientes, poder y malestar / Narrazioni dei pazienti, potere e malessere*, and **4.** *On patients and therapists in mental health care / Pacientes y terapeutas en el cuidado de la salud mental / Pazienti e terapeuti nella cura della salute mentale*.

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 one of our aides from the Editorial Office, Amina De Napoli, 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 *AM* 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 Coordinadores 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 repercuciones 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 Coordinadores 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 simultánea; (*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 tembién 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 espresarse 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 decisió 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 Universitá 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 undestandings 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 Coordinadores 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 segundo volumen de las *Actas* de Perugia, después del *Editorial* de los Coordinadores, confluyen los trabajos que ellos atribuyeron a la segunda de las dos áreas temáticas (*Care and management of illness and distress / Cuidado y gestión de la enfermedad y de la enfermedad / Cura e gestione del malessere e della malattia*), articulados a su vez en cuatro sub-áreas: **1.** *Old and new biomedical technologies / Viejas y nuevas tecnologías biomedicales / Vecchie e nuove tecnologie biomediche*, **2.** *Biomedicine and Alternative medicine / Biomedicina y medicinas alternativas / Biomedicina e medicine complementari*, **3.** *Patients' narratives, power and distress / Narraciones de los pacientes, poder y enfermedad / Narrazioni dei pazienti, potere e malattia*, y **4.** *On patients and therapists in mental health care / Pacientes y terapeutas en el cuidado de la salud mental / Pazienti e terapeuti nella cura della salute mentale*.

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 Coordinadores 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 Coordinadores de las *Actas* no prevén algunas informaciones que nosotros normalmente pedimos. También en el caso de estas decisiones de los Coordinadores 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*) heterogeneidad *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 Coordinadores; y, lo que es peor (c) citas bibliográficas en el texto *que no encuentran correspondencia en la lista fial de las referencias bibliográficas*. Frente a esta triple casuística, la Dirección de *AM* – de acuerdo con Pino Schirripa, uno de los cuatro Coordinadores 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 Coordinadores 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 nuestra colaboradora de la Secretaría de Redacción Amina De Napoli, 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 Curadores 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 volumenes 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 anthropology 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 istituzione 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 secondo volume degli *Atti* di Perugia, dopo l'*Editoriale* dei Curatori confluiscono i lavori attribuiti dai Curatori alla seconda delle due aree tematiche (*Care and management of illness and distress / Cuidado y gestión del malestar y de la enfermedad / Cura e gestione del malessere e della malattia*), articolata a sua volta in quattro sottoaree, **1.** *Old and new biomedical technologies / Viejas y nuevas tecnologías biomedicales / Vecchie e nuove tecnologie biomediche*, **2.** *Biomedicine and Alternative medicines / Biomedicina y medicinas alternativas / Biomedicina e medicine non convenzionali*, **3.** *Patients' narratives, power and distress / Narraciones de los pacientes, poder y enfermedad / Narrazioni dei pazienti, potere e malattia*, e **4.** *On patients and therapists in mental health care / Pacientes y terapeutas en el cuidado de la salud mental / Pazienti e terapeuti nella cura della salute mentale*.

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 consegnatici 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 Amina De Napoli, della nostra Segreteria di Redazione, 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, oltreché 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 *AM* n. 19-20) di questa III sessione della Rete.

Editorial

Care and Management of Illness and Distress

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

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* (Perugia), *Università degli studi di Perugia*, *Universitat Rovira i Virgili* (Tarragona) 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 volume brings together the results of anthropological researches about the ways in which illness and distress are managed in various types of medicines, with or without the help of technologies, in or outside institutions in European countries. They are grouped in four blocks: **1.** *Old and New Biomedical Technologies*; **2.** *Biomedicine and Alternative Medicine*; **3.** *Patients Narratives, Power and Distress*; **4.** *On Patients and Therapists in Mental Health Care*.

The papers in this volume show that health perceptions and health systems are in dialectic relation with global change. They give an understanding of how people react to those changes, and how they wander the different paths to health. This shows how people's health behaviour and ways of caring vary in place and time. The papers demonstrate that illness is a cultural embodied, emotional and moral practice. Several studies raise issues of agency, power and experience, issues that are essential in the management of illness and distress in the context of care. Agency is not straightforward; it gets its shape by the historical context, political events, economic, social or cultural possibilities people have or the presence of others. Some researches discuss suffering and show how persons try to overcome their misery. Building on and expending anthropological theories, the authors provide concrete examples of the controversies, uncertainties and struggles people go through in times of illness or distress. Morality, confidence, control and resistance, colour in many ways the kind of relationships patients have with doctors. Illness is an ambivalent and uncertain process in which social relations, cultural capital and identities are contested and shaped.

This volume of *AM* (n. 19-20), as the previous (n. 17-18), follows the *Proceedings* of the Second Meeting of MAAH, held in Tarragona in 2001, already published in this Journal (n. 11-12 e n. 13-14). It 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

Cuidado y gestión de la enfermedad y de la aflicción

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

En el autumno 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* (Perugia), la *Università degli studi di Perugia*, la *Universitat Rovira i Virgili* (Tarragona) y por la *Universiteit van Amsterdam* – ha reunidos expertos de muchos países que trabajan en diversos temas de la salud y de la enfermedad refiriendo las investigaciones realizadas en sus propias culturas. El punto central de la conferencia ha sido fomentar las investigaciones acerca de los problemas de salud en los estados bienestar. La reunión dió lugar a dos volúmenes: *Health, State and Politics* (*Salud, Estado y política*) y *Care and Management of Illness and Distress* (*Cuidado y gerencia de la enfermedad y de la atención*).

Este volumen reúne los resultados de una investigación antropológica sobre las maneras de que *illness* y *distress* (aflicción) se manejan en varios tipos de medicinas, con o sin la ayuda de tecnologías, en o fuera de instituciones en países europeos. Se agrupan en cuatro bloques: **1.** *Old and New Biomedical Technologies* (*Viejas y nuevas tecnologías biomedicales*); **2.** *Biomedicine and alternative medicines* (*Biomedicina y medicinas alternativas*); **3.** *Patients Narratives, Power and Distress* (*Narraciones de los pacientes, poder y malestar*); **4.** *On Patients and Therapists in Mental Health Care* (*Pacientes y terapeutas en el cuidado de la salud mental*).

Los papeles en esto volumen evidencian como las percepciones de la salud y los sistemas de la salud son en la relación dialéctica con el cambio global. Dan una comprensión de cómo las personas reaccionan a esos cambios, y de cómo vagan en diversas trayectorias de salud. Esto demuestra cómo el comportamiento de la salud de las personas y las maneras de cuidar varían en lugar y en tiempo. Los papeles muestran que la enfermedad (*illness*) es una incorporación cultural, emocional y una práctica moral. Varios estudios plantean las aplicaciones del organismo, del poder y de la experiencia, problemas que son esenciales en la gestión de la enfermedad (*illness*) y de la aflicción (*distress*) en el contexto de la cura. El organismo no es simple; consigue su forma por el contexto histórico, de acontecimientos políticos, económico, de las posibilidades sociales y culturales que las personas tienen o la presencia de otras. Algunas investigaciones discuten el sufrimiento y demuestra cómo las personas intentan superar su miseria. Construyendo o expandiendo las teorías antropológicas, los autores proporcionan los ejemplos concretos de las controversias, las incertidumbres y la de luchas de las personas a través las épocas de la enfermedad (*illness*) o de la aflicción (*distress*). Moralidad, confianza, control y resistencia, tonalidades en las muchas maneras de relaciones que los pacientes tienen con los doctores. La enfermedad (*illness*) es un proceso ambivalente e incierto en el cual las relaciones sociales, el capital cultural y las identidades se disputan y se forman.

Este volumen de *AM* (n. 19-20), como el anterior (n. 17-18), sigue las *Actas* de la segunda Reunion MAAH que tuvo lugar en Tarragona en 2001, ya publicadas en esta Revista (n. 11-12 e n. 13-14). Demuestra el compromiso de la red de MAAH para desarrollar la antropología médica en su propia cultura y para establecer a una comunidad de estudios abierta, para renovar y para refinar discusiones teóricos y para contribuir a la mejora del cuidado médico. Presenta los substanciales trabajos etnográficos y las actuales orientaciones teóricas entre los antropólogos médicos europeo, africanos y latinos. La red *Medical Anthropology at Home* promueve respecto y aprecio de la diversidad en las personas, y desarrolla la crítica en las estructuras sociales y políticas que producen la desigualdad y la exclusión social en cuidado médico.

Editoriale

Cura e gestione del malessere e della malattia

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

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* (Perugia), dall'*Università degli studi di Perugia*, dall'*Universitat Rovira i Virgili* (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*).

In questo volume vengono presentati i risultati di ricerche antropologiche sui modi in cui il malessere e la malattia sono gestiti nelle differenti medicine: con o senza l'ausilio di tecnologie, all'interno o all'esterno delle istituzioni sanitarie dei Paesi europei. Il volume si struttura in quattro sezioni: **1.** *Old and New Biomedical Technologies (Vecchie e nuove tecnologie biomediche)*; **2.** *Biomedicine and Alternative Medicine (Biomedicina e medicine complementari)*; **3.** *Patients Narratives, Power and Distress (Narrazioni dei pazienti, potere e malessere)*; **4.** *On Patients and Therapists in Mental Health Care (Pazienti e terapeuti nella cura della salute mentale).*

I contributi di questo volume illustrano come le percezioni della salute e i sistemi sanitari siano in relazione dialettica con i mutamenti globali, mostrando come la gente si confronti con essi e dando conto dei loro percorsi terapeutici. In tal modo si rende chiaro come i comportamenti di ricerca della salute e i modi del prendersi cura varino a seconda dei luoghi e del tempo. I diversi saggi dimostrano che la malattia è culturalmente incorporata, ed è una pratica morale ed emozionale. Molti di questi si concentrano sull'agentività, il potere e l'esperienza, questioni che sono essenziali nella gestione del malessere e della malattia nel contesto della cura. L'agentività non è univocamente definita, ma prende forma in relazione al contesto storico, agli eventi politici, economici e sociali, o alle possibilità culturali a disposizione, o anche nell'interazione con gli altri. Alcune ricerche discutono la sofferenza, e cercano di mostrare come si tenti di superare la miseria. Avvalendosi delle teorie antropologiche, gli autori forniscono esempi concreti delle controversie, delle incertezze e delle lotte con cui ci si confronta nei periodi di malessere e malattia. Moralità, fiducia, controllo e resistenza informano in diversi modi i tipi di relazione che i pazienti hanno con i medici. La malattia è un processo incerto e ambivalente in cui le relazioni sociali, il capitale culturale e le identità prendono forma e sono messe in discussione.

Questo volume di *AM* (n. 19-20), così come il precedente (n. 17-18), 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.

1.

Old and new biomedical technologies
Viejas y nuevas tecnologías biomedicales
Vecchie e nuove tecnologie biomediche

AM
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1.1 *Biotechnical feasibility, user agency and patients' strategies: how unwanted childless women and men strategically deal with the uncertainties of in vitro fertilisation*

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Introduction: In Vitro Fertilisation and the Question of Agency

Until the beginning of the 1990's *in vitro fertilisation* (IVF) and other biotechnologies for assisted conception have been studied in the social sciences with a primary focus either on their macro-structural societal conditions and effects or their underlying cultural ideas. Far less attention has been paid to the question of how these techniques are put into clinical praxis and how they are experienced and dealt with by the "lay users" – the childless women and men who hope to get a child by the use of these techniques. If the users' encounter with IVF had been researched, then this was done more in terms of *re*actions of users rather than in terms of their active involvement and decision-making (1). In particular many feminist researchers of this time depicted women who use IVF as rather passive objects of a patriarchal biomedicine which seeks to appropriate and exploit women's reproductive abilities (COREA G. 1988, OAKLEY A. 1987, SPALLONE P. 1989). For the affected women one major consequence in this medicalisation of reproduction is, so it was suggested, that the inherent power imbalance between (male) doctors and (female) patients in biomedicine leads to a loss of women's control over the clinical procedures and their life situation. In consequence women lose their autonomy, when they enter the medical domain and undergo IVF-treatment.

When in the early 1990' interest in the actual practice of the New Reproductive Technologies (NRT) such as IVF increased and the "antitechnological romanticism" of earlier feminist studies (RAPP R. 1997: 33) was abandoned, women came to be seen in a less victimised and more active role. As in previous studies of doctor-patient interaction (CONRAD P. 1985, STIMSON G. - WEBB B. 1975), these more recent studies on the practice of the NRT showed that women are not so passive in the clinical encounter with doctors and technologies as was assumed before. Instead of being more or less helpless victims who have no choice they were shown to actively engage in and negotiate what is done and how it is done. This is not to say that they would be totally in control of the situation, but that they – within the constraints of the respective structural conditions of the clinical practice – actively try and find ways to take care of their interests and assert agency and autonomy (RAPP R. 1997, FRANKLIN S. 1997, LOCK M. - KAUFERT P.A. 1998, CUSSINS C.M. 1998, CAMBROSIO A. *et al.* 2000, SAETNAN A.R. 2000, MALIN M. *et al.* 2001).

Perhaps the best known example of this line of argument in medical anthropology is the reader *Pragmatic Women* edited by Lock and Kaufert in 1998, in which the contributors show the variety and complexity of women's active encounter and responses to medicalisation and biomedical technologies. In the introduction Lock & Kaufert characterise these responses as being "pragmatic" in essence:

> «[...] women's relationships with technology are usually grounded in existing habits of pragmatism. For by force of the circumstances of their lives, women have always had to learn how they may best use what is available to them. If the apparent benefits outweigh the costs to themselves, and if technology serves their own ends, then most women will avail themselves of what is offered» [emphasis in original] (LOCK M. - KAUFERT P.A. 1998: 2).

Such pragmatism coupled with ambivalence, so they argue, may be «the dominant mode of response to medicalization by women» (*ibidem*: 2) It however, remains open in what sense these responses should be pragmatic, to what strategies such an attitude may lead and how they are put into praxis.

Sociologist Arthur Greil, writing on the experiences of American middle-class women with IVF, also insists on his informants' «creativity and agency in working within the medical framework to achieve their own ends» (GREIL A. L. 2002: 103), although he sees this to be the case within a rather strict structural frame of constraints of the medical system. He suggests that these responses be best conceptualised as *working the system* insofar as women «try to push medical treatment in the direction they want it to go» and «are problem solvers, operating creatively within a system they do not control» (*ibidem*: 103). Greil identifies two main strategies of how his informants "work the system": (1) gathering knowledge which enables women to negotiate with doctors about the course of the treatment and (2) changing the doctor, when women are dissatisfied with the doctor's performance and the treatment process.

As the last example of how active technology users are conceptualised in the literature I want to mention Ann Saetnan and her concept of *negotiation-as-navigation* (Saetnan A. R. 2000). With strong ties to both technology studies and women's studies, her primary research concern are the questions of how global technologies such as Ivf become culturally appropriated (or "localized") in various societies, what role and means of negotiation lay users may have in this, and how this is best to be approached in the social sciences. Adopting a standpoint in which technology and society are regarded to be mutually dependent and to co-construct each other Saetnan distinguishes two modes of negotiation which among other things are relevant for what form of sociotechnical reality the cultural appropriation of technologies takes on: the first, *negotiation-at-the-table*, refers to the bargaining with another as representatives and spokespersons of the diverse interest groups or key networks may do – in the case of Nrt such negotiators stem from and represent research networks, governmental networks, clinical network and the mass media. The second, *negotiation-as-navigation*, is the predominant form of negotiation for users «who are not seated at the table where designs are drawn and 'treaties' are signed. They meet the results of design and treaty negotiations as a limited set of consumer options or as infrastructures in their daily lives» (Saetnan A.R. 2000: 20). Users negotiate in the sense of moving through or around in a satisfactory manner and «in threading their personal paths through those infrastructures, lay users also negotiate sociotechnical outcomes» (*ibidem*).

Both Lock & Kaufert and Greil as well as Seatnan make important contributions for the development of concepts which help to shed light on the agency of users of Ivf. The flaws, though, which these approaches to user agency have in common with other approaches in the literature are that they remain on the level of attitudes and stop short of telling us much about the actual strategies people use in order to take care for their interest – Greil is here more specific than the others –. A more systematic account of such strategies is still missing. More important to my argument however is, that they – more implicitly than explicitly and here Saetnan is the more promising than the other authors – seem to reduce the question of user agency to a power struggle between doctors and patients. In particular Greil puts forward a widely found view in the literature on the question of agency and control in which the technological and systemic constraints emerge as rather fixed and which in addition rests on the assumption that the autonomy of patients is predominantly threatened by medical experts. The user strategies which Greil therefore discusses are exclusively aimed at influencing patients' relationship with doctors. This relationship is presented as the only realm in which users have the opportunity to negotiate control. Although this may well be often the case, it leaves out other possibly restraining aspects of people's situation and autonomy such as the limits of technologies or competing requirements resulting from a job or partnership. The problem with the concept of control as it is used in Greil's analysis and in the debate about the medicalisation of reproduction in general is that problematic aspects which lie beyond the doctor-patient-relations are not taken seriously. In consequence, discussing control and autonomy may not do justice to what is "at stake" for the users (KLEINMAN A. - KLEINMAN J. 1991), since the goal which people have when they enter the clinic and work for its achievement may lie beyond the doctor-patient relationship as may the obstacles which are seen to be blocking the way to it.

In this paper I intend to show with the case of women and men who use IVF in Austria, that social relations in the form of doctor-patient-relationship are not the only constraints which limit the user's agency, and indeed that they may not even be the most important. In order to achieve their ultimate goal of having an own child the strategies which they use for achieving this goal concern medical experts, but far more importantly these strategies aim to curb the uncertainties which they see connected to the medical treatment of their unwanted childlessness on the one hand and to make becoming pregnant as promising as possible on the other hand. After giving an overview of the study on which my argument is based, I will go into the question of the biotechnological feasibility of producing one's "own child" and the uncertainties which are connected to it as they are seen by our informants. In the following section I will discuss the two main strategies which people use in order to deal with these uncertainties: *investment* and *trying-out*. In the conclusion I will finally consider why these findings should be relevant for medical anthropology. It should be noted here that I shall not investigate in detail the burdens and suffering, which IVF treatment for most people – and in particular for women – certainly entails. However, since the focus of this paper is on user agency, I shall attach more importance to its conditions and how people strategically deal with this rather than to the resulting suffering itself.

The Study

The data and the analysis which I present here stem to a large extent from a study which Monika Lengauer and I did for the Austrian Ministry of

Science between spring 2000 and autumn 2002 and which we further developed for our joint thesis (HADOLT B. - LENGAUER M. 2003). With a special focus on gender aspects our research interest was the ideas, behaviour and experiences of unwanted childless women and men who use the diverse medical technologies for assisted conception which are available in Austria (2). Two aspects of research design were particularly important for our study and distinguish it from others in the field: the first is that we worked not only with women, but also with men. This we thought important not only because male voices are hardly present in the literature on this issue, but also because both the medical definition of infertility (which usually talks of infertility when regular unprotected sexual intercourse of a couple does not result in a pregnancy within the period of a year) and the Austrian legislation have a strong focus on the heterosexual couple.

The second aspect is that we approached unwanted childlessness and people's attempts for a remedy as essentially being a "process in time" and not as a "state" as it is often found in the literature. Methodologically this resulted in the analysis of only a few cases, but these were researched in a rather detailed way and over an extended period of time. Backed up by initial fieldwork in an IVF-clinic and a survey among IVF users the main part of our data is about eight case studies of couples, which we followed in their quest for an own child during a period of 18 months. During this time we accompanied them to their clinical appointments in the IVF outpatient department of a university hospital in Vienna and regularly conducted interviews. For our research strategy and methods of data analysis we drew extensively on *Grounded Theory* (GLASER B. G. - STRAUSS A. L. 1967). The thousands of pages of interview transcriptions and observation protocols were organised and analysed with *Atlas.ti*, a software package for qualitative data analysis.

Following the principles of *Grounded Theory* we integrated our findings in a model which we called *children-making* (in German *Kinder-Machen*). By this we mean the goal orientated endeavour which unwanted childless women and men make in order to get an "own child" with the use of reproductive technologies. As such *Children-making* requires the deliberate decision to pursue this special way and in most cases means hard and burdensome work which often lasts several years. C*hildren-making* is to be distinguished from *children-getting* (*Kinder-Kriegen*) – producing children by sexual intercourse – which is conceived by our informants as the "normal" way of getting a child; becoming pregnant in terms of *children-getting* is thought to come about without much effort and more or less by itself. In our study we look at how it comes that people use IVF, how their quest progresses and when and why they leave the medical domain again; we explore the various dimensions of the *children-making* and the intervening conditions which hinder or foster its progress; we analyse the strategies which people use in order to make the process go in the desired direction and we finally look at the outcomes which this endeavour has.

What follows in the next sections of this paper is part of this model and concerns one of the central intervening conditions of *children-making,* namely that the effectiveness of IVF cannot be guaranteed, and how people strategically deal with this.

The Biotechnological Feasibility of the Own Child and the Uncertainties of Children-making

In the mass media in Austria and elsewhere IVF is often represented as if its effectiveness in producing new humans were beyond questioning. Although statistical success rates may be mentioned (the figures range between 20–30% for a pregnancy per IVF-cycle), the biotechnical procedures around IVF are usually presented in an ideal typical, formal way in which one mechanically leads to another with a child as the result. When people enter the process of *children-making* some of them may also have the expectation that IVF's effectiveness does not pose any problem. But this assumption changes rather quickly, when it becomes obvious in the course of own experiences with IVF or by way of stories from others that this indeed is not the case: notwithstanding any success statistics, when it comes down to the individual case an IVF-treatment cannot assure that a woman becomes pregnant. For users of IVF therefore the possibility and actual experience of failure is an all too real fact which fundamentally crosscuts and impinges on all other aspects of the process of *children-making*.

IVF is a complicated technique in the sense that it requires the correct and timed interplay of a range of human actors (users, gynaecologists, laboratory technicians), bodily materials and functions (eggs, semen, embryos, follicles, uteri, hormone levels etc.), machines (ultrasonic devices, microscopes, incubators, etc.) and substances (artificial hormones, drugs, media for embryo cultivation etc.). Lasting between 4-7 weeks an IVF-cycle is made up by a series of phases or steps, which have to be worked off successfully in order to keep up to the possibility of becoming pregnant. These phases are: the hormonal stimulation of the ovaries in order to produce more fertile eggs rather than only a single one as in a regular menstruation cycle (lasting about 2-5 weeks); the puncture of the follicles which have developed in the ovaries in order to retrieve (or "harvest" as some doctors referred to it) the eggs; the fertilisation of the eggs with the semen[3] in the laboratory – the actual fertilisation *in vitro* – and the cultivation of the resulting embryos up to the 7 days after fertilisation; the embryo transfer, in which 1-3 of the developed embryos are put back into the uterus; and the implantation of the embryo in the uterus (nidation), which at the earliest can be checked by a pregnancy test after a further two-weeks of "waiting period". Each of the phases entails a sort of interim result which has to be of sufficient quality in order to be enable the entry into the next phase: the hormonal stimulation is required to produce enough follicles, the ovarian follicle puncture should result in as many eggs as possible and the fertilisation in a high number of embryos. These results are evaluated to be better or worse (there may be more or less follicle, more or less eggs etc.) and the progress towards the desired goal of the pregnancy therefore is regarded to be more promising or less. Only the result of the implantation phase – the final result so to say – ultimately is not gradable: in the end one can only be either pregnant or not pregnant. In any way, should only one of these phases fail, this would mean that the whole IVF-treatment has failed and everything must start anew.

However, IVF is not only a *complicated* technology, but also a *complex* one in that it involves and builds on aspects of the world which lie beyond technical feasibility. By way of using the ensemble of techniques (for which IVF is the umbrella term) it is supposed to support, to bypass or to replace those bodily aspects of the procreation process which are thought not to be working in the desired way. These techniques, though, cannot substitute the whole body in its reproductive functions, but necessarily build on the reproductive faculties of the body. A pregnancy therefore is the outcome of the interplay of what can be technologically compensated and what cannot be compensated. In spite of all medical technology and notwithstanding the best prospects during an IVF-cycle therefore, becoming pregnant ultimately escapes medico-technical feasibility and has to come about beyond direct human intervention. In this sense it has to *occur* beyond the human realm – nature, luck, fate, a divine authority or however else this realm would be conceptualised. We have called this fact, which is painfully present for users, the *uncertainty-of-occurring* (*Unsicherheit des Passierens*). Since it is decisive for the overall outcome of an IVF-treatment, the *uncertainty-of-occurring* in the first instance refers to the implantation of the embryo; subsequently however this form of uncertainty also applies to the interim results of earlier phases in an IVF-cycle. The fact of the feasibility limits of IVF has the important consequence for users (and medical specialists likewise) that they cannot directly create the desired child. They are merely left to create the conditions and circumstances so that the occurrence of a pregnancy becomes as likely as possible. In this sense the techniques for assisted conception are seen to be mandatory and enabling for a pregnancy, but not to be directly causing it.

The *uncertainty-of-occurring* is but one form of uncertainty in the process of *children-making*. Our informants also often expressed their suspicion about the validity of what they think they know about the causes of their persisting childlessness and failure of medical therapies: is it "really" the case that a hormonal imbalance prevents becoming me pregnant or could the stress resulting from the constants fights with my work colleagues be responsible for it? Did the implantation of the embryo fail, because of my smoking in the past, or because the eggs were not of good enough quality, or because the doctors waited too long with the transfer, or because God does not want me to have a child? Could my assumptions about the whole matter be wrong? In the course of the treatment process, when people meet different doctors, hear different stories from fellow sufferers, look up new information in the internet and not least when treatment fails again and again people become painfully aware of the precarious status of this sort of knowledge: «Everything turns out to be so complicated and you never know for certain what you think you know», one woman complained in respect to this unreliability of knowledge. Because people in these instances do not reliably or sufficiently know what *actually* is the case, we called this phenomenon the *uncertainty-of-the-actual* (*Ungewißheit des Tatsächlichen*). This form of uncertain knowledge concerned various aspects of their unwanted childlessness and the treatment process: how they should interpret particular bodily states and experiences especially during the "waiting period" after the embryo transfer, how a cold would possibly affect the development of the follicles or if the cyst in the uterus had grown further. Most important however were the questions which were either directed to the "actual" causes of their childlessness or of the failure of an IVF-treatment – not least because reliable knowledge about these aspects was thought to be crucial for a successful future treatment.

The third and last form of uncertainty which is relevant here – *uncertainty-of-the-best-possible* (*Ungewißheit des Bestmöglichen*) – is also connected to unreliable knowledge. But whereas *uncertainty-of-the-actual* refers to what is "real", *uncertainty-of-the-best-possible* refers to what should best be done. Our informants described it to be a major problem that they could not know for sure if they had made the right decisions in their pursuit of an own child or if they should better try something else. This difficulty concerned not only the choice between treatment options, between doctors and between clinics, but also how to prepare for the next IVF-treatment, how to behave (and what not to do) during an IVF-treatment or how to organise everyday life circumstances in order to create as favourable conditions for a pregnancy as possible.

All three forms of uncertainties are bound to the awareness of the limits of both knowledge and action. Thus, based on a division between knowledge and its supposed real-world-referents these uncertainties point at aspects of the world which lie beyond people's assured knowledge and direct control: for all of our informants this first and foremost concerned the specific reality of their own physical bodies and their procreative faculties on the one hand and the actual treatment procedures and clinical practice on the other hand. Furthermore, this may also be linked up with ideas about luck, fate or a divine or comic power. However, it is in this transcendent realm, were it is finally decided if the pregnancy occurs or not. This fact provides these forms of uncertainties with its relevance as central intervening conditions for *children-making*. People's efforts to control and deal with these imponderables therefore are at the core of *children-making*. Concerning the *uncertainty-of-occurring*, people's strategies aim to push the feasibility horizon in as promising a direction as possible; and in respect to the *uncertainty-of-the-actual* and the *uncertainty-of-the-best-possible* they try do change their knowledge horizons to be as favourable for their informed decisions as possible. The strategies which people use to accomplish this shall be considered in the following section.

Dealing with Uncertainties: Investment and Trying-out

The *uncertainty-of-occurring* renders the experience of failure an essential element in the process of *children-making* – not only emotionally, but also structurally. Instances of failure of IVF-cycles separate the *children-making* into distinct sections, propels the process forward, gives it a plot and – in the case that no pregnancy has occurred beforehand – finally terminates it usually after several years of "trying". Besides the complexity of IVF and the considerable expenditure of time and work which it involves, the uncertainty of its effectiveness and actual failures make *children-making* into a multilayered long-term project with a beginning, a trajectory and an unknown outcome. Users of IVF thus adopt the fundamental attitude that this project is to be approached in a rather determined and goal-orientated manner which we call *purposive handling* (*planvolle Handhabe*); it constitutes one of the essential characteristics of *children-making*. The handling of *children-making* is to be regarded as purposive, because – notwithstanding all ambiguity, contradictions and unexpected changes of direction involved in it – it follows a plan, is based on a explicit decision to pursue a particular course of action (and not a different one) and because it is assertively put into action. According to Alfred Schütz these are the components which constitute work – or to use his illustration, which distinguishes the leaving of tracks in the snow from treading a path in the snow (SCHÜTZ A. – LUCKMANN T. 1984: 24ff).

Purposive handling of the biotechnological making of children aims at three crucial dimensions: the first concerns the necessary work packages and procedures of the standard IVF-treatment as already outlined in a previous section. To the users it is unambiguous – at the latest after the first IVF-treatment – how these procedures are to be worked out and what they are for. And until further notice they (though not necessarily their results) do not pose any problems in terms of uncertainty. This kind of work requires close cooperation between IVF-experts and users. In particular women are concerned in this respect, because they have to do the most work, since the medical techniques almost exclusively focus on the female body. Among other things this kind of work involves having daily hormone injections, going to the clinic for the ultrasound scan in order to evaluate the growth of the follicles, undergoing the (painful) puncture of the follicles in the ovaries, having the (joyful) embryo transfer and doing the (emotionally demanding) pregnancy test. Even though these activities were generally described to be arduous and burdensome, our informants nevertheless expressed a strong sense of content and confidence about this work, because they felt that they know what to do and are able to actively and personally contribute to their project of the own child. It became on the other hand a big problem, when this was not the case. This became in particular apparent during the two-weeks "waiting period" (as it often was referred to) after the embryo transfer, when all "proper" medical work has been already accomplished and when nothing is left to do apart from waiting and hoping. A woman speaking about the difficulty of not being able to "do anything" said the following:

> «If I would only rely on luck, I would not need to do anything. But I do want to do something! [...] I mean, I they [the doctors] would tell me to do a headstand five times a day, I would do it».

Because of the inability to "do anything" in addition to being faced with the imminent failure, this woman and all other informants regarded the implantation phase the most difficult stage in an Ivf-cycle in terms of emotional tension, anxiety and disappointed hopes.

What we have discussed as the uncertainties of *children-making* in the previous section falls into the second dimension. In contrast to the standard-work of the first dimension this includes the actual biotechnological procedures in their uncertain aspects, but beyond the actual treatment also involves coping with the failure of treatment and the clarification process in which people have to clarify if and how they should carry on with the treatment. This dimension is often indeed experienced as problematic and takes up the main part in people's considerations about the purposive handling of *children-making*.

The third target area of *purposive handling* finally concerns the manifold contingencies which may emerge during of before an Ivf-treatment: a flu, a vaginal infection or the discovery of a cyst in the uterus, but also troubles at the workplace or with the partner, or unforeseen life events such as the illness of the mother. Such contingencies are experienced by users as individual extra obstacles on their way towards the desired pregnancy and they are seen to further complicate, slow down, interrupt or even terminate the treatment routine. They urge users (and medical specialists likewise) to reconsider their original plans and to swiftly adopt them to these new circumstances.

Investment

Given the specific technical and organisational requirements and uncertainties of Ivf, people's main strategies in their quest for an own child can be called *investment* and *trying-out*. By means of these strategies our informants tried to shape *children-making* in its purposive aspects as promising as possible.

As we have seen before the *uncertainty-of-occurring* prevents the own child being achieved unmediated. It is true that people have the choice and ability to work for its enablement, but ultimately the pregnancy has to *occur* beyond human feasibility. "Getting a child" with the help of Ivf is thus a form of *mediated getting*, since it needs a third agent, which mediates between the accomplished work and the anticipated result. In our case this is what the "occurring" refers to – be it thought to be brought about by nature, luck, fate or god. Because of this people cannot "buy" or "produce" their child (which would constitute forms of "unmediated getting"), but only *invest* in a child, or more precisely they can only invest in a mediating object, which in turn will allow the child happen. Since this basically follows the logic of investment and not that of buying and producing, we have called this strategy *investment*.

Our informants themselves used the term “investment”, as is apparent in the following statement of a man, a financial expert, who talked about *children-making* as a sort of a life project which he shares with his wife:

> «This [the IVF-treatment] is a shared project, these are shared experiences. And in order to put it in my occupational jargon, it is a shared investment. If it will bear fruit, the investment, however will turn out».

Other informants talked in terms of “investment” and related idioms with respect of the financial burden which IVF poses to many, but also regarding other resources and outcomes connected to IVF: they talked about a “loss of time” (*Zeitverlust*); or that they had “wasted time” (*Zeit vertun*) or “blown money” (*Geld verpulvern*); that the child would be “worth the expenditure” (*den Aufwand wert sein*); that they had “put in” (*hineinstecken*) so much hope and energy, but now there would be so little “to be got out” (*herausschauen*); that the “yield” (*Ausbeute*) of a puncture had been good or disappointing; or that getting children with medical assistance would “*have its price*” (*seinen Preis haben*).

The resources which people invest have already been mentioned: *work* (in connection to the prerequisite and beneficial things to be done), *time* (which is required both for working and for waiting), *bodily resources* (gametes, good health, bodily suffering etc.) and finally *money*. There are three overlapping fields of objects in which IVF users invest these resources. Some of them are conceived to be prerequisite, others merely beneficial, though nevertheless important.

(1) The first field is made up the working off of IVF procedures and the employment of diagnostic measures and medical means in general. By and large these are seen to be essential.

(2) Investment in the acquisition of knowledge, the second field, may be seen as both essential and beneficial, depending on the status of the respective knowledge. While the basics of how to accomplish necessary IVF work (e.g. when and how to give oneself the hormone injections) were absolutely crucial to all of our informants, some of them found it “merely” helpful to know a lot about things such as new kinds of medical techniques and medications, other people’s experiences with IVF or about other IVF clinics in the same region. All this knowledge may be regarded as beneficial for the evaluation of the actual situation or perhaps for future use, but it is not regarded as enabling a pregnancy in the narrow sense of the term.

In any case, people acquire such knowledge primarily by talking to medical experts, reading the pertinent literature, talking to other users or by looking up relevant topics in the internet. Their doctors were particularly important in this regard, even though people often complained that they provided them with too little information.

(3) As the third field of investment people invest in what can be called "favourable conditions". These refer to bodily, psychic, organisational, temporal and structural conditions and circumstances which are deemed beneficial for the *occurring* of a pregnancy, but not prerequisite. For example, people might decide to have a long break between two Ivf-cycles in order to start the next treatment relaxed and in best state of health; they would take time off work in order to reduce stress during the treatment which is seen to be detrimental to the chance of getting pregnant; they would try to sort out troubling life circumstances before they start with the Ivf-cycle so that they are able to put all their energy into the treatment process. The creation of such favourable conditions were regarded as particularly important during the emotionally demanding implantation stage – not only because there is "nothing else left to do" and such activities were found comforting, but also because this is the crucial phase in which all the former investment culminates and the getting pregnant has to be supported by all possible means. Some women reported that they would drink a lot of water, stop smoking or rest a lot during this time. Others said that they would not have sex, have recreating walks in the wood, avoid any arguments with other people or that they would talk to the embryo and encourage "her/him" to stay in the womb.

So far we have looked at *what* Ivf users invest and *where* they invest it. What remains to be discussed is *why* at a particular point in the process of *children-making* they choose to invest in one particular object and not in a different one. The strategy which people employ in this respect is *trying-out*.

Trying-out

This strategy refers to the evaluative and selective probing of available medical techniques, doctors and clinics for their effectiveness in relation to reaching the goal of the own child. It takes on the form of excluding and eliminating insofar as it puts out of play what does not seem to be appropriate and adequate for getting the own child (any longer). This requires that more than one option be available and that people are able to choose among those available (in its minimal form they have to "take it or leave it"). *Trying-out* is put into practice on the basis of the respective stock of knowledge and experience which people have at hand at certain points in the process of *children-making* as well as on the basis of their current assessment of available paths in terms of success probability, personal preferences and life circumstances and price. Both realms considerably differed among our informants and were also subject of change over time. While for example artificial insemination may have seemed sufficient at an earlier stage of *children-making*, it may be seen as useless after it failed the fourth time. Or somebody may loose their trust in his/her IVF-specialist's competence and therefore change the clinic.

What all our informants had in common, however, was their willingness to "try out everything" and to "do all that one possibly can" (*bis zum Letzten gehen*), as they said. Or as a man put it:

> «I mean, one tries not to miss anything, so that you do not have to reproach yourself and say: ok, why haven't you tried this, why haven't you tried that, isn't it?».

Although not all of our informants actually "tried out everything" in practice, they nevertheless made considerable efforts to know about all available options so that they would be able to make an informed choice.

Trying-out shares with *investment* that it is connected to a process in time which is hoped to be manipulability towards a desired outcome. After all, *trying-out* is intended to control the *uncertainty-of-occurring* and the other uncertainties of *children-making* in a way which enables a pregnancy to occur. *Trying-out* and *investment* however entail different time horizons and become prominent at different points in the treatment process. This is related to the two reference frames of planning which *children-making* involves. One such frame within which people plan and carry out plans is given by the single IVF-cycle as it unfolds from the beginning of the hormone stimulation to the final pregnancy test. This is the preferred perspective which people adopt immediately before and during an actual IVF-cycle. Here the strategy of *investment* is of paramount importance. Another frame of reference concerns the *children-making* in a broader sense and beyond the single IVF-cycle. It brings the whole treatment process and the life project of the own child into view. This perspective is predominantly adopted, when a treatment had failed and when people take a break in order to think things over and to "come back down to earth", as one of our informants put it. Sometimes such a break take only a few weeks until the next IVF-cycle is started; but sometimes it takes several months or even years. Here the strategy of *trying-out* becomes highly relevant.

These two reference frames differ in the status which a failure has in each of them. In the case of the first frame the failure – or the next possibility of getting pregnant, when seen from the time perspective of within an IVF-cycle – marks the endpoint of concrete planning, not least because the treatment outcome is so unsure and people do not want to anticipate the future beyond the current IVF-cycle should it actually fail. As for the second frame, a failure constitutes a sort of milestone, which – notwithstanding its negative appraisal – subdivides *children-making* into different periods and creates its rhythm of "tries" and "breaks". As culmination points of single IVF-"tries" such milestones become a sort of cross-road in the course of *children-making,* because they open up the space for a pause and for the potential for a change of direction in future. *Trying-out* is essentially based on this potential. Whereas *investment*, then, is intended to put into practice the "try" in the best possible way, *trying-out* is the strategy which is appropriated in order to find and decide on what and how to try in the first place. This strategy is central not least for the question of when to terminate the *children-making* altogether: it is only when people have come to the conviction that they have tried out everything adequate in their particular case, that they can stop *children-making* and leave the medical domain without the feeling that they could regret this decision sometime in the future.

Concluding Remarks

I started this paper with the question of user agency and pointed out that in the literature about IVF the negotiation of control and autonomy has been largely reduced to the doctor-patient-relationship. Other aspects which might be relevant in this regard have not been taken seriously enough in the analysis. By looking at how users of IVF in Austria strategically handle certain aspects of their unwanted childlessness I intended to show that it is not always and most importantly doctors and their interests that are seen to narrow people's autonomy. Although they do so to some extent, it is the requirements and limits of the reproductive technologies that for IVF users pose the main problems in their encounter with IVF. Thus, what they struggle to control is not so much social relations, but rather the relations between human feasibility and the realm beyond, since for them these are the key obstacles on the way to what is most at stake, having their own child.

What conclusions can be drawn? I would like to raise two points. The first is that when we talk about user agency we should not merely focus on people as actors who are more or less exclusively engaged with the social dimension, but rather as actors in a more general sense who live and act in multiform and rich worlds in which the social is but one (though, of course, highly important) dimension. The problems which people encounter as curtailing their autonomy are not exclusively to be found in the social. At least in the study of the NRT the focus on the social dimension has led attention away from the technical dimension in spite of its essential role in the quest for the own child. The conceptualisation of how users strategically deal with the obstacles towards the child as *investment* and *trying-out* is an attempt to develop a more integrated view of the social and the technical and intends to do more justice to people's view of their worlds and the kind and scope of agency they have in it. We need to study in a more comparative manner, if these user strategies can also be found in relation to other medical technologies, how and under which conditions and with what effects they are pursued, or if there are other such strategies. Gaining more systematic knowledge about such strategies would be important to the question of how people use biotechnologies and how they are used by them. In any case this requires a profound understanding of how these technologies actually work (and do not work), of what their characteristics are and of how they are put into practice. Despite the huge body of social science literature on the NRT these questions have hardly been tackled.

This brings me to the second point. What we have conceptualised as the uncertainties of *children-making* draws attention to questions about uncertainty, partial knowledge and non-knowledge and how people deal with this. To some extent this has been theorised under the rubric of "risk". Risk too is related to an unknown future and thus belongs to the realm of uncertainty. It is, though, just one form of uncertainty, and *uncertainty-of-occurring* as I have discussed it in the case of IVF would constitute another form. They differ, though, insofar as strategies for handling risk are intended to *avoid* something, whereas strategies for handling *uncertainty-of-occurring* are aimed to *enable* something. For an assessment of its relevance it needs to be investigated in what other phenomena this comes to the fore as well. However, such forms of uncertainty and their relations to the broader category of uncertainty are clearly under theorised in anthropology (though not so much in sociology at least as far as expert knowledge is concerned). If it is the case that our world is becoming increasingly complex and therefore uncertain – and the biotechnical developments in reproductive medicine or the "genetisation of medicine" are cases which would support this view – then user strategies for handling this complexity can also be expected to become more important for people's efforts to shape a satisfactory future. If medical anthropology is to be focused on what is "at stake" for people and how they go about it, then this should become an important topic in future research.

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Notes

(1) In addition, these studies restricted their focus predominantly to women and excluded the perspectives of men or couples.

(2) Similar to Germany, Switzerland or Norway, but in contrast to Great Britain, France or the USA, Austria has a rather strict legislation in terms of admissibility of the various forms of assisted conception and of user access. Austrian law allows IVF only for heterosexual couples who are married or live in a "stable" marriage-like partnership. Singles are just as excluded from access as homosexual couples. IVF and embryo transfer are only permissible with the eggs and sperm of the social parents-to-be, which means that egg donation, embryo donation and all forms of surrogacy are illegal in Austria (BERNAT E. 1992, KOCH H.-G. 2001).

(3) By Austrian law the semen has to stem from the husband or partner.

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1.2 *Reflections on the expectations and experiences of first time hearing aid users in Denmark*

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> «I feel like a chameleon on a tartan blanket.
> I just don't know whether to enjoy or dislike
> being a hearing aid user!»
> (Experience of a first time hearing aid user)

The Construction and Deconstruction of the Right to Hear

The policy pursued in connection with the distribution of hearing aids can be seen as an example of the ability and willingness of a society to rehabilitate its citizens and provide equal conditions for all. In Denmark, the policy reflects a new trend in the administration of hearing health care. The public sector may still provide high quality rehabilitation of the hard of hearing seen in an international comparison. However, cuts in public funding have led to lack of status attached to the profession of medical audiologist and thus a severe scarcity of staff. Moreover, long waiting lists to obtain a hearing aid have paved the way for a private sector subsidised by public funds.

Societal attitudes toward the hard of hearing and to hearing aids are an example of how society treats difference.

> «When people use, develop, test and manage hearing aids, they are simultaneously using, developing, testing and managing notions of hearing loss and categories of human difference. Sometimes hearing aids are inconsequential – that is, they 'don't matter' to people who wear, see, or manufacture them. But more often hearing aids are consequential, marked and remarkable, serving as artefacts of the various ways in which humans have organized physical and social difference through culture and technology» (STRATTON A. 1999: 65).

This paper is based on research carried out for a thesis on the first time users' expectations and experiences of hearing aids in Denmark. The fieldwork started early 2003 and the research is still in progress. To this end, the various factors and agents influencing the process of acquiring a hearing aid are examined. The first part of the paper examines the changing conditions of the welfare state in administering care; the second part utilizes notions of embodiment (SCHEPER-HUGHES N. 1994) in connection with hearing impaired persons and their rehabilitation. The focal point is the reaction of the inexperienced users to the various experts and technology and their set up to include them in the hearing world. The users are adults with an acquired, gradual hearing loss. Deaf people are not included in the study. The Deaf (1) represent a strong and independent culture that can be viewed in a historic and social context. The opposite applies to adults with an acquired, gradual hearing loss. They are in danger of losing or lessening the ties to their social group. Self-help groups exist, but the nature of the impairment can complicate communication with fellow-sufferers, just as the hard of hearing tend to minimise the problem and tend not to identify themselves with other hard-of-hearing people.

Even if society does not pay much attention to hearing impairment, the problem is so common that almost everyone knows someone who is hard of hearing. The number of informants is consequently high, and I have recorded their attitudes and thoughts in a field diary. Moreover, to identify interview partners (in this text: respondents), I approached public and private hearing aid clinics. The Danish hearing health care is characterised by a public sector accounting for about 85% of the prescribed hearing aids and a rapidly expanding private sector (15%). The public clinics were very open and helpful. They invited patients from their waiting list to participate in the study. For a number of reasons, gaining access to the private hearing aid clinics was more complicated. I see part of the problem as the different power relations between the private provider and customer as compared to the relations between the medical staff and patients of the public clinics. The existence of the private provider depends on the satisfied customer, while for the public sector the relationship to their patients is based on science and the institutionalised provision of care. Consequently, the private first time customer, despite lack of experience, is to some extent more in control of the situation than the patient of the public clinic. Also, the users that acquire their hearing aids through the private sector may think of themselves as customers and not – like in the public sector – as recipients of a social benefit and thus more compliant to an invitation to participate in a scientific study. As a result, I had to rely on a positive private provider as well as advertise for respondents in order to get in touch with this group. The 38 respondents are between 42 and 92 years old with an equal distribution of women and men. The distribution is based on coincidence as I accepted almost all who volunteered to participate. I excluded one person at the very beginning of the study because she was too frail to participate. 22 of the respondents are retired and 16 still work. For the latter group, the motivation to acquire a hearing aid was connected to their occupation. For the great majority, the group of retired people represents a highly active group with a wish and need to participate in the activities of their networks. The respondents are all Danish, and their occupations include office staff, shopkeepers, medical staff, teachers, managers, an officer (military), a professor of economy, a lawyer, a bus driver, a social worker, an artisan and a technician. The study is asymmetrical in as much as the degree of contact to the users varies. In some cases, I conducted the first qualitative interviews with the users before they acquired their hearing aids – in others just after the acquisition. Subsequently, I contact the users to learn about their experiences with their hearing aids. When possible, I accompany them to the various institutions where the hearing aids are adjusted and carry out participant observation.

The aim of the first qualitative interview is to clarify the motivation of acquiring the hearing aid. Why do the respondents find it important to hear? How is their personal acceptance of being hearing impaired and being a hearing aid user? Does the hearing loss affect their identity? How do family and friends react to the hearing impairment? Why is the decision to acquire a hearing aid made at that particular time? By whom are they influenced? What are their expectations and, not least, the source of their expectations? Have they had to redefine their relations to other people due to the hearing loss? Are they engaged in activities that require them to attend meetings and quickly perceive what is going on?

Through the interviews, I also want to find out what motivates the respondents to acquire their hearing aids via the private or the public sector. Unlike most other European countries, Denmark does not have a long tradition for private health care. Even within the medical sector, it is in many cases viewed with suspicion to earn one's salary through private health care (expert interview with Torsten Johnsen, audiologist). Here there is a clear difference between hearing care and optical care. The practise of the welfare state has thus construed eye glasses to be a facilitator that is the responsibility of the individual to acquire and pay for. Only in cases of extreme financial need or very poor eyesight will the state subsidy or pay for eye glasses. It is difficult to say whether the difference in the legality of providing subsidies for eye glasses and hearing aids is connected to the costs of the devices, tradition and/or cultural differences in the perception of the nature and degree of suffering. It would be an interesting research question how and whether the state policy reflects the difference between the kind of social relationships poor eyesight and hearing imply. The fact is that different European countries legislate differently in this area. The respondents of this study find it quite normal to obtain their glasses from a high street optician without going to an eye specialist, because glasses are not seen as a health service provided by the state. Hearing aids are regarded along very different lines. Most of the respondents going to the public sector feel they have a right to free hearing aids, and it is stupid to pay for something you can get without payment. They feel they have paid sufficient taxes throughout their lifetime to have earned their hearing aids. A motivation to go to the private sector can be negative experiences of others who have obtained their hearing aids through the public sector, the long waiting lists or a general belief in private enterprise as opposed to public services.

The Best Hearing Care System in the World?

In Denmark, an estimated 500,000 out of a population of 5.4 million have a hearing loss that would justify the use of a hearing aid. However, only about 250,000 have actually opted for hearing aids. In Finland, the difference is even more significant, the size of the population is 5.2, but only about 14,000 hearing aids are distributed a year (without payment through the public clinics; no subsidies for the private clinics) whereas the same figure for Denmark is about 90,000 (private and public) (expert interview with Søren Hougaard, Manager of an international hearing aid company, 2003 - http://www.hear-it.org, 2003). There are a number of reasons for this, but one could be the efficiency of the Danish system from a historical viewpoint, another could be that the Danish language is blurred (BLESES D. - BASBØLL H. 2003) which complicates communication for the hard of hearing.

There is no precise figure for the use of the 250,000 hearing aids in Denmark. Estimates of hearing aids that are not used vary from 8% (Bispebjerg Hospital, public hearing clinic) to 50% (expert interview with Birgit Johnsen, audiologist and private distributor, 2003). An indication of the trend could be that I have made it at habit of talking about my study to people I meet. They almost all know hearing aid users, and most of them tell me about family members who do not use their hearing aids.

From the early days of the Hearing Health Services, since 1951, the system has made it possible for all Danes in need of hearing aids to have these provided free of charge. Users visiting the public hearing clinics are provided with good digital hearing aids and free batteries. The hearing aids provided through the public system are not always up to the very latest technological development, but they are certainly quality devices. However, at present, the political context is changing, which opens up for privatisation within the sector. To preserve and modernize the system as required, it would have seemed appropriate to analyse the system, create a debate, and adapt the system to the contemporary needs of the population and the general financial situation. Instead, the government has left the understaffed public sector to fend for itself. At the same time, it has strengthened the private sector by subsidising the acquisition of hearing aids through a private dealer. According to the government, this has been done to shorten waiting lists and to give the users the freedom to choose between the private and the public sectors.

Although there is heated debate in the Danish media about the poor standard of the public health sector, the confidence in the public hearing care system seems to be considerable. 85% of the hearing users see their ear specialist, are referred to the public hearing clinic and obtain their hearing aids there. In the study, some of the respondents said that they would be quite willing to pay something in order to obtain higher quality hearing aids. However, this is not possible in the public sector. Patients can nevertheless influence what they obtain from the public sector, but in order to choose the most suitable device, it is necessary to know what one can choose from. Nor is it given that one is always offered the option of choosing.

Due to the higher salaries paid by the private sector to audiogram technicians and hearing aid specialists, the consequences for the public sector have been a shortage of staff and thus longer waiting lists, which has again strengthened the position of the private sector. This has been especially problematic for those people with more severe hearing loss who have no financial means to acquire a powerful hearing aid privately. In addition, the private sector is not organised to interact with social authorities and with the labour market to find the best solutions for the hard of hearing with the most serious problems. However, this problem is given much less attention by the counties than previously which has deteriorated the situation for the most serious cases of the hard of hearing. Moreover, the shortage of qualified staff remains a problem. The public institutions train the specialists and technicians who measure the audiograms and adjust the hearing aids. On completing their training, these people are often hired by the private sector, leaving a gap to be filled in the public health facilities.

In order to obtain an overview of the Danish Hearing Health services from a professional viewpoint, I have carried out 27 expert interviews with public medical staff, private providers, politicians, and representatives of the pressure groups for the hard-of-hearing. The politicians agree that Denmark in general is moving from a supply-regulated health sector to a demand-regulated sector. They claim the problems in the sector are structural, and that market mechanisms will solve the issue. They also state that the financial resources are decreasing at the same time as the public demand for hearing aids is increasing. If the hearing health service is not to deteriorate further, the only way to bridge the gap seems to be through increased user payments.

The interviews I have carried out with representatives of the private and the public sectors reveal a highly competitive attitude towards each other. In some respects, they even have contrary interests. The private sector argues that they provide better service and at less costs to the public. Moreover, the same person mostly follows the user through the adaptation process, which makes the user feel more secure. Also, the users are invited to return to have their hearing aids readjusted. The private sector has a vested interest in increasing the number of users and thus rely on promoting a good reputation. As stated above, about 250,000 Danes are potential hearing aid users, which is a significant market potential. The public sector, on the other hand, urges the government to discontinue the subsidies to the private sector. Advocates for this sector stress the importance of the non-commercial prescription of hearing aids, noting the commercial interest of the private sector in selling as many hearing aids as possible and implying that people, who do not need hearing aids, receive them anyway. The number of follow-up visits during the adaptation process is limited to a minimum in the public sector. In order to shorten the waiting lists, the public sector has no interest in increasing the number of patients. Otherwise, administrative and political pressure on the clinic will increase.

The above may sound as if I conclude that the private sector is doing a better job than the public one. That is not necessarily the case. It could be argued that the private sector has the better conditions to provide good service, but the human factor plays an important role. In the public sector, some staff members provide excellent service, and it the private sector there are cases of greed that motivates the sale of a hearing aid.

The power struggle between the public and the private sector is only natural. But the policy pursued by the government seems to tip the scales in favour of the private sector. For instance, the Minister of Health recently attended the opening of a new outlet of a hearing aid chain store, whereas it is difficult for the public clinics to attract governmental attention when they celebrate an achievement.

The Mindful Body and Hearing Impairment

Having described the changing context of Danish hearing health care, the following pages offer an overview of the kind of impairment from which the hard of hearing suffer. To this end, I find it helpful to draw on the concepts of Nancy Scheper-Hughes:

> «The hypothesized "body" of which I speak – *mindful, nervous, consuming, commoditized, fetishized, labouring, anguished* or *disciplined* – is for critical medical anthropologists both unquestioningly real and existentially given, even though its very giveness is always historically and culturally produced» (SCHEPER-HUGHES N. 1994: 230).

The term '*mindful body*', is in itself a powerful declaration in opposition to the «radically materialist thinking, characteristic of clinical biomedicine» (SCHEPER-HUGHES N. - LOCK M.M. 1987: 8) which tends towards a separation of mind and body. For people with a gradual, acquired hearing loss that can be treated with a hearing aid, a simplification of the problem would typically be adapting a hearing aid based on the audiogram, without regard to other factors.

The gradual, acquired hearing loss is a bodily impairment, but it has no physical expression that can be perceived by other people. It does not cause physical pain, and it can rarely be cured. Its representation is social and existential, as it hinders communication, the exchange of ideas and knowledge and the identification of sound, e.g. danger signals.

The International Classification of Functioning (ICF) of the World Health Organisation avoids isolating the physical impairment from its social and cultural consequences. 'Functioning' is an umbrella term encompassing all body functions, activities and participation; similarly, disability serves as an umbrella term for impairments, activity limitations or participation restrictions. The ICF describes domains from the perspective of the body, the individual and society, and it is thus in the interaction of the individual and society that an impairment takes on significance. Hearing impairment entails restrictions on social participation, and the domains involved are learning and applying knowledge, communication, interpersonal interactions and relationships, major life areas, community, social and civic life (WHO 2001: 14, domains listed in ICF applying to hearing impairment, the choice of domains is undertaken by me).

A study of the origins, consequences and rehabilitation of hearing impairment requires the inclusion of technological, physical, medical, psychological, cultural and societal aspects. Prescribing hearing devices is not something that easily remedies a physical defect. Hearing aids may be accepted, rejected, generate stress, become an object of family strife, be seen as helpful or as a nuisance, as degrading and shameful or as something that symbolizes new and greater technology and thus an object used to negotiate social status.

A hearing impairment as such cannot be defined as an illness. Thus, it is not quite compatible with the concept of illness as a form of body praxis (SCHEPER-HUGHES N. 1994: 232) referring to the reaction of the *'mindful body'* to environmental stress factors. In that kind of reaction, establishing a relation between cause and effect requires an analysis of the societal power relations and their representation in the form of the illness. For the hearing impaired person, the link between cause and effect is more direct. Hearing impairment can be caused by hereditary factors, by excessive noise, by serious ear infections, medicine or by other causes. The various causes may interact. People who for hereditary reasons have ears susceptible to hearing impairment, have suffered from ear infections and work in a noisy environment have a high probability of acquiring hearing impairment. In other words, society leaves its mark on the hearing ability of the individual.

The Body as Starting Point

Maurice Merleau-Ponty (2000) sees the body as the starting point for our apprehension and construction of the world. Our sense organs are body parts that we use to perceive the world around us. Whatever we see, hear, feel, smell or taste of the world around us, our body is the indispensable vehicle to enable us to interact with the world. As a case in point, Merleau-Ponty describes various behaviour patterns of a group of people gradually losing their eyesight. Their behaviour falls into two groups. One group behaves as if it still can see. They do not adapt to the loss of eyesight, but they bump into things and seem to ignore the fact that they are getting blind. The other group adapt to the new situation, acquire a blind stick, find their way around without using their eyes although they still may have some eyesight left.

Both of the above strategies aim at staying in control of one's existence although the strategies are opposing and not equally useful. Merleau-Ponty's example of progressive blindness is comparable to the situation of the hard of hearing. Some people will acknowledge that they have a hearing loss; they will adjust their communication strategies and possibly acquire a hearing aid in order to remain part of their social networks of identification. Other people refuse to admit to their hearing impairment or it takes them several years to acknowledge the problem. Hence, an often heard remark is: 'There is nothing wrong with my hearing, if only I could make my wife speak more clearly.' The group that rejects hearing aids does not necessarily consciously turn their back on their social networks, but they are likely to pretend that they hear, and they may develop communication strategies that are seen as different from other people's. Some of the respondents of the study spoke very loudly prior to getting hearing aids because they could not hear their own voice; some spoke all the time to prevent questions they could not hear. For the same reason, some of the respondents tend to participate physically but not socially in larger social gatherings. In literature about hearing, it is described that some even tend to isolate themselves (e.g. HÉTU R. 1996). Only about four of the respondents of this study can be said to have consciously occupied themselves with the development of their hearing problem and have had their audiogram taken to see if measures were required. To a varying degree, the others have considered the problem as non-existent until its impact on their life could no longer be ignored.

Both strategies, i.e. acknowledging or repressing the hearing loss, can be based on strategies that within a certain dialectic might be useful or detrimental. Acknowledging the hearing loss and acting on it is a useful strategy to remain in control of one's position in one's social networks. If we consider the disadvantages of this strategy, it could be a general tendency to focus on morbidity, such that a hearing loss could be used to establish an identity. It could also indicate a possible lack of independence such that one is constantly seeking facilitators. The latter view is not represented by the respondents in the study.

Denying the existence of a hearing loss could on the one hand be based on a desire to appear healthy and fit, which in a positive sense is helpful. In a negative sense, however, it can lead to negligence of a condition that should have been examined. The individual could also be motivated by vanity or by a fear that the hearing aid would be associated with old age or lack of intelligence – views that often are expressed by the respondents and informants. It could be connected to a kind of body alienation (SCHEPER-HUGHES N. - LOCK M.M. 1987) as expressed in the obsessions, and fetishisms of 'modern' life in the post industrialized world. Some hard of hearing idealize the youthful and perfect body to the extent that the hearing aid becomes a taboo (ARVIDSSON T. 2000). In their description of the body politic, Lock and Scheper-Hughes (SCHEPER-HUGHES N. - LOCK M.M. 1987: 25), quoting Pollitt 1982, claim that the politically correct body is the lean, strong, androgynous, physically fit form. Health is the responsibility of the individual, which makes ill health the individual's failure to live in the prescribed way. This means that persons with physical ailments not only have to live with their weakness, they also have to cope with their own sense of guilt and with society's suspicion that they probably did not take enough care to avoid their condition. For the sense of hearing, this statement is supported by medical tests showing a connection between a good blood circulation and good hearing ability. Exercise improves blood circulation (http://www.hoerelse.info, 30 Nov 03). On this point as well, I find an inherent dialectic. The position at one extreme is the idealization of the youthful and perfect body that depicts a sick society focussing on human difference. The other extreme is the total lack of interest in health and well being. When it comes to hearing aids, a balanced strategy is a point where a hearing aid is seen as the difference between hearing and not hearing and not a negotiable emblem making the user more or less worthy in the eyes of the world. At this point, the individual takes an interest in preventing the noise-induced hearing loss or in keeping fit. Comparing this aspect with the respondents of this study, I find statements that support this view in as much as some respondents tend to look at their hearing loss as self-inflicted.

It could be argued that the hearing aid challenges the integrity of the body. In comparison to glasses, hearing aids seem to penetrate the body, thus transgressing a borderline of privacy. When directly asked in an interview situation, the respondents in this study do not have any problems with earwax. It is something that is taken care of through everyday hygiene. This attitude reflects the disciplined individual displaying an embodied civilisation. The same attitude is involved in a medical examination or adjustment situation. Here, the respondents find it embarrassing when the medical staff observes earwax in the ear or on the hearing aids. During the participant observations, I have often heard the comment: 'But I cleaned my ears this morning!' A few respondents in general find hearing aids repulsive because they are associated with earwax or/and prostheses. In addition, some respondents find it unpleasant when they see a hearing aid user operating the volume control or changing between different programs. Our civilisation is embodied to a degree that it is repulsive to touch the ears – even to adjust technology.

Another aspect that touches on fetishizing – not of the body but of the hearing aid – is advertising. Advertising is jubilant about the positive sides of hearing aids – forgetting about the troublesome aspects of becoming a hearing aid user. It creates a fiction of naturalness, a touch of ecology and organic feelings. Sometimes hearing devices are linked to prestigious sport requisites such as golf clubs or tennis rackets. Advertisements of hearing aids depict togetherness and inclusion in social networks – all qualities that the hearing aids as such are unable to produce. Naturalness, ecology and organic feeling illustrate the problem for the hearing aid user. They are indeed very far from hearing aids, but over time, they may become natural to its user. It can be a matter of habituation lasting from a few weeks to six months. When advertising combines naturalness, ecology and an organic touch with hearing aids, it represents an attempt to eliminate the association of the technology-governed individual. The two latter features, togetherness and inclusion in social networks, are exactly the situations from which most hard of hearing feel isolated. Sometimes advertisements promise more participation than the hard of hearing ever had as a normal hearing person. For many hearing aid users, the desire to remain part of a social group is what motivates them to acquire a hearing aid. The public sector blames the hearing aid manufactures for creating unrealistic user expectations. However, few of the respondents have looked at folders or newspaper ads. Few have made an effort to find out what hearing aids are all about, what models are available and what specifications they have. There seems to be a considerable reluctance to occupy oneself with the theme. What matters to the prospective users is that the hearing aids should be as small as possible, though a few have said that it is up to the doctor to decide. Reflecting about something requires experience.

> «Experience contains ordinary acts, from the casual to the most eventful occurrences. It embodies both meanings and feelings, the flowering of individual response that continually gravitates toward typicality, so that afterward we can find words to talk about what happened» (ABRAHAMS R. D. 1986: 49).

Acquiring a hearing aid is formative and transformative and can be seen as a reflection of the *Nervous Body*. It is a distinguishable, isolable sequence of an external event and internal responses to it. It is an initiation into a new way of life (TURNER V.W. 1986: 35). The new way of life is a path that the respondents never desired to take. At the same time, the hearing aid could mean the re-inclusion into the social networks from which the hearing impairment threatens to exclude them. These circumstances are reflected in the varying degree of nervous tension I find during the participant observation of new hearing aid users when they receive their hearing aids.

As shown above, there are more factors to a hearing loss than a declining audiogram. Also, the *Anguished body* play a role. Anguish may stem from feelings of shame and guilt often connected to a hearing loss. Although this may be difficult to understand, there are several reasons for this. As already said, some hard of hearing people try to pass as people with normal hearing, pretending to know what is going on when interacting with others. It may be to avoid being troublesome and appearing stupid because one needs to have everything repeated. The hearing-impaired person is on the one hand being considerate to other people and on the other hand trying to make a good impression (BOISEN G. 1989). But this is a dual misrepresentation: 1) Cheating others is not considerate; 2) One cheats oneself into thinking one is being considerate. The deception is connected to feelings of shame, and the risk of embarrassment is substantial, if for example one smiles happily when someone actually is speaking of a family tragedy.

However, there is something more to it. The act of listening involves a number of factors. On the one hand, listening means capturing and understanding the sound signals entering the ear. On the other hand, it means being smart enough to understand and react to what is being said. Through our upbringing, most of us have been told by parents and teachers that we will get in trouble if we do not listen. This makes some people feel guilty if they misunderstand things. A hearing loss forces the hard of hearing to challenge both their own and other people's assumptions that they did not understand because they were not paying sufficient attention. It is a lose-lose scenario, in which people not only feel ashamed over the hearing loss; they also have to cope with people's irritation over them 'not listening properly'.

The hearing impairment and its consequences seem to counteract the *disciplined body* in the sense of 'The Foucauldian question': «What kind of body does society want and need?» (SCHEPER-HUGHES N. 1994: 132). There is the restriction that the respondents are not without agency, and will react to the pressure exerted on them. The initial degree of confidence in the chosen system is high, but as individuals gain experience with the hearing aids, the intangible will become palpable. Questions may be asked, strategies can be developed to embody the idea of being a hearing aid user – or the hearing aids may be rejected. As already stated, Denmark may still have the best hearing care system in the world. In this respect, the answer to the Foucauldian question is: 'Society wants and needs independent citizens who can communicate and participate in all sectors of the modern state'. Still, only about half the people eligible for hearing aids actually decide to acquire them. If hearing aids are such a wonderful vehicle for individuals to remain in touch with their social networks, then what has gone wrong?

In connection with this study, I also find elements of the *Consuming* and *Commoditized Body*. The hard of hearing consume the services of the public and private health services and hearing aid industry, at the same time, they are the object of the hearing aid industry and the public and private hearing health services. It often takes a resourceful person to become a satisfied hearing aid consumer. It may require many trips to the clinics to come to terms with one's new hearing device. The problem can be the level of amplification, the quality of the sound, the earplugs, how to handle the technology or a psychosocial problem. Acquiring a hearing aid might also lead to an initial or more enduring alienation in as much as the user will have to get accustomed to hearing electronic sound. Although a hearing device can be seen as a means of perceiving the sounds around them, some users complain that the technology forms a barrier between themselves and their environment. They may find the tiny hearing aid difficult to handle. They complain that what they hear through the hearing aids is not natural to them. They may feel alienated because voices of loved-ones sound different. They may experience that they are out of control, that the hearing aid determines how they perceive the world around them. Some people feel controlled by the way the computer regulates the sound levels around them. Many of these problems are transient, and the respondents seem to get used to the different sound quality. They enjoy the fact that they can now hear certain bird songs, can take part in meetings, and gain more pleasure from listening to music. This group is likely to experiment with the technology to establish where a hearing device is helpful and where it is not. But really enjoying being a hearing aid user is something that does not apply to the respondents at this stage.

Lock and Scheper-Hughes ask whether our humanity is being compromised in the process of being put on the machine of modern technology (SCHEPER-HUGHES N. - LOCK M.M. 1987: 23). The following adaptation of Haraway represents a different attitude to technology which I find important, and which I will elaborate on in my future work on this topic. Haraway starts the chapter by saying: «This chapter is an effort to build an ironic political myth» (HARAWAY D.J. 1991: 149). More than irony is implied here; from a feminist viewpoint, she deals with the fear of alienation connected to modern technology. I would like to extend her idea to encompass not only women, but both genders when she writes:

> «Intense pleasure in skill, machine skill, ceases to be a sin, but an aspect of embodiment. The machine is not an *it* to be animated, worshipped, and dominated. The machine is us, our processes, an aspect of our embodiment» (HARAWAY D.J. 1991: 180).

The above quote can be paralleled by the example of one of my informants. She is 82 years old, has an artificial hip, uses hearing aids and has had surgery for a cataract condition. She teaches a German class five days a week, visits museums and goes to the theatre. What would her life be like if she had turned down the offer of modern technology?

Conclusion

The analysis and collection of data for this study has not yet been completed. However, it is not too early to conclude that some people just turn on their hearing aids, they can hear, and they are satisfied. In other cases, it requires a resourceful person to become a contented hearing aid user. Users need to be curious about what life has in store for them, daring to try something new when it appears, persevering when difficulties appear in adjusting to a different quality of sound, persistent when explaining to professional staff why the hearing aid is unbearable to listen to, or why they do not fit. One of the respondents who uses a public sector hearing aid provider remarks: «The staff provide good service before you get the hearing aid, but once you have them, they seem to consider you a burden when you turn up for help!».

The present situation with private and public hearing aid clinics has complicated the situation for the users. The lack of agreement between the involved parties as to the future organisation of the sector affects the users. Their 'journey' through the system is characterised by randomness and routine. Randomness, because the way in which they solve their hearing problem depends on whom they talk to at a given time. Routine because the system they choose propels them towards an outcome that may or may not prove to be effective. It is only during the process that they gain experience. Hence, one of the respondents remarks: «It is not until you come home with your hearing aids that you know what to ask!».

The process of rehabilitation of the hard of hearing through a hearing aid is in many cases a formative and transformative process. Hearing loss makes itself felt in any activity in as much as the sound proof space does not exist in the 'real' world. Consequently, the interaction with the social and material world will gradually be reconstructed and redefined which the hard of hearing with the gradual hearing loss may not notice. If the decision is made to acquire a hearing aid, another process of reconstruction and redefinition lies ahead. Not even the best hearing aid can restore normal hearing, but all the same, the hearing aid can be the bridge to inclusion and participation in many cases.

The Danish welfare state has constructed a system in which hearing aids by many are seen as a natural and rightful benefit. However, the modern welfare state is under attack from several sides, i.e. poor planning, increased medicalisation of society and the increased life expectancy. It remains to be seen if the Danish health care policy in future will define it as a right to hear for the widest possible group of people.

Note

(1) The capital D in Deaf refers to Deaf culture which compares to other cultural or language communities.

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1.3 *The leading edge of the situation: the patient perspective in a health technology assessment*

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Patient Perspective on Electronic Patient Record

An obstetric doctor: «This electronic patient record has a fantastic way of removing ones attention from what it is all about... that is the woman. I have been diversed from the cause. Earlier I listened with an open mind. Now it happens that a woman leaves the consultation without me noticing that she was upset...she left crying...but I didn't notice...».

Woman at the maternity ward: «The doctors and nurses are well informed – they are updated, more so than before the electronic patient record. In the consultation you have a dialogue concerning what to write in the record...it makes me feel important and co-responsible».

This is apparently enough not the exact same experience they are referring to, but they refer to the same frame of experience. What I found was that doctors and midwifes were far more concerned about the drawbacks of the medical record than were the women. The doctors experienced that the medical record was a very problematic new technology affecting the contact between patient and professional to a disturbingly high degree. Where as most woman were very positive and tended to suppress the less positive aspects in favour of the overall good experiences.

So what I am asking myself is; does looking at "the patient perspective version" actually blur what is really going on and is this really "for the good of the patients"? Do the patients realize what they are not getting? And would we in fact be doing the patients a disservice if we let their voices be decisive in this kind of research. Is this in fact another good example of how important participant observation is when trying to convey interaction and put into perspective respectively the doctors and the women's experience? Finally can this be done on a limited budget working interdisciplinary with economists and medical doctors? Especially the last question is a large challenge. In Denmark the task of integrating the anthropological perspective in interdisciplinary research is still some what like introducing an alien in a world where everyone else seems to agree on different research traditions. And the reality is that it is very seldom possible. So as anthropologists we have to make the best of the little "space" we do get.

My paper, "Patient Perspective on Electronic Patient Record" is part of a Health Technology Assessment of the Electronic Patient Record in Frederiksborg County in Denmark. What I would like to achieve with this paper is partly to present some results – a little piece of applied anthropology. Some results which hopefully will illuminate and eventually help better conditions for pregnant women and women giving birth within the Danish health sector. And partly to debate if I can conduct anthropology when I work within the setting and under the premises of the Health Technology Assessment framework and the timeframe constituted by the economy.

HTA of the Electronic Patient Record

It is widely believed that introducing the electronic patient record into hospitals can benefit health care in a number of ways. There has however, been very few studies documenting this assumption, justifying investments in such systems. To address this subject we conducted a study based on the principles of HTA of a new electronic medical record within an obstetric department in two hospitals in Frederiksborg County in Denmark.

The researchers on this HTA was an interdisciplinary team consisting of medical doctor and specialist in health care informatics, Peter Wied, health economist, Anne Hvenegaard, and me as social anthropologist. I was at the time of the survey employed at DSI the Danish Institute of Health Services Research as a researcher and am now employed at the Institute of Anthropology at the University of Copenhagen. The HTA was financed by CEMTV (Center for Health Technology Assessments in Denmark, Frederiksborg County and DSI - Danish Institute for Health Services Research.

What Is a Health Technology Assessment?

A Health Technology Assessment is build over 4 individual analysis – one of respectively the technology, the organization, the economy and the patient perspective followed by a synthesis. A synthesis which is the real challenge as this is to be one joint presentation of results from research very often belonging to very different theories of science.

Personally I believe this framework to be constructive and productive if the researchers with the very different scientific approached relate to one another and have a running dialogue in order to influence the formulating of the synthesis. This however, is very often not the case. Traditionally this framework is used within the medical world by researchers with a medical and an economic background. When the researchers finally arrive at the "patient" part this has for a large part been surpassed. The larger HTA's however, financed by the CEMTV in Denmark have started to use researchers from the social sciences and so has DSI where I worked. It was very evident, however that the invitation to dialogue has to come from the researcher representing the social sciences – our scientific worldview apparently enables us to encompass other worldviews more often than visa versa.

Where and Why?

Frederiksborg County is one of 14 Danish counties numbering a total of 350.000 citizens. At the time of the study there were two hospitals in the county with obstetric service. Both departments were under the same management and were included in the study.

The electronic patient record was implemented in the year 2000 and after implementation and more than one year of experience with the new system both leaders and staff of the obstetric department agreed that much had been gained. There were however, still a number of uncertainties of the consequences of the EMR and it's exact benefits or drawbacks. Moreover it was perceived, that implementation had been costly, but it was not known how many resources had actually been put into the project altogether.

In choosing the analytical pathway we wished to use a systematic interdisciplinary method that would make it possible to illuminate the electronic patient record – in relationship to several perspectives and relate these perspectives to one another.

The focus of my paper is the analysis of the expectations and experiences of the woman over the entire course of maternity and birth. That is from the patient perspective – what are the benefits and drawbacks of the electronic patient record and under what conditions are they perceived?

How Was Data Generated?

Datageneration for the analysis of the technology, the organization and the patient perspective are based on a methodological triangulation. The health economic analysis is a cost-consequence analysis.

Data was generated by:

- observational studies in the wards as well as in the delivery rooms
- questionnaires aimed at both patients and staff
- single qualitative interviews with patients, leaders and selected staff members
- focus group interviews with staff members mixed and in separate occupational groups
- project account data and data extracts from the EMR and other IT systems – which was not used in this particular analysis.

The data pool provided the empirical basis for my analysis focusing on interaction between patient, caregivers and technology.

The data also provided the empirical basis for the organizational and the technological analysis as well and it supported the analysis of the economy. This, I believe was one of the main reasons why we succeeded fairly well in doing a cross disciplinary analysis – we generated most of the data together and had a running dialogue while analyzing it for each part of the HTA.

Observational studies were used to perspectify the interviews and the questionnaires as they are eminent for showing the interaction and relationship between people, and the schisma that can arise between what people say the are doing and what they actually are doing.

Experience, Relationships and Wishes

My paper focus on the women‘s experiences over the entire course of pregnancy, labor, and the post-natal period what are the benefits and drawbacks of the electronic medical record and under what conditions are they perceived? I selected three core themes in order to evolve this focus.

- Does the use of EPR influence the relationship between patient and caregivers and if so in which way?
- Does the use of EPR influence the patients perception of quality of care and if so in which way?
- Does the EPR support the patients wishes and needs and if so in which way?

Being Someone

«One is involved in a dialogue relating to ones own history when the caregivers are writing in the EPR – that feels good», remark from a new mother.

«I felt a bit insecure when the midwife turned away from me during delivery to write in the EPR», a woman expressed after giving birth.

«It is good if we involve the women in the dialogue when writing in the EPR – it makes them more responsible», a caregiver said after a consultation.

«We loose the contact with the socially weak women – they are the loosers», a caregiver said with concern after having experienced a consultation where he overlooked a womans signs of distress while he was using the EPR.

Being involved and feeling co-responsible and updated, are apparently key parameters for feeling confident and safe.

On the drawback side we have the woman feeling left out and alone when the midwife turns away. We also have the caregivers, especially doctors, expressing deep worry concerning the socially weak women – they fear that they (the doctors) are not able to pay attention to the signs and expressions when being absorbed with dataentering in the EPR. This also turned out to be the case during several of my observations. Following one of these the doctor commented «yes, and there she was crying when she left...the young pregnant women, and I hadn't even noticed...»

The women's level of satisfaction reflects the caregivers ability to involve her in a dialog concerning the information being "put into" and "produced" by the EPR. It was experienced as very positive by most women that they themselves were able to keep track of what was being written on the screen and at the same time being able to participate in a dialogue with the caretakers about what was being written.

On the Leading Edge of the Situation

Most women thought that EPR was a useful instrument for the caregivers and this especially came into expression through a perceived improvement of the communication procedures and information flow.

The women experienced that the caregivers were on the "leading edge of the situation" and therefore capable of "putting pieces of information on top of each other" – in other words they knew what had happened or had been said and, what was to happen next. On the other hand the women experienced an information failure or breakdown in the cases where the midwife consultations had no Epr – which was the case in a couple of satellite consultations in the county.

The women's experiences and perceptions thus indicate that the quality of care can be supported by an adequate use of the Epr – provided that information can flow freely and unhindered between all involved caregivers. The information flow – thus – is the precondition for feeling that the quality of care is good.

Quality Confidence in the Caregivers

The women's evaluation of the quality of care was primarily related to their experience of service in the ward and the degree to which they experienced that the caregivers were being supported by the Epr. The women agreed that what really meant something was when they felt that the caregivers were "on top of the situation" that is knew what had been done, what had happened and what was to happen. This meant that the women had confidence in the caregivers and this equals good quality. It was however difficult for the women to determine and relate to the professional definition of quality of the care and treatment. However, the women's experiences and perceptions indicate that the quality of care can be supported by an adequate use of the Epr – provided that information can flow freely and unhindered between the involved caretakers.

Supporting Wishes and Needs

By large the women expressed that the Epr altogether supported their wishes and needs. Well-informed and forward looking doctors, nurses and midwifes were perceived as the precondition for a well-planned pathway for the women (patient).

The fact that the Epr also gave room for a very intentional and direct involvement and thereby created a sense of co-responsibility for the course of care and treatment supported this positive experience furthermore.

Drawbacks were experienced by both patients and caregivers primarily concerning lack of attention in given situations and a tendency towards the technology "favoring" the women whom themselves were able to "build bridges". This meaning that socially weak women might be even more lost if the caretakers are not especially aware of this pitfall.

It seems that

- The practical skill with which the caregivers use EPR is decisive for the degree to which the women are satisfied
- The womens satisfaction is reflected directly by caregivers ability to involve her in a dialogue relating to the information "being put into the EPR" which again is interdependent with the caregivers practical skill
- The womens experiences indicate that the quality of care is perceived as being related to and supported by the use of EPR. The precondition being that information can flow unhindered between all parties involved in the care taking of the women
- Well informed caregivers are perceived by the women as the precondition for a well organized patient pathway

Caregivers thus have to be very aware of the pitfall called "absorbing themselves in technology" instead of "being there, being attentive and actively going into a dialogue with the women". A difficult but necessary lesson in communication!

Finally EPR systems should only be implemented if all parties involved in the patient pathway have access to it – otherwise lacking information is perceived as quality flaw producing uncertain and unsatisfied women.

The synthesis of the four HTA elements (which is a must in a Health Technology Assessment) shows an apparent lack of in depth understanding of the patient perspective contrasting the caregivers perspective – the synthesis does not grasp the great concern expressed by the caregivers and not perceived by the woman themselves – especially not the woman in question – the socially weak woman. The synthesis presents the overall positive patient perspective – and this is what will be put forward to the political decision makers. The synthesis has not captured the "in between conclusions" which could have been supported by more observational studies – which there in this interdisciplinary study was neither money nor understanding for. And with the objectives of an HTA and working with hardcore scientists it was not possible to argue that it was exactly the relationship between the different perspectives that conveyed the essence of the problem. I still wonder if the the patientperspective analysis in this HTA in fact will be of a disadvantage for the patients if the "lost womens voises" are not brought into the synthesis and I wonder if this is possible when working within the framework of four different theories of science according to the HTA framework?

The synthesis was framed as follows: the HTA of all four perspectives showed that EPR indeed held many advantages. However, some of these were only potential. To reap the full benefit further organisational changes matching the new possibilities with an EPR were needed. Patients were generally content and felt confident with the use of computers. A better service and treatment was perceived when the EPR was well implemented and the caregivers had learned the skill of communication and involvement while working with EPR. Implementation as well as the daily use of the system was rather costly especially in terms of staff time needed and loss of productivity.

This is what is presented for the political decision makers and this is what they will act upon...

I believe however, that the results support the ongoing work within the health sector concerning the uncovering of patient wishes, needs and concerns. A weighty amount of patient satisfaction surveys have yet to convey what patient satisfaction really is. I believe my results actually express core elements concerning patient interests. The fact that this does not come clearly through in the present HTA synthesis I can live with if I believe the results point towards a better understanding of patient needs in general within the Danish health sector. And this I do.

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1.4 *From the doctor's psychotropic medication to the patient's remedies, or subversion of medicalisation*

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At the previous seminar we analysed the prescription of antidepressant drugs by general practitioners (GPs) in western Brittany (HAXAIRE C. - BODÉNEZ P. - BAIL P. 2002). Our survey (funded by MILDT, HAXAIRE C. *et al.*, 2003) focused on asking GPs to talk about problems of dependency involving patients seen in the doctor's office in the week preceding the interview. But the practitioners' remarks went far beyond this topic, as they brought up everything which, in their view, came under the general heading of "*psychological*" problems. In addition to certified cases of psychiatric disturbance that the practitioners treat directly or monitor, this vague term encompassed reasons given by the patients for their visit to the doctor, ranging from "*life events*" to "*psychic suffering*" (LAZARUS A. ed. 1994) engendered by new social circumstances (familial or professional pressures, loss of social ties, isolation, exclusion). Prescription of antidepressants, which was the outcome of some of these visits, appeared to be not only treatment of clearly identified depression, but also in some cases a tool in the care relationship. For the practitioner the goal was to liberate speech, to unblock a situation that seemed to obstruct the patient's future. This was done so as to be able to develop a supportive relationship that these GPs value, because it opens up a pathway to more appropriate relief for the problem given as "*the reason*" for the initial distress (1). In these interviews, rather than presenting their practices as treatment of the cardinal symptoms of depression, the practitioners showed that they were attentive to caring for patients that they knew well and that they felt "*were having a bad time*."

Use (consumption and prescription) of psychotropic medication has been analysed as one of the examples of the increasing medicalisation of social problems in the western world (Jaeger M. 1998). These public health issues are the subject of debate in France (Legrain M. 1990, Zarifian E. 1996). Practitioners are seen as prescribing too many anxiolytics and hypnotics in the benzodiazepine family, but too few antidepressants. It is claimed that they do not properly diagnose full-blown depression, while indiscriminately treating grief due to mourning and other circumstantial events. It is clear that if only purely quantitative information is taken into account we will not see the very different practices hidden behind the data, and will fail to understand the prescribing physician's viewpoint, and hence the meaning of this medicalisation.

From the consumers' point of view, recent studies among young people (Le Garrec S. 2002, Fernandez I. 2003) clearly show that psychotropic medication is one of several possible types of psychotropes that can be used in ways not necessarily related to medicine. Attempts at self-medication to treat the blues or psychiatric disorders with all sorts of psychotropes are increasingly well documented (in Barrow S.M. 1999). For earlier generations, tonics and digestive aids, that calmed the nerves, belonged to the class of foodstuffs (Brabant-Hamonic J. 1996, Haxaire C. 2002). One can therefore wonder, in the case of psychotropes, how robustly the medication is controlled by medical practice (cf. the return to etymology effected by Raynaud and Coudert, 1987). What would the situation be if these medications, unrestricted, were left to their function of remedy, a remedy being, according to the same authors, that which fills a gap between what is perceived, by non-specialists, as pathological, and that which is accepted by them as normal. As a minimum, is deviation from the norm perceived as an "illness", for example where sleep is concerned? The tolerance level for insomnia has indeed varied historically. Should the mandatory visit to the doctor (for these products are only available with a prescription) be interpreted as recourse to medical care on the part of those who often submit to care very unwillingly? In this respect as well there is room to wonder what lies behind this medicalisation.

We propose to pursue this question of medicalisation from the standpoint of anthropology of pharmaceuticals (Van der Geest S. *et al.* 1996). As we do not believe that the "naturalisation" of pharmaceuticals goes without saying, either for patients or for their doctors in the context of a therapeutic relationship, we will attempt to grasp the meaning that patient and doctor ascribe to prescription and to consumption. We follow D. Cohen et al. (Cohen D. *et al.* 2001) when they maintain that «prescribed medication [should be viewed] as a multifaceted, fluctuating, and mutating object... constructed ... [as thought and behaviour] in the exchange of symbols between individuals and collectivities», but we shall explore some of those exchanges further.

We will cover here all kinds of psychotropic medication prescribed in general medical practice, and not antidepressants alone as before. We will analyse the traces of consumers' strategies in the prescribers' practices, and confront the two.

Survey and Methodology

We have adopted a consistent methodology for the surveys conducted with general practitioners and consumers. This methodology consisted of compiling accounts of practices along with physical traces of these practices. For the practitioners these traces were notes extracted from the patient's file. Consumers were asked to situate each medication from the family medicine cabinet in relation to the prescribed treatment and the incident of illness involved. Prescriptions for psychotropes were gathered in the broader context of the doctors' daily practice: we asked the practitioners to elaborate on any eventual questions regarding dependency that occurred to them in relation to each patient. Psychotropes were given along with other medication, but also in conjunction with recourse to other non-medication treatments, practices or commonly used products, as the case might be. In this survey we queried ten general practitioners in western Brittany, chosen among those whom we could assume had reasonably up-to-date knowledge, given their proximity to a hospital environment (Tamblyn R.M. *et al.* 1997). Six of these practitioners treated patients on opiate substitute products. These doctors practice in towns as well as in rural areas, with diverse types of clientele (small towns, rural areas, but also so-called tough neighbourhoods in cities, and remote districts in the centre of the region). We met with ten consumers from the same region (including one man). The majority were middle-class women in their 40s or 50s, with some experience – past or present – with antidepressants. Consumers of alcohol, cannabis and tobacco as well (but not of opiates), some had recourse to alternative practices. The small number of interviewees is explained by the fact that in this research we sought to validate earlier survey involving some 30 interviews (Haxaire C. *et al.* 1999), as well as the above-cited results obtained by Fernandez (FERNANDEZ I. 2003) in other regions and among populations with different characteristics (middle-class people, average age 60, in Normandy, and individuals of varying ages, social status and pathologies in Toulouse).

It is noteworthy that, for practitioners and consumers alike, psychotropic pharmaceuticals constitute a group distinct from other types of medication (set generated by the ALCESTE software for statistical analysis of textual data, semiotically based) (2). It is therefore legitimate to undertake an analysis of the specificity of this set (3). We will describe the subsets that emerged, both in terms of content and in terms of the forms of discourse that characterise them, and look at these results in relation to the practices observed.

General Practitioners and Their Psychotropes

For the general practitioners, the specific lexical universe of psychotropic medication is in this analysis a subdivision of the larger set of psychotropes in general (alcohol, ...), which is opposed to ordinary medical practice and treatment.

This lexical universe encompasses the names of psychotropic medications (including Subutex® (4)) as well as the names of the therapeutic class to which they belong (*antidepressant, tranquilliser, hypnotic, neuroleptic*). It includes words that divide up the day (*morning, noon, evening, night, daytime, day*) and the year (*January, October*) as well as words referring to dosages and their fractions (*quarter, milligram*) and adjustment of dosages (*reduce, increase, add, stop*), as we will also see in the patients' discourses. The illnesses or problems are related to sleep (*to sleep, insomnia*), to distress (*anxiety, depression,* "angoisse" – *suffocation*) and to somatisation (*stomach, colopathic disease*). These words are associated with verbs that express the acts of both partners in the therapeutic relationship (*take, prescribe, put*) as well as negotiation on the part of the patient (*ask for, try*) as well as the doctor (*explain, talk about again*). The outcomes of negotiation never seem to be final, and appear to be subject to "*steps taken*" by the patient; the results are called into question at each new "*appointment*". Confronting the "*need*" of a patient who takes a product "*over a long time*", doctors, as we will see below, call medication or behaviour over which they have no control "*stuff*" or "*foolishness*" respectively.

Many adverbs of quantity are found in this universe (*at least, more, how much, more, less*), and temporal adverbs (*at the time, since, always, early, until,* *when, right away, quickly*). There is reference to the patient (*she, he, her, him*) and to the medication that the patient has (dominance of the auxiliary "*to have*") rather than what it is. Modal marks (*why, because, that is to say*) outline a posture in which the interlocutor feels obliged to justify explanations regarding positions that she or he does not dare to declare outright (*I think, maybe*) and acts that she or he "*should*" or "*wants*" to undertake.

The universe of this type of medication consists, for the doctors, of ongoing negotiation about dosage and frequency of medication that the prescriptions imply. For this reason substitute products are not just a part of this universe, they are indeed prime examples of it.

As a general rule it seems that the doctors seek to set a framework for the practices of their patients. Is this because these practices tend to escape their control?

To answer this question we must go back to an analysis, "treatment" by "treatment". It is noteworthy that we can clearly identify enunciatory postures that vary depending on the "treatment".

Within the broad class of "psychotropic medication" distinct categories appear, distinguished not only by the therapeutic class of each pharmaceutical, but also according to the nature of the treatment in which the medication is used (HAXAIRE - RICHARD - BODÉNEZ - LOCQUET, *in press*). In other words, a hypnotic or an anxiolytic associated with an antidepressant or a neuroleptic will be regarded differently than if it is used without other psychotropes. It is thus possible to distinguish the following four categories: hypnotics or anxiolytics prescribed alone ("*little pills in the evening*"), treatment with antidepressants (eventually in association with hypnotics or anxiolytics), "*psychiatric*" treatment including a neuroleptic (with or without antidepressant, hypnotic, anxiolytic), and replacement therapy (5).

If there is one type of treatment that appears to elude the practitioners' control, it is those "*little pills in the evening*". Indeed, the doctors seem to want to keep their distance from treatment involving only hypnotics or anxiolytics, as psychotropes. In these cases the doctors do not assume responsibility for their prescriptive practices, evoking their patients' requests in statements such as "*he takes his little X* [a hypnotic]". These prescriptions are never justified by a medical argument or reasoning, the GPs reiterate the patients' classifications: "*to get to sleep*". The term "*dependency*" does not arise, or is denied. In some cases it may be mentioned, but using the patient's terms and justifications: "*he needs some…*". These treatments are minimised and neutralised in various ways. Lastly, what really distinguishes this category from the viewpoint of discourse analysis is the absence of signs of the doctor's investment in what s/he is saying. The patient emerges as the active subject of consumption: "*he takes his* X", or more crudely, "*he comes to get his stuff*", where the medication is attributed to the patient by the possessive adjective "his".

By contrast, the discourse on antidepressant treatment is medical, both in the way the diagnosis is established and justified, and in the evaluation of the treatment. It is not foreseen that these forms of treatment, undertaken in the wake of serious problems, could lead to addiction. The doctors use the term "*care for*", they take responsibility for this care and the prescription: "*I put her back on X* [antidepressant] *and Z* [anxiolytic]."

Treatment involving neuroleptics is characterised as serious by doctors who use adjectives such as "*awful, monumental, weighty, burdensome*". From the outset their excessive nature leaves the doctors little room for taking charge of treatment. In fact, the diagnoses are not always reported. In half the cases it is a matter of following the prescription of another doctor, the psychiatrist. In other cases problems of violence are mentioned, that go beyond the doctors' habitual capacity for assuming responsibility. In their discourse the doctors keep their distance from their patients, by the way in which they speak of them. Generally they use introductory sentences such as "*This is a lady who...*". Likewise the pharmaceuticals, when they are named, are given in the form of a list, without qualifier and without indication of posology. This contrasts with medication for associated somatic pathologies; "*He came out of the hospital with W [neuroleptic]- 5 drops, I [hypnotic]- one a day, Y [another neuroleptic]- one in the evening*." Inversely, when the GP is the initiator of the treatment we once again find statements like those formulated for treatment (antidepressants) for which the practitioners assume responsibility: "*I was the one who took charge of her treatment.. she has T* [neuroleptic]."

As for replacement therapy, among the doctors surveyed this form of treatment is classed with therapeutic acts for which they assume responsibility, and which they justify and evaluate. Negotiating from one renewal of the prescription to the next, they are precisely attempting to maintain their patients within the framework of treatment, and keep them from sliding back into substance abuse, which one practitioner distinguishes from dependency. Here we find once again the markers of the doctor's viewpoint that we have already noted, i.e. the shift from "*his*" or "*her*" toxic substance to "*undergoing*" treatment. The responsibility for consumption is pushed onto the patient when there is substance abuse – "*he takes his Subutex® in secret*" – in contrast to "*the other patient who is on Subutex®*". The abundance of verbs such as "*explain, convince*", the specific details of posology and dosage reported, attest to the subject of negotiation. But regarding replacement therapy, the aims of patient and practitioner are clearly set forth, each seeks to maintain or restore insertion in society. The doctor evaluates this just as much as the state of the patient's health. In this respect the doctor is fully implicated, and associated with success or failure.

With benzodiazepines, given as treatment to patients who are being weaned from alcohol, there is a change of register. The use of the expression "*on benzodiazepine*" marks a modification of the enunciatory posture of the GP (6).

We could conclude from this corpus that the general practitioners appear to distinguish between several classes of medication according to their degree of investment in the treatment underway. Among these classes, the "patient's treatment" ("*little pills in the evening*") and medication from another doctor (the psychiatrist, the first to prescribe) appear to elude their control. When they implement the treatment and are fully in charge of care, they assume responsibility for the "medication under doctor's orders". Replacement therapy (for opiates, alcohol or benzodiazepines) underscores this change of perspective: it is a question of shifting from the "patient's psychotrope" which carries a relationship of substance abuse, to the "psychotrope under doctor's orders".

If one class of medication is clearly attributed to the patient, it is important for us to understand what, on the consumer's side, is reflected by this distinction.

In the Patient's Perspective: Products or Practices that "Calm the Nerves"

For the consumers of psychotropic medication, these pharmaceuticals are clearly differentiated from pharmaceuticals prescribed for any other illness. This conclusion is based on the results of the survey methodology described above, and on the findings generated by the ALCESTE software for middle-class population groups in two different regions (lower Normandy, western Brittany) and for two successive generations (ages 40-70 and 30-50 years) (HAXAIRE C. *et al.* 1999, HAXAIRE C. *et al.* 2003).

It is noteworthy that, in both cases, the ALCESTE software generated a specific class in which are found all the names of psychotropic pharmaceuticals, to the exclusion of other medication. This lexical universe is characterised by the absence of any reference to the medical world, whether with respect to the actors involved, or to acts, objects or naturally the institutions (7). All the vocabulary is centred around that which "calms". Associated with this central notion are certain words for organising time (*day, night, hour, morning, noon, evening*, etc.) and time markers (such as *at the time, before, yesterday, the day after*, etc.). This shows the extent to which the discourse on psychotropes encompasses issues of rhythm, cycles and habits.

Both corpuses also include many terms referring to dosage of medication (*quarter, pills... half, dose, tablets, drops*). But the fact that the personal pronouns carry little weight, and their non-specific nature ("*I*" and "*You*" as terms of address directed at the interviewer in the first corpus, solely "*I*" in the second corpus), and the infrequent references to prescribers, signal that these pharmaceuticals are considered from the viewpoint of *taking them*, rather than from the viewpoint of usage regulated by *a prescription*. This is the universe of the consumer's autonomous practices.

The weight of verbs, such as *sleep, take, feel*, which are the most present in this class, likewise characterise more intimate and personal practices. In the second corpus, verbs such as *think, calm down, relax, tense up, forget...* further accentuate the impression that the speaker is in a reflective posture, attentive to his or her emotions.

It is in these contexts that the speakers comment on problems of drug dependency (*dependency, habit-forming, habit, habituated* in the first corpus, *need, lack, stop* in the second corpus).

Having analysed these common features, we observe that the universes are slightly different with respect to the courses of action that can be envisaged. They differ between retired people, the majority in the first corpus, and the still active generation which follows, which is more familiar with "*depression*", the disease of the century, as well as with the commonly consumed psychotropes tobacco and cannabis.

For the first group, retired women in Normandy, the world of "*depression*" is fraught with dangerous and deviant behaviour and must be kept at a distance, it belongs to a another universe. Drugs in the class of antidepressants are not recognised as such, but are given as "*medicine for nerves*" or "*for anxiety*". It is not a question of illnesses designated as such, but of "*problems*" encountered in daily life, notably problems with sleep (*stress, insomnia, nightmares* or even *states of anxiety*). Consequently, medication relieving these problems appears as *drugs* in the sense of something that is out of place (BECKER H.S. 2001); they are a bad habit, a rut that one falls into when it would be better to get back to more a more appropriate lifestyle.

For the second group, antidepressants – sometimes but not always recognised as such – appear with "sleeping pills" and with certain hypnotic or anxiolytic drugs in the context of other psychotropes: "*drinks, cigarette, cannabis*" also have the capacity "*to calm, to relax*". This is something that obviously could not be approached by the old people in the first corpus.

In the Normandy corpus, no names of diseases are found in this lexical world. In Brittany, these problems are evoked in the same context as high blood pressure, which for non-specialists is related to "*nervous tension*" (or *hyper-tension* in the English-speaking world, according to Blumhagen, 1980), "*migraine*", also caused by nerves, and "*arthritis*" (undoubtedly a recurrent "*problem*" that it is hard to think of as a "disease".)

Psychotropic medication emerges as products handled in an autonomous fashion, as Haafskens (HAAFSKENS J. 1997) as well as Karp (KARP D. A. 1993) have already shown. This is not a matter of self-medication however, in the way of consumers re-appropriating medical knowledge for themselves, as is the case with common analgesics, for instance. This is shown by the analysis of denominations carried out for the first corpus (CAMBON E. - HAXAIRE C. 2000). It is confirmed by the Brittany corpus, in which we find a specific lexical world for these self-medication products, clearly linked to the universe of medication and medicine, and distinct from the universe of psychotropes, which are attached to events in daily life (TERRIEN K. in HAXAIRE C. *et al.* 2003).

In addition to being autonomously handled practices, these are practices that consumers do not seem to consider to be legitimately part of the medical domain, if the enunciatory marks in the discourses produced are to be believed.

Looking now at the practices, as reported to us, it emerges that for both corpuses, psychotropic medication belongs to the vast category of medication "*for nerves*", with less stable subcategories: "*for sleeping*", "*for 'angoisse'*" (antidepressants). Quite clearly, this medication "*for nerves*" is in a class unto itself. This is reflected in the fact that the products are sometimes kept in plastic bags or in their boxes, separately from the ordinary items in the family medicine cabinet. Their status is ambiguous, they are described as "*dangerous*" but also as capable of inducing dependency, regardless of their therapeutic class.

The respondents' remarks reveal considerable autonomy with respect to the prescription, which is quite surprising on the part of the retired women in Normandy, who follow all other prescriptions very closely, and are not rule-breakers. They follow doses and posology of antidepressant treatment, for instance, even while warning those around them of the dangers of "*falling into the trap*" of psychotropic medication in general. Comparing themselves to others, who are their counter-examples, they see themselves as less old, less dependent (the old man is always older than oneself). Daytime doses of anxiolytics are neglected, in favour of bedtime doses. Doses of medication "*for sleeping*" tend to be diminished, and are taken only on very windy nights, or periodically. Long-term treatment, when it is perceived as circumstantial (problems in relationships at work, for instance) are suspended without difficulty when the problems cease (retirement). When the disorder be attributed to an organic cause, dependency is no longer a concern for the patient even if and when it's occurs. Otherwise, the hypnotic is described as a bad habit, that traps the patient and that must be shaken off. But this is linked to the routines of the patient's daily life, and not to the physician. Thus it is not necessarily a great degree of pharmaco-dependency that means the doctor's control is seen as irrelevant, but simply that sleep, problems, emotions are not legitimately in the doctor's domain, even if the patient talks about them with the practitioner. One is better advised to go to specialists (mediums) who deal with "*life's problems*" (a revealing expression).

Among the younger women encountered in Brittany, it would seem that prolonged or repeated use incites them to develop a certain degree of autonomy. They feel that they "*know*" the drug(s) they take well enough and are capable of suspending, lowering, starting up again or increasing doses without asking their doctors' advice. At this stage they claim that they advise colleagues, and sometimes exchange drugs. It is not infrequent that individuals "*try out*" medication that was not prescribed for them. Antidepressants are dropped after a while. Anxiolytics are taken "*when I feel the need*" and in some cases the doctor leaves them free to decide when they should or shouldn't take the medication. Prescribing this latitude is often, and paradoxically, a way for the physician to keep a degree of control over the prescription and the way the patient follows it. The latitude left by medical personnel is mentioned. The pharmacist is assumed to provide extra quantities of psychotropes other than antidepressants in case of need, and this is experienced, or in any event recounted, as giving the patient broad freedom of access. As the patient tells it, the GP who leaves it up to the patient to adjust doses is giving him or her control over the treatment. Whatever the reality, the interpretations given by the patients reveal their desire to handle this type of problem in their own way (8). Indeed, temporarily suspending treatment in all likelihood does have a function, that of reassuring the patient that he or she is in control of the situation. This management can extend to family or friends – it is primarily medicalisation that seems to be rejected.

Paradoxically, while the interviewees in Brittany are wary of developing a habit and dependency due to the use of psychotropic medication, we observe that some of them use or have used other products, have had addictive behaviour vis-à-vis other substances (alcohol, tobacco, cannabis). These products "*have nothing to do with being depressed*", they say. Some, however, declare that psychotropic pharmaceuticals and alcohol can be considered similar, but with the (significant) difference that prescription drugs do not induce social disruption. Still others turn to cannabis rather than to prescription drugs – the latter make it possible to "*hide*" and are seen as "*running away*" from psychotherapy, and therefore one must "*get rid of them*". Cannabis is regarded as a good substitute for hypnotics: "*she stopped all the prescription drugs, and she smokes little joints in the evening, and she sleeps like a baby*". More frequently use of tobacco, cigarettes, are described as psychotropes for "*calming the nerves*" ("*when you're irritated, you light a cigarette*"), a perception which is denied by the one man interviewed.

Just as the lay person's apprehension of the pathological character of any use of psychotropes is variable, because culturally determined, the deviant nature of consumption of psychotropic medication is estimated and gauged according to autonomous processes within certain communities. These women, whose exchanges we have reported previously, have their own definitions, which are always subject to discussion among themselves, of who is "*strung out*" and who consumes "*normally*". Circumstances, chance events in life, can lead them to transgress their own norms regarding consumption of psychotropes, to preserve their economic and social emancipation by professional activity when they must deal with conflicts at work, or when upheaval within the family is added to work pressures, exceeding their ability to keep on (TERRIEN K. - HAXAIRE C., *in press*). Here again it is a question of "*life's problems*" that medicine cannot resolve. Psychotropes, as medication or "drug", are an ersatz of a solution, a decoy or cosmetic, in short a *pharmakon* (9) in the perception of our interlocutors themselves.

Conclusion

The "*real remedy*" for depression, as given by certain interlocutors, would be "*a close-knit family*". For life's irritations, the best thing, they say, would be to get on the telephone; as for insomnia, the thing to do would be to establish different daily routines, another lifestyle. This touches upon the way in which individuals take care of other people, but also of themselves. “Taking care of myself,” “having other people take care of me”, are not tasks corresponding to the physician’s prime function, which is to diagnose and treat diseases. This is true even if the physician, in carrying out this function, also takes care of patients at the same time as treating them. The medicalisation of “psychic suffering”– in the sense that all psychic suffering should be approached via a diagnosis of “disease” and chemically treated – puts the physician in a position of a substitute – in replacement of social ties – and of prescriber of pharmaceutical substitutes which are supposed to enable the individual to treat the processes that restore and rebuild identity, i.e. sleep, emotions. The patients are not fooled, and intend to use physicians and the substitutes they prescribe, for lack of anything else, but use them in their own way. This is what creates the paradoxical situation of the “*little pills in the evening*” and similar practices. For the patients the pills do not belong to the medical domain but nonetheless they can only be obtained with a prescription. Health care professionals all confront in their practice various strategies for getting around the problem, strategies which seem to focus on resolving this paradox by denying institutional control (10).

The fact that in the popular perception all therapeutic classes of psychotropes are subsumed in the category of “*medication for nerves*”, along with the shifting acceptation of the entity “*depression-depressed*” which tends to encompasse all instances of feeling bad, would be an incentive for patients to adopt this sort of attitude towards new antidepressants (if not towards neuroleptics). This would be especially true if doctors were to relax the strict principles that they appear to continue to maintain regarding these prescriptions, if the discourse of their patients is to be believed. As for the prescribers, the set of “psychotropic medication” is characterised by concern with control over posology and dosage. Even so, as revealed by analysis of their discourse, the “little pills in the evening” escape their control. They are aware of the behaviour described above, and try to uncover it. For general practitioners, prescription of psychotropes is set in the context of taking the patient’s problems of daily life into account, a practice which seems to fall into a universe that is distinct from the universe of common medical practice. This opposition could be analogous to the opposition care/cure. The “little pills in the evening” would in this view come under the heading of care, and the way in which the patients take care of themselves. By this acceptation doctors appear to endorse this paradoxical subversion of what is called “doctor’s care”.

Notes

(1) It would be too simplistic to say that in these cases the general practitioners anticipated a "hidden depression" because this analysis does not do justice to the more global perspective evinced by the doctors.

(2) The Alceste software, designed by M. Reinert, extracts from a body of text classes of enunciations that are related by their vocabulary, called "lexical worlds". Reinert hypothesises that "at the time of locution the speaker invests various successive worlds, and these worlds, in imposing their objects at the same time impose their vocabulary. Consequently, a statistical study of the distribution of this vocabulary should enable us to pick up the trace of these "mental spaces" that the speaker has successively inhabited, traces that are perceptible in terms of "lexical worlds", these lexical worlds referring back to a way of choosing one reference system or another, at a given moment in the discourse." One of the latest papers by the Author presents the software analysis as semiotically based (Reinert M. *in press*).

(3) We do not have room here to go into the contrast with other sets (see report, Haxaire C. *et al.* 2003).

(4) Buprenorphine. A

(5) Our corpus included very few mood regulators.

(6) We verified this by searching for all occurrences of the term using the Lexico software (SYLED-CLA2T, Université Sorbonne Nouvelle Paris 3).

(7) The terms *doctor, physician, pharmacist, nurse... renew... shots, medication, prescription, hospital* etc. are found elsewhere.

(8) The interviews reveal various arrangements. Some consumers use their personal contacts with pharmacists to obtain more hypnotics and anxiolytics than prescribed, and later to get them without a prescription; or obtain prescriptions from doctors who are friends; or use multiple prescribers to accumulate the quantities they want. Some borrow the recommended medication from friends or family, or use family members' prescriptions to avoid seeing the doctor. When a visit to the doctor cannot be eluded, it is well known that the request for renewal of a prescription for this type of psychotropic medication will come at the end of the visit, as if in passing. In some extreme, but exemplary, cases reported to us, the doctor is placed in the situation of having to deliver a product designated by the client, the latter totally rejecting any request for an explanation.

(9) Cf. the deconstruction of this term by Derrida (Derrida J. 1972 [1968]).

(10) Cf. Previous note.

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1.5 *Strategies of order and control: Antabuse medication in Denmark*

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In relation to a follow-up study of patients who went through Minnesota Model treatment for alcoholism ten years ago, I recently talked to a driving instructor in his early forties. He told me that he had not touched alcohol for the past eight years: that is, until last year when he started suffering from fits of dizziness and related anxiety, which in the end prevented him from doing his work. Since he remembered all too well the pleasant experience of calming down with a cold beer or two, he could not resist the temptation. But one became many and after a few weeks of excessive drinking, he ended up in hospital for detoxification and was offered antabuse, the standard treatment for alcoholism in Denmark. Antabuse is a medicine that interferes with the breakdown of alcohol in the body by producing very unpleasant symptoms almost immediately after intake. The drug does not treat alcoholism as such, but is taken as a preventive medicine in order to support the patient's will to stop drinking by providing an automatic physical punishment. This man had used antabuse as a way of controlling his drinking in critical situations many times before, but this time he refused for the following reasons:

I don't like taking antabuse anymore. It seemed to work before and perhaps I needed it just to stop me, but something odd happens when I am on antabuse. I don't know how to explain this, but it is as if it occupies my mind all the time and I start making silly plans. There are so many small tricks you can play with it. As soon as I start taking it, I also start planning when I can stop taking it, and speculate about ways I can control myself again. Antabuse is a reminder. Now, when I don't take it, I know I can go down anytime and buy myself a beer – it takes no planning – and I feel good about that. Then I am in control. When I have taken antabuse, I am so busy with thoughts about when I can start drinking again – as if I have to test it. I may try out with a light beer – that gives me a slightly unpleasant reaction, flushing and heart-beating – nothing serious. Then I know the antabuse works. I wait a bit, then take another, and perhaps one more of the light ones. If that works all right I'll try with the stronger ones – and step-by-step I can drink through it. Antabuse is a reminder – a challenge.

Since then, I have been struck by the number of stories told to me by patients and health care professionals about the challenges of taking antabuse, and the games of control and cheating that are played in relation to the administration of the drug. Antabuse is sometimes referred to as the family's tranquilizer. Everyday life is often unstable and unpredictable in families with alcohol problems and antabuse may help to stabilise the condition. From the point of view of both the patients, the families, and the medical profession, antabuse provides a fairly simple and discrete solution to a complicated problem, at least for a while. In spite of the good intensions, however, attempts to control the damaging personal and social effects of excessive drinking with antabuse, often seem to create new challenges and uncertainties rather than solve the problems.

In this article, I have been inspired by Gregory Bateson's theory of alcoholism (BATESON G. 1973), and by Sjaak van der Geest, Anita Hardon and Susan Whyte's writings on medicines (VAN DER GEEST S. - WHYTE S. 1989, VAN DER GEEST S. *et al.* 1996, WHYTE S. *et al.* 2002) in my effort to reach some understanding of the social mechanisms and inherent contradictions in trying to manage the uncertainties of excessive drinking with a controlling use of antabuse medication. I suggest, that excessive drinking may be seen as an effort to break out of a cramped living space and that medication with antabuse hardly helps the person in this effort, but rather works as a return ticket.

Bateson's Theory of Alcoholism

Looking at anthropological contributions to research on alcoholism, Gregory Bateson's essay on "the cybernetics of the self" stands out as a classic (BATESON G. 1973). The essays deals with the spiritual and organizational principles for recovery after alcoholism suggested by the fellowship, Alcoholics Anonymous (AA). Clearly enthusiastic over the logic of the programme, Bateson argues that the alcoholic's self-destructive behaviour is an accentuation of characteristic features in western culture, and that the ideas AA lay out for personal development and a sober life represent a more desirable way of being in the world. Furthermore, he suggests that alcoholism may be seen as a kind of matching between sobriety and intoxication, so that the latter appear as an appropriate subjective correction of the former. Therefore, the causes of alcoholism must be sought in the person's sober life, and as a consequence it is not to be expected that any procedure that reinforces this particular style of sobriety will reduce the person's alcoholism. In other words, if the sober life of the alcoholic drives him or her to drink, then that style of life must contain an error, and intoxication must provide some sense of correction of this error.

Bateson picked up a concept from AA called "false pride". False pride is characterised by an obsessive acceptance of challenge, a pride in willpower as expressed in the proposition 'I can...' When the alcoholic is confronted with his or her drinking, this principle of pride will be mobilised in the proposition 'I can stay sober'. However, success in this achievement destroys the challenge, since the contextual structure of sobriety changes with its achievement, and thus is no longer the appropriate context for pride. It is now the risk of the drink that is challenging and calls out for the 'I can drink', as illustrated by the example at the beginning of this chapter. Thus, the challenge component of alcoholic pride is linked with risk-taking, and the alcoholic is caught in a compulsive pattern of pride-in-risk.

False pride presumes a relationship to a real, or a fictive, "other". This other may be experienced as part of the alcoholic self or may be represented by the alcoholic's family, other important relations, or society in general. Such relationships may be expressed in either symmetrical or complementary patterns. The alcoholic's relationship to himself, as well as his relationship to the world around him, becomes a compulsory fight of challenges and defeats, and, since both symmetrical and complementary relationships are liable to escalate, the situation develops into what Bateson calls a schismogenetic pattern: the alcoholic is caught in a game of challenges and control no matter whether he drinks or not.

Antabuse and Controlled Drunkenness

Antabuse (disulfram) has been used substantially for more than fifty years in Denmark. The effect of the medicine was discovered in 1947 by two Danish researchers, Jens Hald and Erik Jacobsen, from the biological laboratories of Medicinalco in Copenhagen (HALD J. - JACOBSEN E. 1948). Until the introduction in 1985 of Minnesota Model treatment in Denmark and the following spread of AA groups to all corners of the country, antabuse totally dominated Danish alcoholism treatment. The somewhat rigid and controlling character of the Danish welfare system, stressing collectivism and sameness, combined with a cultural preference for "controlled drinking" rather than abstinence, provided fertile soil for the use of antabuse (STEFFEN V. 1997: 101).

Antabuse is routinely offered to anyone who gets in touch with the public health care system for problems with alcohol, whether this contact goes through general practitioners, outpatient clinics or hospital wards. Research from 1988 shows that antabuse was used in more than 90 per cent of all cases in the public out-patient wards, often under quite coercive circumstances, with one third of the patients claiming that it had no positive effects on their drinking problem (SKINHØJ K. 1988: 23). A report from the Link's outpatient clinics based on data relating to 1736 users in 1992-93, states that 75 per cent of them were taking antabuse at the beginning of treatment (LANDSFORENINGEN LÆNKEN 1996). These findings are confirmed by a recent study showing that antabuse medication still dominates Danish treatment for alcoholism (JÄRVINEN M. 1998). With all of the general emphasis on positive reinforcement being more effective than painful punishment, it is surprising how antabuse treatment has been left out of that larger understanding. Most professionals agree, when asked, that antabuse should only be used with the explicit consent of the patient and in combination with other forms of therapy. In practice, the prescription of antabuse is seldom discussed and supportive activities are only utilized to a very limited extent, because the initiative depends a great deal on the individual patient.

Considering the extensive use of antabuse, one might expect some enthusiasm or at least satisfaction among the users of the drug. In fact, neither the patients who take the drug, nor the doctors who prescribe it, are very optimistic. Most of them would probably agree with the administrative director of the Link Outpatient Clinics in Denmark, who laconically calls antabuse «a chemical extension of good will» (ORBE D. 1996: 11). Usually, the effect of antabuse can be maintained by a dose twice a week and the idea is, of course, that the fear of unpleasant reactions should prevent the person from drinking. According to this logic, the will-power to resist drinking only has to be mobilised twice a week, instead of every time the temptation of a drink comes up. Thus, in contrast to most other medicines, antabuse is meant to work by anticipation and serves its purpose best, when the actual effect is left out, *i.e.* exclusively as a placebo. To some patients, antabuse does indeed seem to have that effect, and some actually manage to stay sober on antabuse for many years. But more commonly, antabuse medication falls into a periodic pattern of three to six months of abstinence, followed by rather dramatic binges of escalating character.

Drinking periods may be more or less consciously planned and arranged with due respect to holidays and feasts, or they may be subject to more subtle and unconscious mechanisms. To some people relapses appear totally unpredictable and immune from personal control, and the uncertainties of the consequences are so incalculable that they seem to prefer any kind of control to prevent it from ever happening again. Nevertheless, most patients first consult a clinic with a deeply felt wish of being helped to achieve some level of moderate drinking, and they consider antabuse a regulatory means in that direction. Professionals, in general, find moderate drinking an acceptable first goal, but many think that abstinence is probably more realistic in the long run. The attitude seems to be, that each individual should learn by his own personal experiences. Gradually, hopes of recovery in terms of moderate drinking fade or disappear with repeated experiences of relapse. Antabuse becomes a pragmatically installed mechanism of self-control, and regular binges an abreaction, perhaps triggered off by the very constraints of control.

The Charms of a Medicine

Examining medicines and therapies as forms of social control is a common approach in medical anthropology (VAN DER GEEST S. - WHYTE S. 1989). Periods of illness are occasions of dependency, when ideas of obligation and morality are mobilised, and therapy is always embedded in various forms of social relationships such as kinship, community, and social institutions. The sick role is associated with both privileges and obligations, just as the role of caretaker is embedded in certain moral demands. One of the primary obligations of the patient is to become well and therefore to comply with the treatment offered by professionals (PARSONS T. 1951). In fact, one of the main purposes of taking antabuse might be to confirm the patient's consent to the unspoken rules of compliance. In that sense, antabuse may be better understood as a ritual treatment rather than a purely medical treatment. The ritual provides the professional with the symbolic power of controlling the patient's intake of the drug, and the patient demonstrates his will to comply with the rules of the game by accepting this external control (ORBE D. 1996: 12).

Normally, medicines are defined by their capacity to change the conditions of a living organism. They are expected to solve problems in undramatic ways and are valued for their effectiveness in alleviating ill health by removing the symptoms. Their concreteness as substances enhances the perception of illness as something tangible, and permits therapy to be separated from social relations. As such, medicines may be an attractive alternative to other kinds of therapy, a treatment that focuses on the individual body, which can be carried out privately – a fact that is particularly important when sickness is associated with shame and might reflect poorly on the patient or family. Thus, one of the charms of medicines is that they allow private individual treatment, and diminishing dependence on practitioners, experts, and kin (VAN DER GEEST S. *et al.* 1996: 154-156).

Antabuse, however, provides a challenging example to these notions of medicines. On the one hand, it fits in very nicely with the need for discretion and privacy in relation to a problem that is considered highly stigmatising. On the other hand, the administration of the drug is embedded in a huge system of public institutions and social control. Firstly, antabuse is a prescription drug and thus requires the interference of a doctor. Secondly, the drug is administered in ways that urge the patient to show up in public to take the medication. Finally, the actual intake is carefully surveyed and registered by representatives of the social system. Such public administration and strict surveillance prevent many, especially women, from seeking treatment at all. A former nurse tells how she secretly developed a substantial alcohol problem over a couple of years and then, desperately needing help, eventually went to see her general practitioner:

> «I went up to my doctor and simply shouted to his face, that if he did not help me right here and now, I would drink myself to death! He instantly gave me some drugs for detoxification and suggested antabuse treatment. But no, no – not for me, thank you! Showing up at the clinic twice a week to take my antabuse, oh no – the secretary would soon find out, and in a small town like this people talk»!

Submitting to the forms of surveillance and publicity involved in the administration of antabuse is felt as shameful and humiliating by many patients. But then, antabuse treatment can still be limited to the intake of a substance, in contrast to counselling and group therapy that involves other people and reveals more sensitive knowledge about the person. Using a medicine has the advantage of making the problem seem concrete and disease-like, it offers a mechanical solution and it clearly demonstrates the patient's compliance.

Cheating

Most patients end up accepting the control associated with antabuse medication, and some will even claim that external control is exactly what they need. Nevertheless, cheating plays an important role. Innumerable stories about how to cheat with antabuse are told, and although some professionals doubt that the stories are in accordance with reality, they do indeed reflect the patients' preoccupation with the subject. Some stories focus on situations in which the patient is subjected to so-called "voluntary coercion" – a self imposed constraint accepted due to the pressure of significant others. Although compulsory treatment with antabuse is not allowed, various forms of motivational pressure certainly take place, particularly when the Prison Service or the Social Security authorities are involved. Agreement to enrol in controlled antabuse medication can play a central role in the negotiation of conditional release from prison, of the commutation of sentence in cases of drunk driving, of parental rights to have access to their children in cases of neglect, of conditions for social security payments, or even of a demand for participation in treatment programmes. Considerable pressure may also be put on the patient by family, friends or employers, and antabuse may provide a visible and simple solution to such pressure. Under these conditions, the patient is often more influenced to take the medication by the prospect of future gains, than by a genuine wish to stop drinking.

When possible, antabuse is given under strict surveillance. Even when legal authorities are not involved, intake is noted down on a small yellow card carried by the patient as documentation of treatment (ironically referred to as a "driver's licence" or "the yellow card"). The medicine is preferably ingested as a tablet dissolved in water, which reduces the number of very simple methods of cheating available, such as hiding the tablet under the tongue and spitting it out later. Another common method is that of sticking a finger in the throat and vomit. Medical secretaries tell stories about patients pretending to drink the liquid, but instead, trying to let it flow unnoticed down their chin and into the jacket. Others try to chat with the secretary until the tablet settles at the bottom of the cup, in order to reduce the concentration of the drug, and then throwing the rest out. More inventive strategies include a patient who hid a wad of cotton in his mouth, to absorb the liquid so that he could spit it out afterwards. A more negotiable way of avoiding antabuse is through complaints of side effects, though most doctors seem to doubt the seriousness of such complaints. or through medication with drugs that counter the effect of antabuse.

Stories about cheating are, of course, well known by patients as well as professionals, and it makes one wonder why they all engage in this game. In his classic study of play, Johan Huizinga notes that society is often more lenient to "the cheat" than to the "spoil-sport", because the cheat, by pretending to be playing the game, acknowledges the basic framework or the premises of the play, in contrast to the spoil-sport who threatens the very existence of the play-community by his non-compliance (HUIZINGA J. 1955: 11). Although it lies at the heart of play that rules should be kept, many examples from popular lore let the cheat win by fraud, as for example in the fable of the hedgehog and the hare (HUIZINGA J. 1955: 52). Perhaps something similar is at stake in antabuse treatment.

Testing

According to the professionals, patients subjected to "voluntary coercion" are a minority at the clinics and attempts to cheat with antabuse are not so common. Listening to the patients, however, another sort of cheating, or rather testing, appears to be very widespread. This testing takes place among patients who have voluntarily agreed to take antabuse, but who nevertheless engage themselves in various forms of self-imposed testing or experimenting with the drug and its effects. A man in his early fifties recounts how he was escorted to an outpatient clinic by his neighbour, after a long period of time with a slowly escalating drinking problem. He had a consultation with a doctor and was prescribed antabuse, which he willingly took. He actually liked coming to the clinic in the mornings to chat with the other patients, and even went there on mornings when he did not have to take antabuse. Anyway:

> «... of course, I had to test it – just to see if it really worked. It was after a while in treatment. A couple of days after taking my antabuse, I felt like having a beer at home. My wife was there, but she didn't say anything – or perhaps I thought it was none of her business – so I drank a plain lager at first. That was okay, nothing really happened. It was near Christmas, so I continued with one of these with a throttle, you know, a Christmas brew. That was it! I simply dropped out on the floor, fainted. My wife got terribly scared of course and called an ambulance, what else could she do? I got into the emergency unit and was checked for all sorts of ills – my heart, blood pressure, and whatever. At least I got a full check-up – usually that is reserved for the car – and fortunately, there was nothing wrong with me. That's nice to know, if I take the positive view on this whole event. Well, then I could say to myself, that at least I tried it. I guess, I am the kind of person that has to learn by his own experiences – and now I don't have to try that

> again! To be honest, it was quite scary, my eyes were swimming and I couldn't control my body – not least for my wife it was scary. I could have dropped dead, if I had had a weak heart for example».

Others have less dramatic experiences and simply manage to drink through the unpleasant effects by tolerating the symptoms until they eventually stop. For people with weak hearts this method is considered life-threatening, but it is not uncommon and often talked about with a touch of pride. A carpenter in his late thirties told me how he simply 'forgot' that he was on antabuse after a detoxification and the next day went to the local bar, for a beer after work:

> «My heart started beating very fast and my face turned extremely red. It was scary for a while. But you know, it passes and then I don't care. The first time I drank on antabuse the effects were much worse, but now I know that after a while it's over – it's no hindrance, if I want to drink, I drink»!

Strategies of Order and Control: Antabuse as Transformation or Return Ticket?

In families dominated by alcohol abuse every day is a struggle to gain control over lives that have become unmanageable. With alcoholism basically understood as a loss of control as such, a condition that seems immune to the exercise of personal willpower, quotidian life becomes unpredictable and full of uncertainties. In this situation, neither the alcoholic nor the family knows what to rely on or what to expect from day to day. They are also uncertain about how to solve the problem. For many people the prospect of giving up drinking altogether is almost unbearable, even when moderate drinking turns out to be extremely hard or even impossible to manage. To a wide extend, the uncertainties and the ambiguities of the alcoholics about treatment options are shared by the medical profession. Both sides know very well, that the effort to control the intake of alcohol by inflicting a mechanical physical punishment, is an uncertain strategy in the long run. Antabuse is not a drug that cures a disease, it hardly removes the symptoms. But at least it gives the impression that something is being done. It may even provide a placebo-like sense of control and order that can help both alcoholics, their families, and the professionals to manage the uncertainty for a while. This effect may explain why many patients seem to comply with the drug, at least for a while. On the other hand, the attempt to control the situation by the prescription of antabuse also creates new uncertainties by challenging the very means of control itself. The various ways patients try to contest the effect of antabuse by cheating, testing, and experimenting with the drug, show how control often results in strategies to counter the restraints of control. Finally, the way professionals tacitly accept the state of affairs, shows that they are not too interested in giving up the impression that they are in control; that they know what they are doing. Cheating does not spoil the game as such, but it blurs the outlines of the current state of play, apparently, in the interest of many parties.

For most people in western societies drinking alcohol is a normal social and recreational activity. Although we tend to think of intoxication as a breakaway from more formal behaviour, alcohol researchers have argued that drinking patterns in general are governed by ritual rules leading towards feelings of transformation and redemption (ELMELAND K. 1996). This suggests, that excessive drinking may be seen as a personal development process, an effort to break out of a cramped living space. The effort is rarely successful, partly because the goal is too vague, and partly because the means are not appropriate. Antabuse, however, will hardly help the person in this effort, but will rather work as a return ticket sending the person back empty-handed (ELMELAND K. *et al.* 1990: 74). Bateson stated, in one of the premises of his theory of alcoholism, that if the sober life of the alcoholic somehow contains an error, it makes no sense to send the person back to this previous condition. This is exactly what antabuse seems to do.

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1.6 *Repitiendo para no repetir. II. Atención a personas en fin de vida desde la atención primaria*

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1. Introducción

Esta comunicación recoge, de modo provisional, los elementos más significativos de las entrevistas realizadas a enfermeras, médicas y médicos que desde su trabajo en Atención Primaria (A.P.) atienden a personas en fin de vida.

Se plantea como continuación de otro anterior en el que se plasmaban una serie de reflexiones en torno al trabajo que sobre la práctica asistencial en Atención Primaria, llevo realizando durante los 10 últimos años, con un grupo de sanitarios, médicos y enfermeras que desde sus consultas, atienden también a personas en situación terminal (1).

En el primer artículo se hace referencia, en primer lugar, a la dificultad inicial con la que se vieron confrontados estos sanitarios cuando comenzaron a hacerse cargo de la atención de personas en fin de vida, de las crisis personales y profesionales que se les plantearon, y de la forma en que, cuando fue posible (2), las resolvieron.

A continuación se señala de forma sucinta los puntos fundamentales de la filosofía de los cuidados paliativos (persona enferma como referente principal, y como sujeto de decisión, trabajo orientado a los síntomas, con principal incidencia en el dolor, escucha de los malestares, reconocimiento y cuidado de la familia, en tanto que soporte asistencial, ...) (3).

La filosofía paliativa choca de plano con la formación hospitalocéntrica (4) que recibieron los y las sanitarias que componían el grupo. Pero choca también con la que mayoritariamente continúan recibiendo los estudiantes de medicina y enfermería actuales. Cuestiones tales como la orientación del trabajo asistencial hacia la persona enferma y no hacia la enfermedad, hacia el cuidado (ante la imposibilida de la curación), la evidencia de una tarea asistencial que se prolonga en el tiempo, (lo que supone el necesario desarrollo de una relación clínica intensa, y de una necesaria implicación profesional), así como el hecho de que una buena parte de las consultas se realicen en el domicilio de la persona enferma... ..., remarcan algunos de los elementos diferenciales cruciales de esta tarea asistencial y en consecuencia, hacen referencia a los aspectos en los que se manifiesta su dificultad.

Esta “nueva” (5) orientación recoge – en teoría – algunos de los planteamientos que sobre la experiencia de enfermedad y su manejo, han sido señalados y trabajados, entre otras disciplinas, por la Antropología de la Medicina, (MENÉNDEZ E. L. 2002: 210). No obstante, este autor señala también la dificultad que supone materializar estos planteamientos en la práctica cotidiana, cuanto más en una práctica asistencial encuadrada en una parcela de la biomedicina.

La atención a personas en fin de vida desde A. P., constituye lo que se puede considera como un parcela asistencial “periférica” respecto del modelo biomédico (6) y de su centralidad hospitalaria. Ya de por sí, la A. P. es un sector asistencial considerado de menor “prestigio” y los sanitarios que en ella trabajan de “menor categoría” respecto de sus compañeras y compañeros hospitalarios (7); además, al desarrollar una tarea asistencial que requiere una menor tecnificación, constituye la parcela más barata del sistema sanitario oficial (8).

Los elementos diferenciales señalados hacen pensar en la posibilidad de considerar estas periferias como núcleos a partir de los cuales se puedan generar sinergias asistenciales que permitan desarrollar otros modelos asistenciales menos rígidos que los actuales desde los que se pueda otorgar una mayor importancia a la relación clínica, pues la asistencia se prolonga en el tiempo, se reconozca y se respete la autonomía de la persona enferma, respecto del manejo de su propia vida y de su salud, ... Consideramos que la filosofía “hospice” puede – debe – ser extrapolable a otras parcelas asistenciales como la atención a personas con enfermedades crónicas. Pero no resulta tarea sencilla, pues cuestiona el modelo hegemónico.

No obstante, para realizar un abordaje global de la terminalidad, creemos necesario potenciar espacios intermedios de reflexión, intercambio y colaboración entre las cc. humanas y sociales y la biomedicina, y así hacer real la aproximación sociocultural al binomio salud-enfermedad. Tender puentes entre ambas disciplinas deberá permitir hacer menos costos y difícil, tanto para las personas que lo experimentan como para los y las sanitarias que les cuidan, la experiencia de por sí penosa que supone la enfermedad.

Por este motivo, consideraba conveniente recoger el testimonio de algunos profesionales que trabajan en este sector, al objeto de poner de manifiesto algunas de las claves que puedan aportar luz sobre la complejidad del tema y así, si fuera posible poder "dejar de repetir".

2. Un camino costoso

Los protagonistas

En este apartado se recogen, de modo provisional, los elementos más significativos de las entrevistas realizadas a enfermeras y médicas y médicos que desde su trabajo en Atención Primaria, atienden a personas en fin de vida.

El objetivo de estas entrevista es, por un lado, el de tratar de comprender, entre otras cosas, qué es lo que ha hecho que personas que han recibido una formación sanitaria (médicos, enfermeras) conforme al M.M.H., se encuentren en la actualidad trabajando de forma diferente en la "periferia" de ese mismo sistema sanitario (en nuestro caso, OSAKIDETZA). Por qué decidieron asumir esta tarea, además de las que caracterizan su tarea asistencial cotidiana (cuando podían haber elegido no asumirla, sin que esa decisión hubiera tenido consecuencias laborales). Y cuales son los elementos que les permitieron comenzar a sumir dicha tarea y qué es lo que ha hecho posible su permanencia en esa dinámica de trabajo, así como el balance que realizan sobre su experiencia.

Los informantes de esta primera fase son médicos y enfermeras de A.P., con más de 20 años de experiencia profesional (9), y más de 15 en la atención a personas en fin de vida. Desde el punto de vista profesional se trata de 2 enfermeras y 4 médicos, de los que 4 son mujeres y 2 hombres (de las 4 mujeres, 2 son enfermeras y dos médicas). Se trata de personas conocidas con las que vengo compartiendo ese trabajo desde hace ya más de 10 años.

No forman un grupo compacto de trabajo, pues no todos lo hacen en el mismo Centro de Salud. Cuatro de entre ellos (3 médicos y una enfermera trabajan en el mismo Centro; otro médico y otra enfermera lo hacen, cada uno, en Centros diferentes (10).

En su totalidad manifiestan haber tenido una inclinación temprana por realizar formación sanitaria (enfermería, medicina): En el caso de los médicos, todos hicieron una opción temprana por la medicina de familia, querían ser médicos de "cabecera". Para unos la opción estuvo clara desde el comienzo, otros lo fueron descubriendo en la carrera: «desde 4º curso pasé todos mis tiempos libres en el hospital haciendo prácticas voluntarias viendo pacientes, pero era una visión muy hospitalaria del trabajo médico, allí me faltaba algo; quitando a los crónicos, muy crónicos, allí los médicos veían siempre a pacientes que no acababan de conocer del todo, o no les conocían bien en todas sus variables psicosociales. [...] Al acabar la carrera tenía claro que no quería trabajar en hospital, podía haber elegido cualquier especialidad, ya que por plaza de MIR (11) podía haber elegido cualquier otra especialidad, y al final elegí Familia, si fue vocacional, me parecía que era la mejor manera de atender, pues junto con los geriatras, los pediatras, los internistas, creo que somos los únicos que mantenemos una visión más global de la persona enferma».

Para las enfermeras, el comienzo fue diferente. Si bien ambas dos partieron de una elección voluntaria de los estudios de Enfermería (en aquel momento Ayudante Técnico Sanitario), al finalizar la carrera su principal objetivo de trabajo profesional fuel el hospital. No obstante, y debido al cambio de consideración académica que en el estado se produjo en torno a la calificación de la formación en enfermería (pasando de Ayudante Técnico Sanitario, formación impartida en los hospitales, a ser un primer ciclo universitario). Todas las personas tituladas con anterioridad a 1978 debieron realizar un Curso de Convalidación. Ambas señalan dicho curso como "elemento clave" en el que "descubrieron", a partir de la asignatura de Salud Comunitaria, otro ámbito de trabajo enfermero diferente al hospitalario: el trabajo en Atención Primaria. Con posterioridad, ambas realizaron un Curso de Postgrado en la materia. Como elementos significativos de su "descubrimiento" y de su trabajo en Atención Primaria señalan los siguientes: los elementos que acompañan al enfermar, el trabajo multidisciplinar y un trabajo con mayor autonomía profesional (12); consideran estos elementos como un rasgo diferencial del trabajo enfermero en A.P. respecto al del hospital.

Si bien ninguno de entre ellos posee formación en Antropología, todos ellos han continuado formándose. A excepción de uno que lo ha hecho de modo principalmente autodidacta, los demás han realizado diferentes formaciones de postgrado. Resulta cuando menos curioso el hecho de que todos ellos son terriblemente discretos yo diría incluso humildes, respecto a su formación (de postgrado u otras). La información recogida sobre el tema la he tenido que "sacar con sacacorchos". Lo poco que he recuperado ha sido gracias a mi insistencia y a los años de trabajo en común que ofrecen un conocimiento mayor de sus actividades formativas y que dan un cierto permiso para insistir en el tema. No la consideran como elemento diferencial de prestigio. Entienden la formación continua y el estudio cotidiano como parte de su quehacer profesional. Y esta opinión es compartido por enfermeras y médicos.

Respecto de las y los médicos y al margen los cursos puntuales de formación – que continúan haciendo –, y a excepción de uno que ha seguido una formación autodidacta, de los demás, dos de médicos comenzaron ya haciendo el MIR en Medicina de Familia; para una de ellas, resultó determinante para interesarse en el tema el curso de Educación Sanitaria realizado en este contexto; al finalizar el MIR esta persona realizó el Master de Educación Sanitaria en Perugia. Otro, – bastante más joven – realizará formación específica en Cuidados Paliativos en el Hospital de Vic de Barcelona. La otra médica, pionera en Atención Primaria, (MIR en Medicina Interna), fue docente de la primera promoción de los MIR en Atención Primaria, y realizó junto con esta primera promoción los cursos teóricos de formación en Medicina de Familia. En la actualidad, todos ellos son docentes del MIR en Medicina de Familia.

Desde el comienzo de su trabajo profesional, consideraron necesario continuar formándose. Los médicos, porque: «en la carrera nos enseñaron a curar, y curamos poquito». La imposibilidad de curar y la muerte se hacen presentes, «en el trabajo se descubre que la gente se muere». El trabajo cotidiano les hace redescubrir la complejidad de su profesión. Esta circunstancia hizo evidentes sus carencias en el manejo de los aspectos psicosociales (13) que intervienen en el enfermar: «la formación de la carrera no me sirvió para atender a una persona».

Respecto de las enfermeras, ambas dos han realizado un Curso de Posgrado en Salud Comunitaria. También acogen en su Centro de Salud a alumnado de 3º curso de enfermería en formación práctica. Desde el pregrado que realizaron íntegramente en el hospital, sintieron la necesidad de «trabajar de otra manera». Como señala una de ellas al referirse a la formación práctica de la carrera y a su posterior trabajo durante un tiempo en un hospital, «quizá en aquel momento sólo eran intuiciones, pero yo no me sentía bien trabajando de aquella manera y tratando, de hecho a la persona hospitalizada como si fuera un mueble más de la habitación». Entiende que hoy es mucho más exigente consigo misma a nivel profesional, pero considera que quizá fue este malestar el elemento determinante que marcó su trayectoria profesional.

Con posterioridad, al comenzar a trabajar en Atención Primaria y tener que llenar de sentido y de contenido su quehacer profesional, encontraron en la formación en Salud Comunitaria algunas de las claves al cuidado de las personas en fin de vida.

El comienzo

A continuación se recoge el modo en que este grupo de profesionales comenzó a trabajar con personas en fin de vida. Algunos de entre ellos, lo definen «por pura y dura necesidad». Aunque lo definan como tal, qué duda cabe que si no hubiera habido una cierta sensibilidad hacia el tema, este tipo de demandas no hubieran sido recogidas. Pero los que señalan este comienzo que podemos calificar como "brusco" lo recuerdan también como una situación para la que sentían no estar preparados y sin embargo no podían eludir, pues entendían que se trataba de una demanda que debían asumir y dar respuesta pues consideraban que era parte de su profesión. «Me parecía que formaba parte de la medicina aunque yo no estuviera preparada para ello; fui consciente de que ahí tenía que hacer algo, porque formaba parte, también,n de la vida».

Para algunos pues, el comienzo fue traumático en el sentido de que debieron enfrentarse a una demanda para la que no estaban ni preparados ni formados; para otros fueron acontecimientos de su vida privada, – muerte de familiares cercanos y la reflexión sobre su comportamiento y vivencias en esa situación – lo que les impulsó a buscar una mayor formación profesional en el tema, y a partir de ese momento incluirlo en su práctica asistencial. Para otra, el comienzo estuvo en principio relacionado con el cuidado de personas mayores; no obstante, señala el impacto que siempre le había causado la atención a las personas jóvenes con enfermedades oncológicas de pronóstico grave. En los primeros casos que atendió se manifestaba un malestar que provenía de lo que en ese momento ella sentía como «el no poder hacer nada» (14). Señala que fue la posibilidad de compartir esta experiencia con sus compañeros de trabajo, y el hecho de que alguno de ellos se encontrara atendiendo a casos similares en ese momento, lo que propició que en su C.S. comenzara a desarrollares una vía de sensibilización y formación específica sobre el tema.

Respecto de las enfermeras, ambas señalan que comenzaron a trabajar con personas en fin de vida, «encontrándose con ellos». Respecto del trabajo de enfermería en el cuidado de personas en fin de vida, siempre se ha considerado que existía una mayor dificultad, si no imposibilidad, de trabajar en esta parcela del cuidado de forma individual, sin el trabajo complementario de un profesional de la medicina. Pero curiosamente, una de la enfermeras entrevistadas lleva trabajando en "semisoledad" desde hace bastante tiempo. Por eso resulta interesante lo que su testimonio puede aportar. Es consciente de que su situación no es ni la ideal ni la deseable; no obstante constata que el trabajo en solitario: «es posible, se puede hacer y mucho; no puedo recetar morfina pero hay otros muchos aspectos en los que puedo incidir, como son, el mostrar disponibilidad, el planificar citas (en C. Salud) o visitas (domiciliarias), dependiendo de su estado, es decir, hacer un seguimiento, centrar los cuidados y formar a la familia en el cuidado y buscar un cuidador principal» (15). Respecto de las familias y de su rol de cuidadoras dice que: «las familias responden fantásticamente bien». Y respecto de su trabajo casi en solitario añade que ella se apoya mucho en el Departamento de Servicios Sociales del Ayuntamiento (16), trabajando codo a codo con la Trabajadora Social; también se apoya en los otros recursos, que aunque insuficientes, posee la Red de Osakidetza como son, la Consultoría de Cuidados Paliativos y el Servicio de Hospitalización a Domicilio. Así mismo trabaja con las asociaciones de afectados y con el voluntariado.

Un tema de preocupación y conflicto profesional, sobretodo para las y los sanitarios médicos es el relativo al no poder curar. Aquí también habrá que marcar una pequeña diferencia respecto de la experiencia y el posicionamiento profesional entre enfermeras y médicos. Para las enfermeras nunca ha supuesto una contradicción pues recibieron una formación orientada al cuidado; no obstante entienden que la supuesta limitación profesional (y personal) respecto de la capacidad de curar, debe ser más difícil para las enfermeras hospitalarias*:* «por la dinámica intervencionista propia del hospital». No obstante apuntan también la dificultad del tema: «Personalmente tengo muy claro que nos tenemos que morir, [...] eso no quita que haya… pues que cuando te toca atender a alguien de 40 años, ¡se te caiga el alma a los pies!». Otra de las enfermeras, refiriéndose explícitamente la diferente formación respecto de los médicos dice que para ella nunca ha supuesto una contradicción, aunque a renglón seguido añade que trabajar en este campo no hubiera sido posible sin una formación posterior; sobre el cuidado puntualiza: «nosotras, las enfermeras, utilizamos mucho la palabra curar, con las heridas y así, y yo desde hace mucho tiempo estoy viendo que si se cuida, puede acabar curándose, pero sólo si se cuida» (17).

Para los médicos en cambio, la constatación de esta realidad fue un "descubrimiento" que se les hizo evidente al comenzar a trabajar, y que en algunos de ellos puede ser calificado de traumático. Al referirse a sus comienzos, unos lo califican como fracaso, otros como susto, pero no tanto como una contradicción: «Susto!, estaba claro que tenía que hacer algo, pero yo no había sido formada para eso... no estaba contemplado». A excepción de uno, más joven, y cuyo contacto con la medicina paliativa fue menos brusco, pues pudo beneficiarse, entre otras cosas, de la experiencia de sus compañeros del Centro de Salud en el que trabaja, todos los demás se refieren a un primer momento que les marco; pero también refieren que no fue un comienzo casual. Así, todos están de acuerdo, que para atender a personas en fin de vida, han debido apoyarse en una formación que voluntariamente buscaron; de modo paralelo han debido realizar un trabajo personal. Entienden que ha sido la complementariedad de ambos elementos lo que les ha permitido llegar a entender la terminalidad no solo como una parte de su tarea asistencial sino también como una parte de la vida.

Enfermeras y médicos coinciden en que cuidar a una persona y a su familia es gratificante, uno de entre ellos señala que él llega a sentirse egoísta, pues siempre recibe más de lo que da. El agradecimiento lo reciben tanto de la persona enferma como de la familia. Refiriéndose a su situación actual, manifiestan sentir pena cuando un paciente fallece, no siempre por igual y dependiendo de cada persona, pero en la actualidad, cuando un paciente fallece, no manifiestan un sensación de fracaso: «Hay satisfacción por haber contribuido a que una persona fallezca... con tranquilidad, en sus (18) mejores condiciones posibles». Esto no quiere decir que lo vivan de modo banal. Manifiestan sentir tristeza por la pérdida de una persona a la que han cuidado de forma intensa hasta el final de su vida.

Queda pues de manifiesto que para algunos de entre ellos el comienzo no fue fácil. Recordaban los primeros casos primeros casos que atendieron y el impacto que les produjo. Por eso me pareció interesante ver si podían rescatar, desde el aquí y ahora, algún elemento positivo de sus primeras experiencias. La respuesta fue afirmativa en todos los casos. En este sentido se refieren al contacto con una forma de trabajo diferente, donde la multidisciplinaridad deja de ser un concepto para convertirse en una realidad, donde se hace evidente la necesidad de trabajar en equipo, en referencia no solamente al miniequipo formado por profesionales de medicina y enfermería, pues la demanda, en estos casos, es casi siempre global (19). El trabajo con los Servicios Sociales de los Ayuntamientos, con los Centros de Salud Mental, con el cura del pueblo, ... se hace evidente y necesario. También ha supuesto el descubrimiento de que existen otros elementos además de los medicamentos, que pueden producir alivio, como puede ser la visita de un amigo, el participar en las fiestas del pueblo, ver la vuelta ciclista, ...; del mismo modo han tomado conciencia de la existencia de otros malestares de origen no físico o fisiológico, para los cuales la medicación carece de efecto y de sentido, como puede ser una preocupación, «el tener cosas pendientes y desear solucionarlas», la culpa,... También señalan el haber necesitado realizar el aprendizaje del respeto de la dinámica de la persona enferma, en referencia a que han tenido que aprender a diferenciar entre mostrar a la persona enferma y a su familia, su disponibilidad, su deseo de colaborar con la persona enferma y su familia para que las "cosas salgan bien" y el respeto del las pautas que marca la persona enferma. Todos señalan que para ellos y ellas ha habido un antes y un después, a partir de estas primeras experiencias y ello ha repercutido, positivamente piensan, en su quehacer profesional.

Otro de los aspectos de la atención en fin de vida, es que se trata de un proceso de atención definido por ellos como largo e intenso. Si bien no cabe duda en que se trata de un proceso intenso, con visitas al domicilio, en muchas ocasiones de 2 y 3 veces por semana, donde la relación «exige mucho, tanto a nivel clínico como humano», lo que no es tan evidente, es que objetivamente sea largo. Sabemos que las magnitudes siempre son relativas respecto al elemento con el que se comparen. Así, si comparamos la atención en fin de vida con la que requiere cualquier proceso agudo, efectivamente es mas larga, pero si la comparamos con cualquier proceso crónico, esta cualidad se desfigura. Desde mi punto de vista, lo que en la atención en fin de vida provoca la sensación de ser un proceso largo, no es tanto su prolongación en el tiempo puesto, que existen otras patologías que requieren el desarrollo de una atención bastante más prolongada en el tiempo, sino la intensidad de la relación clínica que se produce entre los sanitarios, la persona enferma y la familia . Sobre este particular todos han señalado lo intenso de la relación. Se trata de una relación que necesitan diferenciar de la de amistad, que exige una formación clínica adecuada, pues se deberán controlar síntomas variados y con oscilaciones constantes y además, el desarrollo de una relación clínica que permita recoger la demanda, evaluarla, asumir lo propio, derivar lo que sea competencia de otros profesionales y además, ofrecer un cierto soporte emocional. Unos entienden que esta forma de posicionarse y de actuar tiene que ver con calidad humana de los sanitarios, otros entienden que simplemente se trata de profesionalidad.

Por tratarse de una situación asistencial intensa que exige mucho de los sanitarios tanto a nivel clínico como relacional, algunos de ellos muestran una cierta preocupación por la dificultad añadida relacionada con la situación personal de cada profesional en los diferentes momentos de su historia, el eco particular que la atención a una determinada persona puede tener en su vida, e incluso en su equilibrio personal, lo cual hace que el cuidado de ciertas personas o durante determinadas épocas, resulte más difícil o costoso, también a nivel personal. También señalan la soledad con que se puede vivir la atención en fin de vida*:* «de esta soledad no se habla; se habla mucho de la soledad del enfermo terminal, pero de la del médico en esta situación, es algo terrible!. Y sin relación con otros compañeros,... Cuando se puede compartir con otros compañeros, puede que la soledad no sea tan enorme».

Lo relacional

Aunque va quedando patente el papel de los aspectos relacionales, pregunto directamente sobre ello, y si bien todos manifiestan conformidad en otorgar un valor muy importante a los aspectos relacionales, sienten también la necesidad de señalar que los aspectos relacionales deben ser considerados como una herramienta más de la atención sanitaria, pero no la única. Para que tengan su justo valor y sentido deberán estar siempre acompañados de una buena atención clínica. A través de la escucha encuadrada en la relación clínica, se pone de manifiesto la complejidad de la demanda y la importancia de los demás profesionales, en particular la del miniequipo médico enfermera, pues como señala una médico, «en esta situación la enfermera y mi relación con ella tiene un papel crucial, porque ve las cosas desde otro prisma y porque generalmente, las personas "se abren" antes a la enfermera que a mí». También se hace evidente la relación y el trabajo con sanitarios de otros niveles, en referencia a oncólogos, radiólogos, ... y con otros servicios como los de Hospitalización domiciliaria, la Unidad del dolor, ... Una de las médicos es muy tajante al respecto; otorga a lo relacional un valor 10 y continua diciendo que si la relación clínica funciona, todo irá mejor, incluso se necesitará menos analgesia. Pero para que realmente funcione, la persona enferme «tiene que creer que yo le creo, y es mi obligación hacérselo saber». En esto coincide con la enfermera que trabaja sola, ya que señala que: «lo relacional, en ocasiones, es más importante que los mórficos, que sepan que te tienen ahí y saber que no están solos, para echarles un cable, para orientarles en la gestión de otras necesidades...».

Un elemento imprescindible en la relación es la escucha. La escucha es una herramienta que permite recoger la demanda. Se trata pues de una escucha activa, con un claro fin asistencial, «supone escuchar y recoger cuestiones relativas a la demanda de eutanasia, de sedación, ...o de hospitalización cuando no la esperabas o no la considerabas conveniente». Esta misma persona marcan una diferencia entre escuchar y oír; habiendo recibido una formación orientada al signo y al valor de las pruebas clínicas objetivables, han debido realizar un camino, en ocasiones individual, que les ha conducido a "redescubrir" el valor de la subjetividad en la vivencia de los procesos de enfermedad. Cuando se escucha, se recogen demandas que pueden resultar difíciles o incómodas, o peticiones que pueden estar en desacuerdo con el juicio clínico. Sin embargo, todos coinciden en que hoy no pueden trabajar sin escuchar: «yo no puedo actuar sin saber lo que el otro siente, quiere, necesita, o cómo lo vive». Además y como ha quedado reflejado en lo relativo a la intensidad de la relación, la escucha «supone compartir situaciones y decisiones... que implican algo más que recetar un fármaco (20)».

Pero la escucha activa requiere un tiempo, un tiempo de más que debe ser "robado" al tiempo que habitualmente la Administración otorga a cada consulta. La atención a personas en fin de vida es considerada por quienes la asumen como "un valor añadido" que algunos sanitarios deciden hacer desde sus consultas; supone asumir una tarea asistencial que entre otras cosas, requiere más tiempo. Si la gestión del tiempo resulta ser uno de los temas más difíciles de manejar en el contexto sanitario en general, en este trabajo es un elemento determinante

La escucha, junto con los aspectos relacionales, son temas para los que ninguno de ellos recibió formación en el pregrado. Puede que esta carencia, vivida y sentida como tal, haya sido uno de los elementos que provocó la búsqueda de una formación que les hiciera más hábiles en lo relacional y les permitiera manejarlo mejor.

Señalan la existencia en todo ellos una cierta predisposición hacia la escucha así como una cierta intuición sobre su valor (21). Su formación posterior les ha permitido resituarla, manejarla y valorarla en el contexto clínico.

Una enfermera hace referencia a cómo la escucha en la relación clínica pueden servir para poner de manifiesto necesidades, otras, que las puramente clínicas de la persona en fin de vida, en este sentido señala la necesidad de recoger y evaluar también las necesidades de la cuidadora principal.

Al preguntarles por lo que a cada uno de ellos le ha resultado más difícil del tema, se refieren a varios aspectos como son, el manejo de situaciones en las que la relación anterior no era fluida «porque tú quisieras que lo fuera, porque (si la relación es buena), los fármacos y la atención, todo va a estar mejor», para otros lo más difícil está en comunicar el pronóstico, es decir, poder hablar con tranquilidad de la situación real en que se encuentra la persona enferma (no el tiempo de vida), para otros la dificultad está en «saber respetar los tiempos del otro, en no responder antes de tiempo, ... escuchar los silencios». Y para otros, poner límites, es decir, encuadrar la escucha en es contexto terapéutico concreto y orientada hacia unos objetivos asistenciales concretos.

Siguiendo con el tema, resultaba necesario poner de manifiesto el valor que otorgan a la palabra de la persona enferma. En la actualidad, por lo menos en teoría no se suele cuestionar el valor de los aspectos relacionales y de la escucha en la relación clínica. Además, en teoría, la escucha, la actitud empática otorgan una cierta connotación de calidad a la asistencia sanitaria. Pero por desgracia, no suele ser tan evidente el valor que se otorga a la palabra de los y las pacientes. Se suele cuestionar el valor de la palabra de la persona enferma con relativa frecuencia. Por este motivo pregunto sobre el tema, pues de lo expuesto hasta el momento parece que se va haciendo evidente el valor que estas sanitarias y sanitarios otorgan a los síntomas y a otros elementos que pueden acompañar a la terminalidad haciendo más difícil esta etapa de la vida, difícil en sí misma. El dolor es uno de los síntomas que con frecuencia sufren las personas en fin de vida, en tanto que síntoma es principalmente reconocible y valorable a través de la palabra de la persona que lo sufre, por eso pregunté si consideraban que se pueden fiar cuando una persona dice que tiene dolor. La respuesta ha sido unánime, subrayando que además que no es suficiente con creer a la persona enferma que manifiesta tener dolor pues se le debe hacer saber, con palabras y hechos que se le cree. Sobre este tema añaden otra serie de cuestiones que resultan interesantes y que remiten a temas tales como el poder en la relación clínica: «Le creo, necesariamente, si me dice que le duele mucho es que le duele mucho, y si no, debo barajar otra información para contrastarla, la expresión no verbal, la familia..., para ver si es cierto, si le duele y dice que no le duele para "tenerme contento", o porque no se atreve, ...».

Continuando con el tema del poder en la relación clínica, no parece ser un tema de preocupación general. No obstante, para algunos resulta evidente el hecho de que la relación clínica está mediatizada por el poder, y en consecuencia, existe una preocupación por manejarlo correctamente y no abusar del mismo. Una persona matiza que el abuso de poder puede llegar a tener consecuencias graves en el estado general de la persona en fin de vida, por ejemplo, respecto del control del dolor, pues es solamente un médico quien puede prescribir morfina: «Muchas veces me he planteado la historia del poder, y en fin, como persona que pertenezco a una sociedad, creo que uno no puede tener en sus manos tanto poder, como puede ser el poder de controlar un mórfico [...] El hecho de que hoy en día se siga permitiendo que una persona viva con dolor y que el médico no recete un mórfico ....¡me parece terrible que no utilice un medicamento que alivia el dolor y que puede permitir disfrutar de esos últimos momentos...¡Y eso está en manos de un médico!, pero este caso se une con otras muchas cosas en las que se manifiesta el poder del médico».

Pero en general no parece un tema de preocupación importante ni para médicos ni para enfermeras. Estas últimas manifiestan una menor preocupación que los médicos respecto de este tema. Dicen haberlo visto ejercer por otros compañeros y compañeras, pero creen no ejercerlo. Son ellas las que señalan el riesgo de que el poder también se manifieste en la relación entre ellas y los profesionales de la medicina.

Sobre el cambio de paradigma

Aunque algunas de las referencias anteriores van ya perfilando una forma de entender el trabajo sanitario que marca claras diferencias respecto del modelo hospitalocéntrico en el que se formaron, se exponen a continuación algunas de las causas que les movieron a "trabajar de otra forma", así como sobre los elementos que lo hicieron posible.

La filosofía "hospice", si bien no plantea nada nuevo, sí recoge algunos de los elementos que han caracterizado a las medicinas tradicionales y que hace suyos desde un punto de vista metodológico la antropología de la medicina, como son, el orientar la atención hacia la persona enferma (y no a la enfermedad), la importancia de los síntomas y su control, con especial énfasis en el dolor (dando así importancia al aspecto vivencial, es decir, a la subjetividad de la persona respecto del manejo de la enfermedad), la atención de la persona enferma y de su familia desde una perspectiva biopsicosocial,... Se parte de la idea de que esta "nueva" perspectiva supone un cambio respecto del paradigma que subyace en nuestra medicina oficial, y en consecuencia, las sanitarias y sanitarios entrevistados han debido realizar un cambio de orientación respecto de la formación de base que recibieron.

De lo reflejado con anterioridad va quedando más o menos de manifiesto, que se trata de profesionales que "intuyeron" desde el comienzo de su carrera profesional la conveniencia o la necesidad de trabajar de "otra forma". Para hacerlo posible, emprendieron una búsqueda de recursos teóricos y metodológicos que les permitiera hacerlo posible. Así, el primer elemento a señalar es la búsqueda de formación como elemento común a todos ellos. Todos, a excepción de uno, han seguido formaciones de postgrado regladas. Consideran que esas formaciones constituyeron la base que les permitió enmarcar su trabajo profesional en una perspectiva global. No consideran que la filosofía "hospice" plantea un modelo nuevo de abordaje de la salud, sino que entienden que recoge perspectivas planteadas con anterioridad, (en los ámbitos de la salud publica, la salud comunitaria, la medicina social, e incluso como señala una de las enfermeras, la de los antiguos médicos de cabecera). Consideran que es un modelo "exportable" a otros ámbitos de la atención sanitaria, pues entienden que tiene más ventajas que inconvenientes. Comenzando por los inconvenientes, citan el tiempo como factor limitador, pues se necesita más tiempo. La implicación en el trabajo profesional es mayor pues desarrolla la autocrítica. Al tomar conciencia desde la tarea asistencial de la complejidad de la situación y de la demanda, se hace más difícil si no imposible desarrollarlo de modo individual. Plantean un riesgo añadido, puesto que si bien existen profesionales de enfermería y medicina que de motu propio han decidido asumir estas demandas asistenciales, no hay un Centro de Salud en toda la Comunidad Autónoma Vasca, que todos los sanitarios trabajen así; si bien señalan que cada vez hay más compañeros y compañeras que asumen el cuidado en fin de vida, muchos de entre ellos trabajan en solitario. Y esto supone un riesgo añadido.

En lo que concierne a las ventajas, señalan que les permite situarse mejor respecto de su trabajo, de los objetivos del mismo y de las demandas que plantean las personas enfermas y sus familias: «yo estoy mucho mejor en el trabajo y eso evita que me queme», además hace posible un trabajo más eficaz y en consecuencia, más gratificante. En general, al hablar sobre este tema, son parcos en palabras, es como si el tema fuera tan simple y evidente que no necesitara ser explicado. En clara referencia a que entienden que esta "nueva perspectiva" tiene más ventajas e inconvenientes, consideran que es un modelos exportable a otros ámbitos asistenciales de la Atención Primaria, como es, la atención a las personas con patologías crónicas, e incluso a ciertas parcelas de la atención hospitalaria, siempre y cuando se cuente con la formación necesaria, ya que es imposible que se produzca un cambio sin una formación que lo haga posible. La intuición no es suficiente, y la búsqueda de formación a la que se han sentido obligados, ha supuesto para cada uno de ellos un camino lo suficientemente costo, personal y profesionalmente, como para pretender que sea generalizable.

En la medida en que esta "nueva perspectiva" supone un cambio importante respecto al modo más generalizado de atención de la medicina oficial, quise preguntar sobre cómo les ven o cómo reaccionan frente a ellos las compañeras y compañeros que no trabajan de este modo. Entre los elementos a destacar, y aún teniendo conciencia de que todavía son una minoría quienes así trabajan, señalan el cambio que se ha ido produciendo con los años. Cuando comenzaron, (mitad de los 80), se les consideraba como locos y transgresores, por "creer" a los pacientes, por prescribir morfina...: «todavía hoy algunos piensan que somos bastante loquillos, pues los que van en nuestra misma onda son los menos».

Son terriblemente respetuosos con sus compañeros de A.P. que no atienden a personas en fin de vida; aluden a cuestiones tales como la falta de formación, la falta de tiempo, ya que ciertamente se requiere más tiempo para trabajar de esta forma, el miedo o desconocimiento respecto del manejo del dolor y de los mórficos, y los miedos personales como elementos que hacen difícil el poder asumir esta parcela asistencia. No obstante dicen de sus compañeros que: «aunque no lo hagan, saben que es algo que está ahí y que habrá que hacer».

Respecto de los compañeros, sobretodo respecto de los que trabajan en hospital, desearían que tuvieran una mayor sensibilidad hacia el trabajo que realizan. Les gustaría que entendieran que «la persona enferma no es de nadie sino de sí misma». Consideran necesario que se respeten sus decisión respecto del lugar y las condiciones en las que desea pasar el final de su vida y por si quedaba alguna duda, apuntan que no siempre tiene que ser su domicilio.

Otro tema que me interesa, es el de saber si consideran que su trabajo es valorado por la Administración, por Osakidetza. Como ya se ha reflejado, sienten que tienen el reconocimiento de la persona enferma y de su familia y esto les gratifica, pero respecto de la Administración ya es otra cosa. Entienden que comienza a haber una cierta sensibilidad hacia el tema, pero de momento, la atención a personas en fin de vida que realizan desde A.P., se sustenta en la buen voluntad de algunos sanitarios que a título personal la asumen. Consideran que esto resulta ser un "valor añadido" del sistema sanitario público vasco, y la falta de reconocimiento pone en riesgo su continuidad, por el "queme" de los profesionales que voluntariamente lo asumen. Una enfermera explica así la situación: «se trata de una demanda que realiza la persona enferma a su médico de referencia y no a la Administración a la que éstos pertenecen». Si a esto añadimos que el modelo de gestión organizado principalmente desde una perspectiva hospitalocéntrica desde el que la A.P. es considerada como una atención sanitaria de segundo orden (o de categoría inferior), nos encontramos con una serie de ingredientes en los que se evidencia la confrontación entre centralidades administrativas y realidades periféricas .

En lo asistencial, se reflejan también carencias importantes en la práctica asistencial respecto del hospital. Tanto desde los profesionales de enfermería como desde los de medicina, se manifiesta la dificultad añadida que supone el que una persona en situación terminal, cuando va del hospital al domicilio "pierda" una serie de recursos que debido a su condición particular de salud gozaba en el hospital. Aunque su condición precaria de salud sea la misma, dichos recursos desaparecen si la persona regresar a su domicilio. Nos referimos a elementos materiales tales como una cama articulada, una grúa para el baño, ... elementos materiales que hacen más fácil su vida y su cuidado en el domicilio y que en ocasiones se hacen imprescindibles.

También señalan el menor coste que para la Administración representa el que las personas elijan ser atendidas en este periodo de la vida en sus domicilios. Es un hecho conocido que la Atención Primaria es más barata que la Hospitalaria, y si a esto sumamos la falta de cualquier tipo de reconocimiento respecto del trabajo sanitario y del de cuidado que asumen las familias, el ahorro económico resulta evidente: «probablemente en este momento, el nacer es más caro que el morir». Existe una petición unánime, la creación de una Unidad de Cuidados Paliativos que permita que las personas que así lo deseen o lo necesiten, puedan vivir la última etapa de la vida en el hospital, en las mejores condiciones posibles.

No obstante, desde la Administración se comienza a plantear la necesidad de homogeneizar criterios asistenciales, organizar un flujo de derivaciones, planificar una formación, ...

El futuro

Para finalizar, y en la medida en que todos ellos están implicados en un mayor o menor grado en la formación de las futuras generaciones de sanitarios, me interesaba saber cual era su visión sobre los elementos que pueden facilitar el cambio, algunos de los cuales ya se han ido manifestando cual es la formación. Consideran que en la formación pregrado con especial énfasis en la formación en medicina, se debe trabajar no solamente sobres los aspectos relativos al curar sino también sobre el cuidar, sin que esto deba suponer ni un menoscabo ni una limitación en el quehacer médico. Se debe introducir la perspectiva biopsicosocial aplicada al trabajo cotidiano, la multidisciplinaridad como elemento fundamental del trabajo sanitario, y dejar claro y trabajar el hecho de que la muerte es una realidad que forma parte de la vida. Respecto del valor que otorgan a los aspectos socioculturales, conviene señalar que son profesionales sensibles a las diferencias culturales y señalan la necesidad de recibir formación en el pregrado para saber manejarlas, en la medida en que las migraciones actuales se caracterizan por una mayor diferencia respecto de ellos mismos y de la población autóctona. Puede que el hecho de trabajar en poblaciones que sufrieron el flujo migratorio que vivió el País Vasco a partir de los años 40-50, por haber experimentado de forma palpable esta circunstancia haya agudizado su sensibilidad hacia el tema. Así mismo consideran necesario planificar una formación postgrado que permita a los nuevos graduados recibir una formación específica que les permita asumir el cuidado a personas en fin de vida, y al mismo tiempo asegure el reciclaje de los sanitarios que lo deseen mediante una formación organizada, evitando la "improvisación". Consideran que se debe evitar, como sucede en la actualidad, el que la formación continuada corra a cargo de los laboratorios farmacéuticos, pues si bien esto supone un ahorro importante del gasto de formación que la Administración debe ofrecer a sus trabajadoras y trabajadores, se trata necesariamente de una formación sesgada.

Se plantea también la conveniencia de explorar el potencial de las medicinas alternativas, considerándolo como un recurso a valorar.

Respecto de la situación actual, se apuntan dos cosas, la necesidad de realizar un plan desde la Administración que reconozca esta parcela asistencias y que se planifique y facilite el trabajo y la comunicación entre los diferentes niveles asistenciales.

Otro elemento deseable sería: «que la Administración invirtiera más en Atención Primaria, pues es la puerta de entrada al sistema».

Si bien la dinámica general respecto de este tema es de optimismo, una sanitaria manifiesta lo siguiente: «no lo veo fácil, económicamente no es rentable, es mejor no abordar lo psicosocial (en mucha ocasiones causa de los malestares) y tratar sólo el síntoma».

3. Los silencios

Como final de este primer análisis de las entrevistas realizadas quiero señalar algunos de los puntos que se me han ido planteando durante el trabajo. Cuando desde la Antropología de la Medicina nos referimos a la biomedicina, la consideramos como un sistema homogéneo y no dudamos en aplicarle una serie de características. Creo que se puede afirmar que el sistema es complejo y este trabajo muestra otra faceta de esta parcela asistencial, si bien periférica, pero que difiere en buena medida de lo que mayoritariamente se suelen considerar como elementos característicos de la biomedicina. Periférica, si, pero sospecho que no es la única. Si bien el modelo de gestión se organiza respecto de las centralidades, estas otras parcelas también existen, y en ellas encontramos buenos profesionales comprometidos con un trabajo asistencial para el que no fueron formados y que para continuar desarrollándolo han necesitado buscar en otros ámbitos instrumentos que les permitan, en la actualidad, continuar haciéndolo.

Pero además de lo recogido creo que ha habido cuestiones que han aflorado de modo indirecto y sobre las que creo puede resultar interesante profundizar, como son, el poder en la relación clínica, las particularidades de la atención domiciliaria, y temas tales como hasta qué punto es posible basar un modelo asistencial en trayectorias personales, y si es posible continuar trabajando en solitario y sin que desde la Administración exista reconocimiento de este trabajo, ni respecto del realizado por los sanitarios ni del realizado por las familias.

Note

(1) El mencionado artículo recoge una amplia bibliografía sobre el tema (VALDERRAMA M.J. 2002).

(2) El hecho de verse confrontados con demandas asistenciales para las que carecían de recursos, ha hecho que muchos profesionales que con "buena voluntad" comenzaron atender a personas en fin de vida, principalmente como medida de salvaguarda personal. Otros, como se desprende de los testimonios de los entrevistados, emprendieron un camino de búsqueda de formación y recursos técnicos y metodológicos.

(3) Sobre el holismo y el cambio de paradigma que al igual que otras disciplinas recoge la filosofía Hospice, resulta muy interesante el análisis de Menéndez (MENÉNDEZ E.L. 2002).

(4) Como una de las características de la biomedicina actual.

(5) El entrecomillado hace referencia a que, como queda reflejado, la filosofía Hospice, no plantea nada nuevo en sí misma.

(6) Y a sus características particulares. Sobre el tema, ver Menéndez (MENÉNDEZ E.L. 1979, 2002).

(7) En referencia a un país vecino, valga como muestra esta frase: «ce sont les médecins de l'échec, qui d'ailleurs, sont moins bien "honores" que leurs confrères spécialistes. "Mauvais" médecins censés soigner de faux malades, ils sont resentís comme des fosiles et certains se demandent à quoi ils peuvent bien servir à part orienter les patients vers le spécialiste adapté» (GALAM E. 1996: 13).

(8) En lo que respecta al cuidado en fin de vida, se trata de una práctica asistencial poco tecnificada y que reposa en el "buen hacer" de algunos sanitarios y en el deseo o el "compromiso moral" de una familia que asume la tarea del cuidado en el domicilio; sobra decir que ninguna de estas dos formas de cuidado, ni la profesional ni la familiar, están reconocidas, valoradas o incentivadas por la Administración Sanitaria.

(9) A excepción de uno, más joven, con 15 años de ejercicio profesional.

(10) Este elemento de la dispersión será señalado por ambos como una dificultad añadida al trabajo profesional, ya de por sí duro, suponiendo pues un mayor riesgo de desgaste personal y profesional.

(11) Examen estatal que permite a los Licenciados en Medicina acceder a la formación en especialidad. La elección de la especialidad se realiza en función de la nota de examen. De entre más de veinte mil aspirantes, sacaron plaza unos dos mil quinientos, él sacó el doscientos y fue el segundo en elegir la especialidad de Familia en todo el estado.

(12) El colectivo de enfermería siempre se han quejado de la falta de autonomía profesional y de la excesiva dependencia de los profesionales de la medicina. Curiosamente estas dos enfermeras

señalan este "descubrimiento", tanto respecto del trabajo como de replanteamiento profesional. En consecuencia, señalan una diferencia entre ellas y sus compañeras que ejercen en el hospital, principalmente en relación al valor de los aspectos que acompañan al enfermar, valor de la comunicación, del síntoma, en suma.

(13) Quiero señalar que esta terminología es propia de ellos; no la introduzco yo en la "reelaboración" de su discurso.

(14) Esta persona relata su "primer caso" como el de un hombre joven, con esposa e hijos pequeños; en su "no poder hacer nada" se refiere tanto al no poder evitar que muriera como a no saber que hacer, es decir cómo orientar y manejar la problemática social en la que quedaba su familia.

(15) Respeto el género utilizado por ella, pero tanto ella como el resto de las personas entrevistadas constatan que la figura de "cuidador principal" en la familia, es asumida por mujeres en un porcentaje cercano al 100%.

(16) Esta es una práctica habitual de todos los sanitarios entrevistados. Posteriormente se hablará de ello, referido principalmente a la escucha.

(17) Me pregunto si se trata únicamente de una diferencia semántica o se refiere a una intuición sobre el papel que la persona enferma desarrolla en el proceso de "curarse".

(18) El subrayado no es mío.

(19) Se puede necesitar desde una cama de hospital a gestionar una incapacidad u otros, y la persona puede plantear problemas de tipo legal, relativos por ejemplo al testamento, o de tipo religioso, psicológico, social, ...Entienden que entra dentro de sus competencias recibir y derivar estas demandas.

(20) Una de las enfermeras diferencia entre escuchar e informar y pone el siguiente ejemplo: si voy a una casa y veo que la persona enferma tiene los pies sin hidratar, si en vez de preguntar el por que «dices, pues el pie no lo tiene hidratado y le explicas lo que tiene que hacer y no le escuchas, puede que la familia lo esté haciendo así todos los días y por las razones X no absorbe, y si sólo le digo lo que tiene que hacer, pues no vamos a ninguna parte, [...] entonces, antes de dar nuestro "discurso profesional" habrá que preguntar qué es lo que ha hecho la familia, o la persona enferma, y partir de ahí para corregir o no lo que están haciendo. Es decir, si no aprendemos a escuchar, difícilmente podremos trabajar eficazmente».

(21) No les ha resultado fácil resituar la escucha en el contexto clínico, diferenciarla de la "cortesía", de los "buenos modales". Su comprensión actual en tanto que herramienta de trabajo, es el resultado de un largo tiempo de trabajo y discusión.

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2.

Biomedicine and alternative medicines
Biomedicina y medicinas alternativas
Biomedicina e medicine non convenzionali

AM
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2.1 *The domestication of “Wild medicine”. Complementary and Alternative medicines (CAM): organisational strategies for their supply and institutional processes for their official recognition*

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The Unconventional Universe and the “Seven Sisters”

Similarly to what has been happening in Europe and in the rest of the West for the last two to three decades, the diffusion of complementary and alternative medicines (CAM) is also increasing in Italy. According to the latest statistics available (1), more than nine million Italians had recourse to complementary and alternative medicines between 1999 and 2000. Becoming increasingly aware of the various courses of treatment open to them as different individuals, they appear to turn above all to homeopathy, acupuncture, phytotherapy and manual therapies. More and more people have borrowed and reshaped the notions of personal health and well-being that are conceived in cultural situations that develop a so-called “alternative” logic, compared with those that dominate the social system and that are typical of the health services of wealthy societies. More or less consciously and coherently, through their behaviour these people criticise the uniqueness of a medicine considered as standardized and make a case for medical pluralism and freedom of choice among the different options for the handling of health/illness processes (2).

The decision to carry out a medical anthropological research project matured in this socio-cultural context. It was characterized by the epistemological cognition that in-depth research conducted during a circumscribed period and in a circumscribed area, being a “particular case of the possible” (3), would bring interesting cognitive details to light that might facilitate the comprehension of the phenomenon. In order to explore the prospect of an integration of medical systems, we decided to transcribe what we learned in a health sector action planning policy tool (the *Piano Sanitario Regionale della Regione dell'Umbria* [The Umbrian Regional Health Plan]).

The Fondazione Angelo Celli per una cultura della salute, in collaboration with the Umbria Region and the Sezione antropologica del Dipartimento Uomo & Territorio, Università di Perugia [Anthropological Section of the Man & Land Department, University of Perugia], has conducted a study entitled *Terapie non convenzionali: indagine descrittiva sulle offerte e sull'utenza nella Regione dell'Umbria* [Complementary and alternative therapies: descriptive research on supply and users in the Umbria Region] (4), which focuses on the CAM phenomenon from a medical anthropology approach. The research programme, which developed between August 2000 and August 2002, concentrated on the geographical area under the administration of the Umbria Region. Within this area, in-depth study was conducted in districts that are representative of the diverse geographical contexts: Valnerina, Foligno-Spoleto, Eugubina, the Higher Tiber Valley, Perugia, Lake Trasimeno, Orvieto-Tuderte and Terni.

Open questionnaires, forms of participative observation, forms for the reconstruction of therapeutic itineraries and case studies were addressed to the professionals and the persons who have recourse to complementary and alternative medicines. The main characteristics considered as regards the professionals were the following: their educational careers, cognitive horizons, fields of activity, catchment areas and finally the way they work. The qualitative approach adopted towards those who avail themselves of complementary and alternative medicines aimed at identifying the reasons for their decision, their relative levels of satisfaction and their attitude towards "official" health services. This approach also intended to rebuild fragments of life stories, narrations of illness experiences, "self-healing" episodes and therapeutic itineraries.

Altogether the study produced 200 in-depth interviews in the seven areas of the region, 500 hours of surveying-recording, 2,500 hours of analysis and processing and 5,000 pages of documentation.

Among the interesting achievements of the study – the results will be soon available since its publication is imminent – we would like to point out the number of the different kinds of complementary and alternative medicines recorded: 59. This data is still more significant if we consider that the Umbria Region – which has an area of 8,456 km^2 for a population of under 805,000 inhabitants – is one of the smallest regions in Italy.

The table below recapitulates the different kinds of complementary and alternative therapies counted and surveyed in the context of our research and puts them into relation with the various categories of healers identified. The table provides information on the professionals who work in the field of complementary and alternative medicines and practices in Umbria. At this point we confine ourselves to making an observation concerning the category that we have called "modern healers". Under this category we find operators who are not medical graduates but who have followed training courses and belong to different cultural and ideological horizons that syncretize various medical systems.

Category of professional	Complementary and alternative therapy practised
Traditional healers	Clairvoyance, Exorcism, Love potions, Phytotherapy, Pranic healing, Radiesthesia, Tarot card reading, Divining
Modern healers	Aromatherapy, Aura reading, Channelling, Chelation (aura clearing), Chromopuncture, Chromotherapy, Craniosacral therapy, Crystal therapy, Dance therapy, Egyptian shamanic and energy healing, Energy reading, Fasting therapy, Flower therapy, Foot reflexology, Holistic (Ayurvedic) massage, Humoralism, Iridology, Kinesiology, Knowledge of previous lives, Lymphodrainage, Macrobiotics, Mediumistic contact with the dead, Music therapy, NAET (Nambudripad's Allergy Elimination Technique), Naturopathy, Osteopathy, Postural re-education methods (Feldenkrais, Souchard, Mézières methods), Pranic healing, Pyramidology, Reflexology, Reiki, Shiatsu, Watsu, Yoga
Graduated in medicine	Anthroposophical medicine, Ayurvedic medicine, Chinese medicine (Acupuncture, Fire cupping, Moxibustion, Phytotherapy), Chiropractice, Flower therapy, Homeopathy, Homotoxicology, Iridology, Microchiniopuntura, NAET (Nambudripad's Allergy Elimination Technique), Ozone therapy, Phytotherapy, Reflexotherapeutic manipulative medicine.

By coincidence or by chance – if we really do not want to recognize the social characteristics of history – the FNOMCEO [Federazione Nazionale degli Ordini dei Medici Chirurghi e degli Odontoiatri (Italian Federation of Councils of Physicians and Dentists)] Convention (Terni, 17 May 2002) "La professione medica e le medicine non convenzionali: rischi e opportunità" [The medical profession and complementary and alternative medicines: risks and opportunities] took place during the same period and once more in Umbria. This Convention can be seen as the expression of the recognition that the medical establishment is ready to give to complementary and alternative medicines as well as to the phenomenon of its diffusion. On that occasion, the chairpersons of the 103 Provincial Italian Medical Councils existing in Italy drew up a document representing the FNOMCEO guidelines on complementary and alternative medicines and practices. This document, approved on 18 May 2002 by the FNOMCEO National Council (5), is the medical profession's reference for CAM. From our point of view there are at least four remarkable elements in the text: the reasons for its having been drawn up, the list of the complementary and alternative practices, the attribution of the category "medical act" and the measure of protection to be adopted. The reasons for the drawing up of these complementary and alternative medicines and practices guidelines lie first in two European Community Resolutions (Resolution 75 of the European Parliament, 29 May 1996, Resolution 1206 of the Council of Europe, 4 November 1999) and secondly in Europeans' general and more and more frequent recourse to complementary and alternative medicines. The same line of argument is used to enumerate the seven medicines and the two practices called "complementary and alternative" (acupuncture, phytotherapy, Ayurvedic medicine, anthroposophical medicine, homeopathy, traditional Chinese medicine, homotoxicology, osteopathy and chiropractice) that are clearly defined as medical acts. These medicines correspond to the definition of a medical act since they can exclusively be practised or handled by a doctor or a dentist, who are the only persons legitimised to make a diagnosis, to organize a treatment plan and to ensure that it is carried out on the patient. The reference to the medical act is essential to state the need for sanctions against every person who, though not being a doctor, practises complementary and alternative medicines or treatments; the necessity of regulated training paths and finally the need to adopt a minimum rate for health care services.

There is a significant gap between, on one hand, the results from the field research on the supply that responds to the demand for individual health and, on the other hand, what is admitted and recognized as a medical act by the professional medical organizations. Indeed, the universe of complementary and alternative medicines and practices is particularly heterogeneous in Umbria as well. This heterogeneity is due to the residues of traditional medicines, the products of heretical deviations from official medicine, the practices of alternative naturopathy medicine, the derivations from the New Age paradigm, charismatic rituals, the reflections of the major Chinese and Ayurvedic systems and the fragments of African and Afro-American therapeutic rituals. The FNOMCEO document on the recognition of the "seven sisters" appears to be the partial concession, subject to restrictions, made by a now monopolistic body that is tending to remove the political advantages, the social reasons and the historical stages thanks to which it has succeeded in playing this role, and is sweeping away the basic and persistent polarisation of medicine both in the direction of science and in that of art.

Well-being versus Evidence-based Medicine

Over the last decades, in Italy as well as in the rest of Europe and the so-called industrialised West, individuals' attention to the issues related to their own health has significantly increased. In a general manner, the aspects that are not directly curative and that have to do with health promotion and disease prevention have become more important and are receiving more attention; "life styles" are not eclectic products of a literary élite any longer, but rather behaviours deriving from health-conscious attitudes towards every daily detail that constitutes the life cycle; the medical humanities – to stay in the "conventional" field – are acquiring recognition and academic space. The intellectual superstructures that define the characteristics of the "health care needs in the post-modern era", into which the health/illness representations from diverse medical systems are syncretically intertwining, are based on the evolution of epidemiological frameworks, on changes in the dominant diseases inside pathocenosis (6), on raising life expectancy and, paradoxically, on the outcomes of 19th and 20th century biomedicine (7). We have moved from the conception of health as the condition of the absence of disease to a conception of health as a procedural reality in a psycho-physical general well-being that biomedicine and its health bureaucracy do not seem to welcome easily, while complementary and alternative therapies appear readier to encourage it.

The representation of health that we have previously defined as post-modern can easily be traced back to the protest movements of the system that have introduced into Western society the revaluation of creative thought, the taste for the transgression of norms, an ecological sensitivity, emancipation from the roles imposed by age or gender, spiritual research outside the Catholic tradition and the enchantment of exoticism. This framework encourages the "aesthetics of health" that accompanies the recourse to complementary and alternative medicines. Once the characteristics of militant "counter-culture" and political commitment were lost, the movements of the late sixties and the seventies impregnated individuals' intimate dimension, induced the pursuit of originality in the definition of one's own identity and found a favoured field of expression in the shift involved in the consideration of the body from a mechanistic device to a place of meanings (8). The detailed record and the sociological characterization of the users and the practitioners of complementary and alternative medicines allow us to note the depth and the cross-cutting character of the cultural sedimentations determined by this conception of the body and these aesthetics of health.

The research in the Umbria Region conducted by the Fondazione Angelo Celli enabled what has been affirmed up to this point to be specified with reference to ethnography. First of all, we must emphasize that recourse to complementary and alternative therapies does not exclude recourse to biomedicine. It is complementary to it. The CAM patient is often the actor in an individual itinerary through the diverse medical systems, whose efficacy he is disposed to bear witness to, as well as to become a builder of cosmologies. In general, he starts from the search for solutions to pathologies that conventional medicine fails to consider or for which it does not succeed in structuring either diagnostic references or adequate therapeutic settings. Once a pharmacological therapy has been tried, the patient is moved by the desire to avoid their undesirable effects and heads towards complementary and alternative medicines, relying on credible witnesses to their efficacy in order to find his bearings. Sometimes, too, the patient is moved by mere curiosity.

The framework of the various motivations peculiar to a person who has recourse to CAM that we have just reconstructed has many points in common with the itineraries of the graduate doctors who practise complementary and alternative therapies. The reasons why they come to CAM may be family heritage, the influence of esteemed colleagues or personal experience as a CAM patient. These practitioners are those who express their dissatisfaction with the biomedical system, its organization, the way it works and its efficacy in a more circumstantial and well-argued manner. Doctors who practise CAM criticize the too invasive forms of treatment, the de-personalized doctor/patient relationship that penalizes the patient and reduces him to a passive subject in an asymmetrical communication relationship and the excessively bureaucratic and alienating environment. They also mention their own disappointment with the medical profession practised "conventionally" (nowadays, we call conventional a system based on scientific research and on the acquisition of knowledge, while an unconventional system means traditional medical knowledge. The meaning of the adjective is far removed from the concrete reality).

It is interesting to see how spaces in the market are opened up for all these reasons: chemists, another of the targets of the study *Complementary and* *alternative therapies: descriptive research on supply and users in Umbria* all build up the same picture from this point of view. They turned to CAM in the early eighties, a period that we could certainly characterize in many different ways connected with the social dimensions of history but that coincides above all with the change from the protesters of the decade before to consumers, who have good purchasing power even if they are niche market customers. Laboratory preparations made in the back shop the way apothecaries used to do it, following criteria of aseptically anonymous packaging, were quickly replaced by industrial and para-industrial products on offer from counter dispensers, whose packaging is conceived to convey a sense of ancient alchemic knowledge to customers imbued with their freshly acquired health consciousness.

As far as the genesis and the supply of preparations are concerned, we can easily compare the case of the herbalist workshops to the case of pharmacies.

In this context, we can cite another aspect that was ethnographically confirmed in the Fondazione Angelo Celli study: the substantial loss of importance of both the traditional iatric activities and the figures of the operators who practiced these activities. An area called Valnerina was selected in the planning phase of the study owing to its conservative reputation for the traditional medical practices largely widespread in Umbria until some years ago. The significant downsizing of rural society due to the changes in the organization of the agricultural sector in Umbria and to the consequent migratory flows led to the disappearance of the so-called "medicine of our women". We can still find some remaining forms of this medicine in developed areas on the outskirts of towns (9).

Our outline of some of the characteristics of the health needs in the post-modern era was made possible by the combination of aspects such as international trends and ethnographic reports, globalization dynamics and local changes. This demand for healthcare is the result of population migrations and/or world conceptions related to the new worldwide social structures, the manifestations of hegemony that express themselves in the body's conceptions and the forms of resistance against these manifestations.

In the post-modern era, health needs are expressed by the educated and the well-to-do classes. On one hand, this encourages the diffusion of complementary and alternative medicines. On the other hand, however, this provokes an apparently defensive reaction on the part of biomedicine and its management and administration apparatus, which invokes the question of efficacy as a defence. Efficacy can only be measured through protocols developed within biomedicine, which imposes, through its organisations, the levels of healthcare, the Essential Levels of Health Care (ELHC) provisions, which are now the constant parameter common to all policy planning documents in the health sector. Nonetheless, the planning of the Health Services policies based on the ELHC can not be measured with the aesthetics of health/illness that goes with the diffusion of complementary and alternative medicines. The professional bureaucracy that has developed inside the institutions of biomedicine is responsible for the lack of dialogue between the worlds of biomedicine and of CAM. Indeed, the professional bureaucracy, in order to follow a conduct of presumed scientific rigour, underlines only the ratiocinating aspects of the *arte medica*. As a consequence, it does not recognize that medicine, apart from being science, is also art. Medicine is science and art and should include the evidences of experimentation laboratories as well as the individual variables of human organisms. Epistemologically, we can define medicine as a practice able to make use of scientific knowledge and technological equipment that could start a constructive dialogue with CAM. The motivation should not be the presumed absolute truth of its beliefs but rather its capacity to organize its expertise and make it available.

The Doctor, the Judge and the Anthropologist

The spreading of complementary and alternative medicines, in its reasons, its forms, its pervasiveness and the consensus that surrounds it, is an essential phenomenon for the understanding of the backgrounds of the building of health/illness representations that form the basis for citizens' health needs. The official medical system should take it into account; research centres as well as professional bureaucracies should act in order to understand and to provide services in the light of a perspective of integration of the various medical systems.

The scientific paradigm that has been structured in the West is able to overcome the contrasts between biomedical or energetic metaphysics and the methodological aporiai deriving from the evaluation of efficacy. Moreover, it is conscious of the necessity of turning to the criticism available thanks to the historical reconstructions of its background and the other backgrounds. Finally, it also knows how to structure open research programmes. There are favourable conditions for an integration of the various medical systems that would have interesting repercussions on the interpretation, diagnosis and treatment of illness and, in general, on the redefinition of the relationship between humanity's biological and social aspects.

From this point of view, we are the Third World. In fact China, Nepal and Korea have developed, both in professional training and therapeutic practice, an integration of medical systems that constitute an interesting development of the medical pluralism that we are still far from having achieved in Europe (10). The legislative and organizational approaches to complementary and alternative medicines commonly found in Europe are substantially of three types (11). First, there are the "monopolistic" systems that exclusively recognize conventional medicine as lawful, considering every other form of unconventional medicine as an abusive exercise of the medical profession. These systems are widespread in Southern Europe, France, Austria, Luxembourg, Iceland and Poland. Secondly, we find the "tolerant" systems that, though the only form they explicitly recognize is the conventional medicine, allow unconventional therapists to practise. This is the case in Germany, Great Britain and Ireland. Third, there are the "mixed" systems in which some medical acts, established by the law, are restricted to conventional medicine while other medical practices are freely admitted. We find these "mixed systems" in Belgium, Netherlands, Portugal and the Nordic countries. It is worth noting that attempts at EU legislation governing complementary and alternative medicines have been hampered by the medical traditions of the different countries (the recognition of the *heilpraktiker* or of anthroposophical medicine in Germany and the discipline of herbal remedies in Great Britain, to name but the most well-known cases). These difficulties have thrown into sharp new relief the questions connected with medical pluralism, which, at last, is no longer considered an anthropological and cultural notion associated with exotic countries. We should also stress the European Community's desire, prompted by the pressure of public opinion, to establish general norms in the field of complementary and alternative medicines. The difficult relationship between the demands expressed by public opinion and the building of a popular consensus on one hand and scientific research and administrative policies on the other hand is becoming obvious and emphasizes the fact that complementary and alternative medicines can be considered as the "critical consciousness" of our health organization.

The Italian legislative approach to health care is such that it must be considered as falling under the category that we have previously defined as monopolistic. Indeed, in Italy, only the practice of conventional medicine is recognized as lawful. From the legal point of view, the Italian health system is still based on two articles of law. The first is Article 2229 of the

Civil Code, which allows the practice of the intellectual professions only to persons that have notions and a level of education previously established by the State. The second is Article 348 of the Civil Code, which represents its criminal law equivalent and punishes the abusive exercise of all professions (12). It is worth noting that these two laws apply to all the intellectual professions. These norms appear to be the expression of a political and philosophical concept on the basis of which the State punishes abuses in the sense that it is the sole supervisor of the production and the transmission of culture through school and university administration. It should also be noted that the Italian legislative system is another illustration of the correspondence between bureaucratic State centralisation and the unequivocal medical knowledge that, according to Foucault, represents the genetic conditions of the modern clinic. In accordance with this, the health professions (doctors, veterinaries and chemists) were instituted by a Royal Decree, namely the 1934 Consolidated Health Act. After this, health professions that were considered "auxiliary" until 1999 were instituted. Fourteen figures have been established by as many decrees issued by the Health Minister from September 1994 to March 1995 (the chiropodist, the speech and language therapist, the orthoptist, the dietician, etc.).

It should also be noted that the notions of medical profession and medical act – calibrated by the legislator to the characteristics of curative medicine operators – that provide the basis for the Italian legislation are not adequate to cover the whole sector of preventive medicine and health promotion. Moreover, if we consider the effect that complementary and alternative medicines have on the conceptions of well-being in the broad sense of the term, it is easy to understand the difficulties in the application of the system of sanctions.

In any event, during the 14th legislature (from June 2001 to October 2002) eighteen bills were presented to the Chamber of Deputies and three to the Senate. This is a noteworthy production, to which parliamentarians from every political party contributed and which can be considered as an example of the cross-cutting approach (a trendy expression in the political field) to questions related to the non-conventional medicines. But it can also be interpreted as a manifestation of a legislative will that is perhaps too dependent on and sensitive to movements representing public opinion. At this point it might be of interest to make an overall evaluation of this legislative production. First of all, we appreciate that the recent proposals are no longer characterized by a concern to stigmatize and by the desire to inflict penalties, which shows the legislator's more mature knowledge of complementary and alternative medicines. Moreover, the principles of "scientific pluralism” and of therapeutic freedom of choice have spread, not problematically but rather with a connotation connected with the Italian social context in which they are inserted. In general, we note the attempt to overcome the Health Ministry’s bureaucratic centralism. Nevertheless, the individual’s right to freedom of choice concerning the most suitable type of treatment is established with difficulty. Recognition is easier in the case of associations or lobbies that have established themselves as corporatist Cam groupings.

We wish to conclude this article with an important and hopeful consideration: the fact that legislative activity seems to be in the course of offering the prospect of integrated medicine, inspired by Article 33 of the Italian Constitution. This Article lays down the freedom of art and science and the legislative power that has been recently granted to the Regions, some of which (Piedmont, Tuscany, Valle d’Aosta, Umbria) have already made interesting experiments in this field.

Notes

(1) Istituto Nazionale di Statistica, *Condizioni di salute e ricorso ai servizi sanitari, Indagine Multiscopo 1999-2000*, Istat, Roma, 2001. This Italian Statistical Institute survey concerned a sample of 30,000 families. Though Italy occupies a low position in the European ranking, the number of people who have recourse to complementary and alternative medicines has doubled between 1991 and 1999 in this country. MEP Paul Lannoye has mentioned, in his Report on the status of the complementary and alternative medicines to the Committee for the Environment, Public Health and Food Safety of the European Union, that between 20% and 50% of the European population have recourse to complementary and alternative therapies.

(2) For further information, see: Cavicchi Ivan, *Pluralismo o Babele medica? Chi, come e che cosa scegliere per curarsi*, pp. 63-84 in *Medicina e multiculturalismo. Dilemmi epistemologici ed etici nelle politiche sanitarie*, preface by Sebastiano Maffettone, Apèiron, Bologna, 2000. For a systematic picture of the question, see: G.P., *Salute/malattia*, pp. 394-427, vol. XII, in *Enciclopedia*, 16 voll., Einaudi, Torino, 1977-1984.

(3) Bourdieu Pierre (1995 [1994]), *Spazio sociale e spazio simbolico*, in Bourdieu Pierre, *Ragioni pratiche*, translated from the French by Roberta Ferrara, Il Mulino, Bologna [original edition: *Raisons pratiques. Sur la théorie de l’action*, Éditions du Seuil, Paris, 1994 / original edition of the essay: *Espace social et espace symbolique*, conference held in the University of Todaiji, October 1989].

(4) Fondazione Angelo Celli per una Cultura della Salute, *Terapie non convenzionali: indagine descrittiva sulle offerte e sull’utenza nella Regione dell’Umbria*, in collaboration with the Umbria Region and the Section of Anthropology of the Dipartimento Uomo & Territorio at the University of Perugia.

(5) The document can be found on www.fnomceo.it.

(6) For the definition of dominant diseases and pathocenosis, see: Grmek Mirko D. - Sournia Jean-Charles, *Le malattie dominanti*, pp. 417-450, vol. III. *Dall’età romantica alla medicina moderna*, in Grmek Mirko D. (editor), *Storia del pensiero medico occidentale*, 3 voll., Laterza, Roma-Bari, 1993-1998.

[7] For a conceptual framework and its contextualization in a medical anthropological work perspective, see: SEPPILLI Tullio, *Antropologia medica: fondamenti per una strategia*, "AM. Rivista della Società italiana di antropologia medica", no. 1-2, October 1996, pp. 7-22.

[8] On this subject, see the various essays in: COLOMBO Enzo - REBUGHINI Paola, *La medicina che cambia. Le terapie non convenzionali in Italia*, Il Mulino, Bologna, 2003.

[9] For a presentation of traditional medicine in Umbria, see: FALTERI Paola, *La medicina popolare/ Umbria*, pp. 160-165, in SEPPILLI Tullio (editor), *Le tradizioni popolari in Italia. Medicine e magie*, Electa, Milano, 1983. The sentence in italics in the text refers to the work of a general practitioner from Perugia. He worked in the Umbrian countryside and was interested in folklore, especially medical folklore: ZANETTI Zeno, *La medicina delle nostre donne*, anastatic reprint by M.R. TRABALZA, with an essay by A.M. CIRESE, Foligno, 1978 [original edition: ZANETTI Zeno, *La medicina delle nostre donne*, a folklore study that was awarded a prize by the *Società di antropologia*, including a letter by Paolo MANTEGAZZA, Città di Castello, 1892]. This book is to be considered as one of the most famous treatises on the studies of popular culture of the late 19th century.

[10] The legislative approaches to this matter have been classified into "monopolistic", "tolerant", "mixed", "inclusive" and "integrated" by STEPAN J., *Traditional and Alternative Systems of Medicine: A Comparative View of Legislation*, "International Digest of Health Legislation", vol. 36, no. 2, 1985.

[11] We are referring here to: DEI Fabio, *Normative europee sulle medicine non convenzionali, uno sguardo antropologico*, an intervention during the Congress on *Medicine non convenzionali. Esiti della ricerca in Umbria e percorsi per l'integrazione nel Servizio Sanitario Regionale* (Perugia, 5 December 2002), organized by the Fondazione Angelo Celli per una cultura della salute, the III Permanent Umbria Region Committee and the Umbria Region Department for Health Protection and Healthcare, in the context of the research project *Terapie non convenzionali: indagine descrittiva sulle offerte e sull'utenza nella Regione dell'Umbria*". Acts still being printed.

[12] RENZO Michele, *Professione medica e medicine non convenzionali: linee costitutive e problemi aperti della normativa italiana* and CROCELLA Carlo, *Analisi delle proposte di legge presentate al Parlamento alla luce di alcuni principi sui diritti del cittadino malato*, interventions during the Congress on *Medicine non convenzionali. Esiti della ricerca in Umbria e percorsi per l'integrazione nel Servizio Sanitario Regionale* (Perugia, 5 December 2002), organized by the Fondazione Angelo Celli per una cultura della salute, the III Permanent Umbria Region Committee and the Umbria Region Department for Health Protection and Healthcare, in the context of the research project *Terapie non convenzionali: indagine descrittiva sulle offerte e sull'utenza nella Regione dell'Umbria*". Acts still being printed.

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2.2 *Biomedicina, terapias "alternativas" y el proceso de su integración en la atención primaria. Investigación en una área de la Italia central*

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Introducción

En este trabajo se presentan los resultados de una investigación, que tuvo lugar entre los años 2000 y 2002, sobre las actitudes y las decisiones operativas respecto a las terapias "alternativas" de un grupo de médicos de familia y pediatras de libre elección que trabajan en Umbría. Ambas tipologías de operadores están comprometidas en la llamada "medicina de primer nivel". Los medicos de familia se ocupan de los pacientes a partir de los catorce años y los pediatras, de los pacientes de cero a catorce años. En los dos casos están encargados de la educación y prevención sanitaria de la población y de hacer intervenciones diagnósticas y terapéuticas. Constituyen, además, la llave de acceso a las estructuras sanitarias organizadas presentes en el territorio.

Las entrevistas con ellos abarcan tematicas de integración entre las terapias "alternativas" o y la biomedicina. Se ha tratado de conocer qué terapias no incluidas en la biomedicina conocen, en qué modo las insertan en su propio paradigma científico y en la práctica cotidiana, y qué evaluaciones hacen de ellas en relación a la concepción de salud/ enfermedad elaborada a lo largo de su trayectoria profesional. Éste tema tiene una estrecha conexión con las intensas dinámicas de cambio hoy en acción dentro del cuadro de las nuevas configuraciones hegemónicas que abarcan las problematicas del cuerpo y de la salud/ enfermedad en el Sistema Sanitario Nacional en sus varias articulaciones; los nuevos criterios legislativos que se están delineando en Europa y en las regiones italianas; y la atención que la Iglesia Católica ha prestado últimamente a las medicinas "alternativas".

El campo de la salud/ enfermedad se constituye hoy como uno de los ámbitos en el cual se desarrollan los procesos de hegemonía que incluyen a la biomedicina, las prácticas folclóricas, la Iglesia y, finalmente, las terapias "alternativas". A propósito de estas últimas denominación es importante destacar que en este trabajo se entiende por tal término «una vasta acumulación de representaciones, saberes y prácticas dirigidas a contrastar la patología y a conservar la salud, que no hacen referencia a un único corpus, ni desde el punto de vista teórico ni desde el práctico y que son más o menos extrañas a la biomedicina» (1). «Nos encontramos entonces frente a evocaciones actualizadas de las viejas medicinas folclóricas rurales y urbanas o de la tradicional herborística familiar; a procedimientos extraídos de los grandes sistemas médicos orientales como, por ejemplo, la acupuntura; a la "occidentalización" de procedimientos "exóticos" como el training autógeno (derivado de las técnicas hindúes del yoga) o la correspondencia entre los mapas de aplicación de la acupuntura y de la terapia láser; a prácticas presuntamente paranormales; a participaciones totalizadoras en grupos culturales neo-religiosos de diferentes orígenes; y finalmente a líneas heterodoxas de desarrollo de la misma medicina occidental, como la homeopatía» (SEPPILLI T. 1996 [traducción de la Autora]).

Es importante destacar que la denominación "terapias alternativas" no es del todo exacta, porque me refiero a terapias a las que se recurre paralelamente a la biomedicina y no en alternativa a ella. "Terapias no convencionales" quizás sería la exacta traducción del inglés "unconventional medicine" o del italiano "terapie non convenzionali", no es un termino usual aunque en mi opinión es más adecuado.

El objeto de esta investigación es la relación entre la biomedicina y las terapias "alternativas" que, en esta particular fase histórica, se configura como un proceso de negociación: la biomedicina se abre hacia las llamadas terapias "alternativas", aceptando algunas y excluyendo otras y dando vida a una integración que se caracteriza por ser de procedimientos terapéuticos más que de horizontes ideológicos de referencia. En este particular período histórico la biomedicina se ve necesariamente obligada a "dialogar" con una infinita variedad de terapias "alternativas" a las cuales un considerable número de personas está recurriendo hoy en día.

El estado de la cuestión

Conviene citar al menos algunas de las investigaciones, predominantemente cuantitativas, efectuadas para evaluar el avance del recurso a terapias "alternativas" por parte de los usuarios en los últimos años. Haré una breve referencia a la investigación conducida por el CENSIS 1983, al informe Doxa del 1999, a la investigación Istat publicada en 2001 *Condizioni di salute e ricorso ai servizi sanitari 1999-2000*, en *Le condizioni di salute della popolazione anni 1999-2000*, y a la conducida por la OMS el 2000 (Ernst E. 2000b) que registran un constante aumento del uso de tales terapias. Los resultados de la investigación del Istat, en particular, hablan de nueve millones de italianos que en el bienio considerado (1999-2000) recurrieron, al menos una vez a ellas, principalmente a: homeopatía, acupuntura, fitoterapia y tratamientos manuales (Istat 2001). De todos modos se trata de itinerarios terapéuticos que no presumen casi nunca la exclusión de la biomedicina de la gama de elecciones posibles, ya que los pacientes recurren a las diversas terapias "alternativas" según el problema de salud que tengan que resolver. El cuadro que se abre frente a nosotros, parece, pues, ser extremadamente dinámico y atañe a una serie de ámbitos en la biomedicina, sus criterios de validación de la eficacia, los operadores, su rol en el Sistema Sanitario Nacional, su formación y finalmente los modos en que éstos conciben las terapias "alternativas" y cómo se confrontan y se relacionan con ellas. Además, la falta hasta ahora de indicaciones precisas respecto de estas terapias por parte de los canales oficiales hace que este ámbito de investigación sea todavía más interesante.

Aspectos legislativos

En base a lo antedicho no pueden no tomarse en cuenta los nuevos ordenamientos legislativos que se delinean en Europa y en diversas Regiones italianas y consecuentemente la función de control social y de mediación que la legislación ejerce. Tomar en consideración el ámbito legislativo es importante porque el reconocimiento normativo se vuelve el terreno en el cual se juegan los procesos de hegemonía entre la biomedicina y las terapias "alternativas". Legislar en materia significa definir cuáles son las terapias "alternativas" aceptadas y cuáles no, establecer cuáles son las sus modalidades de acceso, incluyéndolas en las ofertas del Servicio Sanitario Nacional y, finalmente, obtener la exclusividad sobre todo en lo que se refiere a la formación de los profesionales de la materia. Algunos países europeos como Alemania, Bélgica y Suiza han reconocido algunas terapias "alternativas" como acto médico, por lo cual se incorporaron a las terapias a cargo de sus servicios sanitarios nacionales.

En Italia, la propuesta de ley n. 1103 de la *XIV Legislatura* presentada por la Cámara de Diputados, tiende a individualizar un núcleo orgánico de normas que aseguren el reconocimiento de las principales terapias "alternativas" practicadas por los médicos. Las reconocidas son la acupuntura, la fitoterapia, la homeopatía, la homotoxicología, la medicina antroposófica, la medicina tradicional china y la medicina ayurvédica. Además, muchas regiones italianas, que tienen estatutos de autonomía (2), están introduciendo en los respectivos Planes Sanitarios Regionales la fitoterapia y la acupuntura dentro de su oferta y prevén financiamiento para incrementar las investigaciones sobre la oferta y la demanda. La única región que ha legislado sobre las terapias "alternativas" es el Piemonte que, en octubre de 2002, con la Ley Regional n. 25 promulgada por el Consejo Regional, ha reconocido doce terapias "alternativas", estableciendo normas precisas en cuanto a la formación de los que las practican.

La situación en Umbria

En cuanto a la Región de Umbría, el Ordine dei Medici (3) de Terni, ha reconocido nueve de tales terapias imponiendo que sean practicadas exclusivamente por médicos. En Perugia, la capital, entre la oferta de la Unidad Sanitaria Local n. 2 hay un consultorio para la terapia del dolor, donde se introdujeron tratamientos de acupuntura y homotoxicología asociados a terapia farmacológica. Una contribución cognoscitiva importante a nivel regional fue ofrecida por la investigación bienal (2000-2002) *Terapie non convenzionali: indagine descrittiva sulle offerte e sulla utenza nella Regione dell'Umbria* (4), financiada por el Ministerio de la Salud a través de la Región de Umbría y conducida por la Fondazione Angelo Celli per una cultura della salute y con la Sezione antropologica del Dipartimento Uomo & Territorio de la Università degli studi di Perugia. El proyecto apenas concluido (diciembre de 2002), por su carácter cualitativo, se aparta de todas las otras investigaciones italianas e internacionales que se han mencionado anteriormente. Aunque el muestreo utilizado porrean operadores "alternativos" y sus pacientes, farmacias y herboristerías, en el presente trabajo se ilustrarán brevemente sólo los resultados obtenidos que se refieren a los operadores "alternativos" y los pacientes. Los datos reunidos han permitido la individualización de tres categorías de operadores diferentes y que se ha convenido en llamar "curanderos tradicionales rurales", "curanderos modernos" y médicos. Por "curanderos modernos" se entiende aquéllos que no tienen un título de medicina y cirugía, pero que han participado en cursos de especialización para aprender terapias prácticas (shiatsu, reiki, reflexología podal...) y que, en la mayor parte de los casos, integran tratamientos de varios tipos. Muchas veces los médicos entrevistados practican las terapias "alternativas", como los tratamientos de medicina tradicional china y de homeopatía, junto con la medicina, sin poner en discusión los principios de la biomedicina e integrando los diferentes sistemas y prácticas médicas, antes de la tan esperada normativa en materia. La oferta de terapias "alternativas" por parte de los operadores de salud de nuestra Región es un fenómeno en crecimiento, de límites frecuentemente poco definibles. Durante los dos años de investigación se individualizaron cincuenta y nueve tipos de terapias "alternativas". Generalmente, los pacientes son individuos con alto grado de escolarización (diplomados o titulados), con una edad promedio de cuarenta y cinco años, y sobre todo de sexo femenino. Las principales motivos que inducen a los pacientes a recurrir a ellas son: el deseo de evitar los efectos colaterales de la terapia farmacológica, la eficacia comprobada a través de conocidos "creíbles" que experimentaron la misma terapia para la misma patología y, finalmente, la búsqueda de una solución alternativa a una patología persistente que la biomedicina no ha podido resolver.

La posición de la Iglesia Católica

La postura de la Iglesia Católica dentro de las nuevas configuraciones hegemónicas desarrolladas alrededor del cuerpo y de la salud/enfermedad, es relevante. Teniendo en cuenta el constante aumento de la población que recurre a las terapias "alternativas" con una postura mística, examinaremos dos publicaciones a través de las cuales la Iglesia Católica expresa su posición. Son un ejemplo significativo de la heterogeneidad de posiciones con respecto a ellas en el seno de la Iglesia Católica. *Gesù Cristo portatore dell'acqua viva. Una riflessione cristiana sul New Age* (PONTIFICIO CONSIGLIO DELLA CULTURA - PONTIFICIO CONSIGLIO PER IL DIALOGO INTERRELIGIOSO 2003) expresa un juicio muy duro y trata de hacer, a través de las contribuciones de máximos exponentes del pensamiento católico, una redefinición de la ideología católica respecto a la elaborada por la New Age, para establecer lo que está admitido y lo que está fuera de la religión. En el texto se alude a las diversas terapias "alternativas" y se alerta sobre de los horizontes ideológicos que entran en abierta colisión con aquellos vehiculados por la religión. «Chi si chiede se sia possibile credere sia in Cristo sia nell'Acquario sappia che questa è una situazione nella quale o si sta da una parte oppure dall'altra. "Nessun servo può servire due padroni: o odierà l'uno o amerà l'altro, oppure si affezionerà all'uno e disprezzerà l'altro" (Lc 16, 13)» (5). Está claro el intento, por parte de la Iglesia, de reestablecer una distinción entre salvación y salud, de defenderse de orientaciones espirituales ya ampliamente presentes y tomar posición con respecto a rasgos culturales más generales por los cuales se siente de algún modo amenazada. Un mes después, en “Famiglia Cristiana”, semanario católico de gran difusión y con posición progresista, se publica en la colección *I libri della salute* el volumen *L'altra medicina* (MARZORATI P. 2003). El texto es de signo completamente opuesto al anterior: no deja ningún espacio a la demonización de las diferentes terapias “alternativas”, de las cuales ofrece una precisa descripción y proporciona consejos terapéuticos e indicaciones sobre la elección de operadores a los cuales recurrir, precisando que se tiene que informar al propio médico sobre el itinerario terapéutico que se piensa seguir. En la sección dedicada a las técnicas de meditación se lee: «Non è necessario essere seguaci di una particolare tradizione religiosa per accostarsi alla meditazione. [...] tutte queste pratiche hanno un obiettivo comune: aprire alla realizzazione interiore» (6).

Una investigación en una área de la Italia central

La investigación que presento en este trabajo se sitúa en el cuadro en el que he intentado delinear a grandes rasgos. Como introducí antes, con ella quise indagar las actitudes y las decisiones operativas de un grupo de médicos de familia y pediatras de libre elección de la Región Umbría en cuanto a la integración de terapias “alternativas” con la biomedicina.

La elección de estas dos tipologías de operadores sanitarios y no de médicos especialistas se debió a la posición que ocupan dentro del Servicio Sanitario Nacional y a las características de su actividad profesional. La posibilidad de tener un trato reiterado con un gran número de pacientes que, virtualmente ayuda a construir una relación médico/ paciente menos despersonalizadora, y el ser la llave de acceso a todos los servicios ofrecidos por el Sistema Sanitario Nacional, constituyeron la base de esta elección.

En el pasado, los médicos en Italia cubrieron un rol importante en los procesos de medicalización, y junto con obstetras y pediatras fueron los primeros en vehícular de y difundir los modelos interpretativos biomédicos de los procesos de salud/enfermedad. Ahora estamos de frente a un fenómeno contrario. Los médicos de familia y los pediatras de libre elección, gracias a su posición (presencia fundamental en el territorio, amplia cantidad de pacientes y estrecha relación con los mismos, llave de acceso a todos los otros servicios sanitarios ofrecidos por el servicio público) están actuando como “filtro” con respecto a las terapias “alternativas”. Son los primeros operadores sanitarios que entran en contacto con ellas gracias al trato reiterado con pacientes que siempre más a menudo recurren a tales terapias. Es particularmente en el campo de la pediatría en donde se actúa una importante integración entre biomedicina y homeopatía.

La investigación se llevó a cabo en dos fases sucesivas.

En primer lugar, mandé cuestionarios postales anónimos a los ciento sesenta y cuatro médicos y pediatras de los municipios de Corciano, Deruta, Perugia y Torgiano. Luego, focalicé el la unidad de observación en los municipios de Perugia, Corciano y Torgiano ya que la A.S.L. n. 2 estaba reorganizando sus distritos agrupando Perugia, Corciano y Torgiano en el distrito n.1 y Deruta en otro. En esta segunda parte se llevó a cabo una investigación de campo por medio de entrevistas individuales con un cuestionario semiestructurado. Tras haber subdividido el universo de médicos de familia y pediatras de libre elección operantes en el distrito n. 1 en cuatro cohortes decenales , seleccioné el 20% de cada uno de los grupos, número que se aproximaba al porcentaje de respuestas recibidas por medio del cuestionario postal (treinta y cuatro). La selección de los sujetos fue hecha de manera casual.

Elcuestionario postal anónimo, acompañado de una carta de presentación, preveía cinco preguntas. Una definición de las terapias "alternativas"; una opinión sobre su eventual eficacia; la presencia o no de pacientes que recurren a tales tipos de terapias y con qué propósito; la eventual disponibilidad por parte del entrevistado de dirigir a sus pacientes hacia un operador alternativo y en qué casos y una opinión sobre las motivaciones que en Europa llevan a un número siempre mayor de pacientes a recurrir a operadores "alternativos".

El cuestionario semi-estructurado de las entrevistas estaba subdividido en tres ámbitos temáticos dirigidos a investigar la formación de los entrevistados (en biomedicina o en terapias "alternativas"), su actividad profesional y las evaluaciones relativas y, finalmente, el ámbito de las terapias "alternativas" (definiciones, conocimientos, decisiones operativas, opiniones sobre su eficacia y sobre las modalidades de integración).

Los resultados de las respuestas al cuestionario postal dejan ver que la mitad de los encuestados realizan una elección operativa en dirección de las terapias "alternativas". Los sujetos dan indicaciones sobre el momento del itinerario terapéutico en el cual toman una decisión de este tipo (sólo tras haber constatado el fracaso de la medicina oficial); sobre el tipo de terapias "alternativas" hacia las cuales deciden orientar (acupuntura, reiki) y por último, las patologías (por lo general alergopatías) para las cuales las aconsejan. Hay que subrayar que casi todos los encuestados consideran eficaz un alto número de terapias "alternativas", sobre todo la acupuntura y la homeopatía. Mientras la primera, según ellos, resulta eficaz para resolver problemas de naturaleza álgica, la segunda demuestra su validez especialmente en el ámbito de las alergias. La homeopatía y la acupuntura resultan ser las terapias "alternativas" a las cuales recurre el mayor número de pacientes, como ya resultaba de las investigaciones anteriormente citadas. A propósito de esto, es interesante notar que los médicos que respondieron positivamente a este sondeo afirman recibir información sobre la terapias "alternativas" directamente de los pacientes. En lo que se refiere a las motivaciones por las cuales la población recurre siempre más a menudo a las terapias "alternativas", se señala una significativa heterogeneidad de opiniones.

En mérito a la definición de las terapias "alternativas", un número importante de entrevistados evita pronunciarse por la falta de experimentación clínica controlada que comprueben la eficacia y las eventuales contraindicaciones.

De las entrevistas hechas en la segunda fase de la investigación sobresale la apertura por parte de los operadores hacia las terapias "alternativas" que parecen conducir a elementos constitutivos de su propia profesión, como por ejemplo la relación médico/paciente, las concepciones de salud y enfermedad, y el rol que cumplen. La posibilidad que estos operadores tienen de entrar en contacto constante con un número conspicuo de pacientes, permite construir una relación médico/paciente basada en la confianza.

El conocimiento personal y del contexto en el cual el paciente se inserta permite a los médicos y a los pediatras construir una relación terapéutica poco despersonalizadora. La importancia que el sujeto-usuario asume en esta relación permite, a los trabajadores sanitarios, construir definiciones de salud y de enfermedad que pasan a través de una concepción estrictamente biomédica. De hecho, mientras la salud se define como bienestar psico-físico, que puede subsistir o faltar más allá del cuadro clínico presentado, la enfermedad es vista como la pérdida de tal bienestar. Como se deduce de tales concepciones, resulta fundamental a los ojos de estos operadores lo que el paciente "siente" y "percibe". La vivencia subjetiva de la enfermedad y de la salud se convierte así en el punto de referencia principal al intentar definir estos conceptos.

Lo que probablemente nos lleva a una definición de salud y de enfermedad de este tipo, se reconduce a las patologías por las cuales los operadores son consultados generalmente. Éstos, de hecho, además de tener que dar una respuesta a toda la vasta gama de patologías que se definen agudas, tienen que encontrar soluciones terapéuticas a patologías de tipo degenerativo, crónico y cardiocirculatorio para las cuales la biomedicina no ofrece respuestas. Hay que señalar ulteriormente la presencia de una serie de disturbios definidos como borderline que resultan difícilmente interpretables etiológicamente y que se leen como patologías que encuentran su ámbito en lo psíquico. Focalizar la atención sobre el sujeto en su interacción con la enfermedad, significa de algún modo, para los entrevistados, encontrarse en la constante posición de mediadores entre la interpretación biomédica de salud y enfermedad y una interpretación en la cual el paciente cubre una posición principal. El paciente, por lo general ignaro de la definición biomédica de los dos conceptos, parece reencontrar en este caso su centralidad: de esto deriva una notable tendencia de los operadores a un acercamiento holístico al paciente que caracteriza su rol en la continua confrontación con los otros operadores sanitarios, particularmente con los médicos especialistas. De hecho, aunque se tenga conciencia de la importancia del rol que tienen estos últimos, se les llama "curadores de órganos". En los casos en que se señalan intervenciones especializadas que, en su mayor parte, se resuelven en terapias muchas veces inconciliables entre sí, resulta necesaria la presencia de alguien que pueda "mantener el control" y modelar, a través de una interpretación global de la situación del paciente, la totalidad de dichas intervenciones. Los médicos de familia y los pediatras de libre elección consideran esta tarea central para su rol. Más allá de "filtrar" las solicitudes que los pacientes les ponen, otra tarea a la que dan gran importancia está conectada con la educación y la prevención sanitaria, cuya realización viene obstaculizada por el aumento excesivo de los roles burocráticos de su profesión.

Tales consideraciones sobre la relación médico/ paciente, sobre los conceptos de salud y enfermedad y sobre las definiciones de roles parecían importantes, como se ha señalado, para tratar de comprender la actitud demostrada por los médicos y por los pediatras frente a las terapias "alternativas".

Es importante decir que los entrevistados parecen conocer un gran número de terapias "alternativas". Las más citadas son la acupuntura, la homeopatía y la pranoterapia.

La primera, por lo general, no está incluida en la categoría de terapias "alternativas". Su inclusión en el consultorio de la A.S.L. n. 2, junto con la posibilidad de interpretar sus mecanismos de funcionamiento a través de instrumentos dados por la biomedicina y, en algunos casos, el reconocimiento de su tradición milenaria, contribuyen probablemente a esta postura.

Se puede observar también que de las terapias “alternativas” mencionadas se tiene una definición que no considera el horizonte teórico donde están insertadas, pero focaliza la atención sobre su eventual eficacia y/o inocuidad. Los médicos y los pediatras, encontrándose en la condición de no poder recibir información respecto a tales terapias a través de los canales oficiales de la biomedicina – como surge de los resultados de la investigación – y teniendo contacto constante con un número siempre mayor de pacientes que recurren a tales terapias encuentran, sea en éstos que en sus experiencias personales, los canales preferenciales a través de los cuales recibir informaciones (se pueden añadir las lecturas y las experiencias directas). Se asiste, así, a una transposición de atención que del plano teórico pasa a uno estrictamente empírico.

Parece legítimo pensar que sea justamente este continuo intercambio de informaciones entre los operadores sanitarios y sus pacientes, a través de una relación constante y directa, el que guía a los primeros a tomar decisiones operativas dirigidas a las terapias “alternativas”.

De los resultados de la investigación surge que un alto número de médicos y pediatras deciden orientar a sus propios pacientes hacia aquéllas, pero según diversas modalidades. De hecho, en el análisis de la selección de este ámbito, me di inmediatamente cuenta de que se pueden reconocer tres modalidades diferentes: la primera es por iniciativa del operador, la segunda por petición del paciente y la tercera es cuando el operador aconseja, en el ámbito de las terapias “alternativas”, aquélla que le merece más confianza. Como he dicho antes, la acupuntura resulta tener la mayor parte de los consensos. Casi la totalidad de los entrevistados afirma dirigir a los pacientes hacia operadores que practican terapias “alternativas” pero que tienen un título profesional en medicina. Los dirigen sobre todo a causa de patologías degenerativas, patologías osteoarticulares, patologías crónicas y finalmente toda la serie de trastornos relativos a la esfera de la psiquis, difícilmente interpretables etiológicamente. Se subraya que las patologías por las cuales, en la mayor parte de los casos, se decide orientar a los pacientes hacia terapias “alternativas” son aquéllas por las cuales son mayormente consultados, pero también aquéllas para las que la biomedicina no ofrece respuestas ciertas.

Las opiniones con respecto a la falta de contraindicaciones de algunas terapias “alternativas” lleva a otra parte de los entrevistados a asumir una posición neutra respecto de las peticiones por parte de los pacientes. En este caso particular los operadores sanitarios no toman ninguna decisión operativa en primera persona, dejando la responsabilidad de tal decisión al paciente.

Como se resalta en los resultados obtenidos, los entrevistados mantienen una actitud frente a las terapias "alternativas" que contempla una escisión neta entre lo que es el plano empírico y el plano del reconocimiento oficial de las mismas. Sobre el plano empírico, sus mismas decisiones operativas constituyen un primer paso importante hacia una eventual integración; sobre el plano del reconocimiento oficial la conditio sine qua non, a través de la cual esta integración podría llevarse a cabo, es la experimentación clínica controlada.

En conclusión, se podría afirmar que la actitud tomada por los médicos de familia y los pediatras de libre elección constituye, sobre un plano meramente empírico, un primer espacio de integración en el ámbito terapéutico.

Note

(1) SEPPILLI Tullio, *Discurso de abertura del congreso "Medicine non convenzionali. Esiti della ricerca in Umbria e percorsi per l'integrazione nel Servizio Sanitario Regionale" (Perugia, 5 dicembre 2002)* [traducción de la Autora]; citado por BAGAGLIA C. - FLAMINI S. 2003.

(2) En Italia, el Estado delega específicamente en las regiones todo lo que concierne a la salud. El esercicio de la misma se realiza en autonomía legislativa y en parcial autonomía económico-administrativa.

(3) Congregación de médicos inscriptos en un específico elenco oficial que los habilita para ejercer la profesión. Para acceder a este elenco, llamado Albo, es necesario redir un examen.

(4) FONDAZIONE ANGELO CELLI PER UNA CULTURA DELLA SALUTE, *Terapie non convenzionali: indagine descrittiva sulle offerte e sulla utenza nella Regione dell'Umbria*, en colaboración con la Regione dell' Umbria y con la Sezione antropologica del Dipartimento Uomo & Territorio della Università degli studi di Perugia, Perugia (en fase de publicación).

(5) «Quien se pregunta si es posible creer sea en Cristo que en Acuario, que sepa que ésta es una situación de la cual se está o de una parte o de la otra. "Ningún siervo puede servir a dos señores; porque o aborrecerá al uno y amará al otro, o estimará al uno y menospreciará al otro (Lc 16, 13)"» (PONTIFICIO CONSIGLIO DELLA CULTURA - PONTIFICIO CONSIGLIO PER IL DIALOGO INTERRELIGIOSO 2003) [traducción de la Autora].

(6) «No es necesario seguir una particular tradición religiosa para inclinarse a la meditación [...] todas estas prácticas tienen un objetivo común: abrirse a la realización interior» (MARZORATI P. 2003) [traducción de la Autora].

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2.3 *Unconventional medicine in Hungary: medical eclecticism in a post socialist society*

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Multiple medical identities and mixed medical realities are under our scope to demonstrate how the hegemony of biomedicine of late socialist modernism has been transformed to acknowledge postmodern medical diversity in a consumer-driven health care environment.

Medical pluralism is outlined not only at macrolevel of medical systems, but at the personal eclecticism of healers and patients with attention to postmodern multiple narratives. Syncretism, eclecticism, or hybridization of different medical worlds appears as unconventional medicine rises in the changing medical system of post socialist Hungary. Although the ontological basis of this complex and divergent medical subuniversa may be diverse, the political economical context usually creates the common framework.

Medical pluralism is usually depicted as field of conflict between the official, dominant medical system and alternative medicine, including diverse healing traditions of competing medical philosophies, traditions, or even as a plaza of diverse medical realities. This jungle of medical metaphors, explanatory models needs a theoretical frame for understanding patterns not only at the level of the medical system but in case of multiple and contradictory experiences and practices in which healer and patient engage. An ecocontextual approach is offered to uncover dynamic changes of medical systems and personal ecclectic praxis of healers and patients in a society of social-political transition.

A Systems Approach to Different Medical Realities

The given medical system (Wellin E. 1977) is a changing entity, which is made up of identifiable parts, which are mutually interdependent, so that each part tends to influence and to be influenced by other parts and together the several parts and their interrelationships form a system as a whole. The diversity of the medical system is changing in time and place. The responses of a given sociocultural (and medical) system to the introduction of new (technical, ideological, or social) elements can be explained neither solely by the nature of the system nor alone by the nature and mode of introduction of the new elements but by the complex interaction of both. Reciprocal or feedback processes occur. That is, the introduction of new health-related elements can be expected to affect the hosting sociocultural (and medical) system; in turn, the latter will also affect (shape or reinterpret) the new elements. This is true in case of nationwide medical system and it works at personal cognitive level too.

In our sample the introduction of liberal free market system had changed the economical environment for health-related enterprises. Changes in the social and political organisation may enhance or restrict medical pluralism. Totalitarian systems may strengthen the hegemony of biomedicine and liberal free market system is expected to pluralise the system. Sometimes the opposite may also take place, as a Chinese example proves. When China's leadership had turned towards western values in the period of the Kuomintang, cosmopolitan medicine advanced, and Traditional Chinese Medicine (TCM) had been almost made extinct from authorised ways of healing, while in the second half of the twentieth century Mao Tze Tung strenghtened the system of TCM, and gave free way to the "barefoot" doctors and acupuncture with its several thousand years tradition. The other great eastern medical tradition, the Ayurvedic professional medical system may also thank a lot to Gandhi, who gave support to this tradition as part of cultural resistance against western medical (and cultural) expansion.

Applying Boulding's ecodynamical analogy to medical systems one can reveal the dominant, tolerant-neutral or symbiotic eco-relationships between mainstream or cosmopolitan biomedicine and alternative medicine.

Landscape of Healing, Ecosystem of Medicines

The landscape of healing in Hungary shows variable diversity. Even within the same biomedical field, as psychiatry one can find harsh debates between social psychiatric approach and biological psychiatry. A disease itself may also be the target of plural approaches in the same discipline based on the ideas of different schools and expert communities. Contents of biomedicine are to a high degree culturally shaped and constructed through social negotiations (COLLINS H. - PINCH T.J. 1982) of different scientific and economical interest groups that are involved. Sometimes the philosophy of healing makes a difference. Bio-psycho-social framework, psychoanalytic oriented psychosomatic or pure somatic orientations may create diverse cultures from the mainstream practice including associations, institutes, journals, and protocols of diagnostics and therapy.

The ecology of medical "information units" or memes (1) (BLACKMORE S. 1999) may uncover the ecodynamic relationships between metaphors, explanatory models and representations of different medical realities.

If a meme is supported by more energy (more reliable scientific validation with more money in research, more impact factors, citations and negotiations of consensus conferences, more pharmaindustrial or medical technological interest in the background), it will gain a dominant position. If another medical meme like healing by "the laying on of the hands" or distant healing – regardless of the historical data and the convincing experience of healer and client – has only anecdotal value lacking double-blind statistical verification and systematic research regarding its effectiveness, materialistic explanation, then it is to be handled as pure belief, unconventional method or quackery.

Different needs and expectations sustain different patterns of memes. The same consumer of given medical memes may turn to different healers without any internal conflict, cognitive dissonance or giving up scientific commitment. This ecosystem of healing practices is itself a plural medical system embedded in the wider social, technological and natural or even supernatural reality.

Science, technology and society are "shaped and acquire their meanings in (a) heterogeneity of social interactions" (BIJKER W. 1995) creating a network of mutual influences of an ecological kind. This ecodynamism (BOULDING K. 1978) may appear in the interactions of different patterns of medical memes evolving into dominating versus submissive interrelationship, neutral ways of coexistence or symbiotic mutualism.

The interaction of medical worlds of different traditions in a so called inclusive medical system may create cooperative, sometimes symbiotic ecorelationship. One can find the most articulated symbiotism in the integrated system, where official promotion of the integration of two or more systems exist within a single recognized service.

But the eco-relations between medical memes may be mutualistic even in the tolerant medical system – at least at the level of patient and the healer.

For example in Hungary the alternative healing is more preferred by those who visit medical doctors more frequently as in Buda's (2002) studies. This finding supports the idea that people do not necessarily think in terms of mutually exclusive alternatives. Higher educational status increases likelihood as white-collar workers are 1.6 times more inclined to use AM in the future than blue collar workers.

That means that the energy feeding the circulation, sustainment and renewal of these memes of healing does not depend on scientific approval or information engineering by authorised biomedical power only. There are other sources, like the desire for a miracle, lack of trust in biomedicine, curiosity, need for hope, counter-culture attitudes, as Astin writes «Along with being more educated and reporting poorer health status, the majority of alternative medicine users appear to be doing so ... because they find these health care alternatives to be more congruent with their own values, beliefs, and philosophical orientations toward health and life» (ASTIN J. 1998).

Multiplication of Medical Reality in Hungary

In the socialist Hungary a monopolistic system of biomedicine dominated the landscape of healing with strict legal exclusion of alternative medicine except the analgesic, pain clinic-like use of acupuncture until the late 1980s. Folk healers, were stigmatized as fraudulent or ineffective practitioners. The class-struggle ideologies implied ideological fight against spiritual or traditional healers, the representatives of dangerous magico-religious beliefs. These healers had become the victims of political persecution as Vincze Engi Tüdő or István Dóczi. (GRYNAEUS T. 2002).

The deconstruction of the ideological hegemony of Marxism as an exclusively materialist approach took place as result of a social-political transition in Hungary in 1989. The shift towards a monetarian free-market post-socialism was accompanied by change in the medical system.

The earliest data of research regarding alternative medicine in the 90' s proved that shortly after the collapse of the communist system, in 1991 6.6% of the adult population had already consumed some forms of alternative medicine and 39% were open to use it in the future. On the other hand this study revealed a commonly held belief that AM users were thought to be hopeless people with terminal illness (especially with cancer), or people primitive and credulous enough to trust in these methods (ANTAL Z.L. -

Szántó Z. 1992) reflecting the influence dominance of biomedical paradigm. The results of Buda's research on unconventional medicine changed these preconceptions showing that alternative medicine in Hungary attracts people of higher social status. Higher education seemed to be important background factor among those who use alternative medicine in Buda's research study (Buda L. *et al.* 2002). After a few years of transient, limitless tolerance towards unconventional medicine, it has become a legitimate part of the health care system as a result of three pieces of legislation enacted in 1997. Decree n. 11/1997 (V. 28) of the Minister of Welfare. According to the Decree a medical doctor should govern diagnosis and therapy while the practitioner of unconventional medicine may only complement the physician's activity, whose orders he should not modify or change. The Decree identified those areas that can be practiced within unconventional medicine and in which a board examination is possible. These developments created free way to practice different ways of healing together, such as biomedical and diverse forms of alternative medical activities. The terrain of complementary medicine was conquered by 'dissident' medical doctors. This eclecticism was helped by a regulation according to which some activities including Homeopathy, Manual medicine, Traditional Chinese medicine, Ayurvedic medicine, Traditional Tibetan medicine, Biological dentistry and Anthroposophical medicine may be carried out by a medical doctor only.

Acupressure, Alternative gymnastics and massage, Lifestyle therapy, Reflexology, Alternative physiotherapy, Bioenergy, Phytotherapy (Herbalism) and Kinesiology have been opened for those alternative practitioners without biomedical background. The Government Decree 40/1997 (111.5) integrates unconventional medicine into the health care system to complement scientifically based medical practice.

The post-modern free-market of health services created a spontaneous "creolisation" of consumers' medical culture in Hungary. As the borders opened up for Chinese and Ukrainian immigrants, the tendencies in alternative healing were strongly influenced by them.

Acupuncture: People and Knowledge on the Move

Acupuncture was taught in Hungarian postgraduate medical courses mainly for experts working in the field of rheumatology and pain clinic in the late 1980s. Although the number of doctors with acupuncture knowledge and experience had been growing, acupuncture clinics were not allowed to open, and the official sceptic, scientific opinion was made obvious by books dealing with acupuncture in a very critical and sceptic way at that time.

The breakthrough was partly the result of the social-political transition, but the scientific reception of acupuncture preceded the clinical one, as first results of electrical measurability of acupuncture points appeared. A scientist dealing with biophysics of acupuncture, Ajándok Eőry gained his doctoral degree by electroacupuncture studies of the acupuncture points and the meridian system. His life career is a good example of radical eclecticism, and "post-modern" fusion of professional identities. His words reflect one possible direction in the progress of alternative medical thinking.

> «I am originally a biologist, my dissertation included research of acupuncture points with diagnostical relevance in 1969. We formed the first legal scientific research group of acupuncture in 1984. This group has grown to as large as counting 100 members, where I was the only person without medical competence. So at age 43 I began my medical studies at Semmelweis University, and I finished all the courses required by curriculum at age 50. At present I'm preparing for an exam in specializing as GP».

Eőry is real pioneer in the field not only because of the scientific research of acupuncture, but he renewed acupuncture in Hungary by inviting colleagues of a Chinese TCM Academy in the early 1990s. He radically mixed the most authentic Chinese acupuncture tradition with his pioneer scientific work in a process of ecodynamic symbiotism, where two different medical realities with their metaphors, explanatory models, roles and tools are brought together. This fusion of experimental neurophysiological approach and authentic TCM tradition offers a mutual deconstruction and reconstruction of therapeutic forms. Working with Dr. Eőry in the research of physiologic explanatory models of acupuncture we could prove the effectiveness of acupuncture in several vascular diseases by blood pressure monitoring, Doppler ultrasound and thermography, (LÁZÁR I. - SHUMING J. - GUO Z.Z. 1995) and we found immunological influence on the activity of Natural Killer cells, too (LÁZÁR I. *et al.* 1992). The results of neuroimmunologic and vascular research of acupuncture therapy were presented at international congresses.

Working with the American Paul Zmiewsky, an expert of ear acupuncture treatment of drug addicts, the Foundation offered free acupuncture intervention for homeless alcoholics and drug addicts too. As the head of the Foundation, Dr. Eőry organised teaching courses of authentic TCM, lead scientific research of physiological background mechanisms of acupuncture sponsored by Hungarian Scientific Academy, and published several books of TCM. Based on these achievements his activity is also a sample for the process of institutionalizing expertise through the stages of development of associations, building an educational system and pursuit for licensure (WILENSKY in ABBOTT A. 1988).

Eőry's approach proves success of articulated eclecticism integrating undisturbed authentic oriental tradition and western scientism. The two different medical systems with their tools, concepts and methods are in the process of being fused together into a new mix of reshaped boundary objects forming a new framework for new ways of perceiving health and disease.

This success is partly based on scientific research, because a major source for legitimization of a profession today lies in «reliance on scientization and rationalization of technique and on efficiency of service» (ABBOTT A. 1988).

Eőry articulates this hybridzation, telling: «In my mind the two worldviews stand together. The accurate diagnosis is western, while Chinese medicine strengthens the clinical practice. I am fond of integrativity. There is no conflict between them, what you are missing in one, you can find it in the other».

Medical Dissidents

The social structure of Hungarian alternative medicine had been transformed during the early 1990s. Those without a medical degree were pushed to the periphery of the competition. The ecodynamics of professional dominance created niches for "medical dissidents" from biomedicine in the case of field such as Homeopathy, Manual medicine, Traditional Chinese Medicine, Ayurvedic medicine, Traditional Tibetan medicine, Biological dentistry and Anthroposophical medicine.

Those, having biomedical background but affinity with unconventional medicine had to adapt to the milieu evolved from an earlier stage of alternative medicine movement. Gabriella Hegyi is one of the first medical doctors who turned towards unconventional medicine in the late 1990s.

She prefers the term:

> «integrative or complementary medicine. There is only one medicine, which contains traditional western medicine and complementer medicine in harmony. A Decree No. 11/97 of Welfare Ministry "emancipated" TCM with the western medicine. Otherwise there are independent TCM faculties at the

> universities of Bristol, Saarbrucken, Prague, Moscow and even at Harvard. There is no conflict between oriental and western medicine in my mind; they don't exclude each other. The integration is the essence of the holistic approach. Holistic is related to Holy, and the "Whole" too».

She is the founder and the head of the Yamamoto Institute, where high tech methods are integrated with traditional healing. There is a Vietnamese acupuncturist who works in the team. She is an immigrant, who did not return to Vietnam after her medical studies.The origins of her acupuncturist knowledge roots in her homeland. Bioresonance, neuraltherapy, and homeopathy are also practised at the Institute.

This Institute and the above mentioned Chinese TCM Clinic are really centres of cross-roads for shifting professional identities, intercultural encounters, places where different sort of emigrants have their asylums. The routes have different directions from biophysics through TCM to the western medicine or from biomedicine to unconventional medicine; from China and Vietnam to Hungary; leaving the official medical system or the scientific practice for establishing institutes and foundations which enables them to manage another way of healing, which also works. But the source of their radical eclecticism is the same. These niches are hot spaces of interacting diverse medical memes and different medical realities.

Táltos Healers

The so called Táltos healers – representing a reinvented tradition of esoteric healing practices – named themselves after the ancient Hungarian shamanistic healers and magicians. Táltos healers, bioenergetists and Reiki masters with distant healing, with meditation and prayer have a different niche in the ecosystem of alternative healing. Dissident doctors do not endanger their position. Their healing is rather part of a sub- or counterculture, than the so-called complementary medicine. One cannot find such therapy listed of COST B4 report. The esoteric healers of Táltos medicine delineate themselves form alternative medicine, although they have all the certification and official permisson for healing. The Táltos clinical practice is basically spiritual and/or esoteric including reflexology, homeopathy, chiropractics and psychotronics and other imagery technics.

The Táltos healers followed the same process of institutionalization through the stages of development of social network by the help of media: videos, journals, home page, building an educational system and pursuit for licensure.

The first step towards becoming a Táltos is to become familiar with radiesthesy. Learning the practice of dowsing is a sort of initiation rite; it makes the communication with the Inner Self possible. It makes a person sensitive to geopathic radiation of several kinds to prevent diseases caused by these 'earth radiations', and enables him to become open to internal intuitive reception of energetic and spiritual information. This is the way these healers get information about changes in others' aura, being invisible for them otherwise. If complementary medicine is told to be eclectic because it synthetizes western and traditional oriental medicine, homeopathy etc, this type of healing would be more radical in extending the diagnosis and intervention to physical, energetic (aura, chakra system), astral, mental and spiritual levels. This ideology differs from antroposophic esoterism by acknowledging its Christian background. But possessive spirits and soul loss are real etiologic factors again. Evil eye, damnation, spelling: these are realities calling for defence.

Training and indoctrination of Táltos healers can be considered as a process of cultural emigration to an alternative culture with its special cosmology, belief system and ethics. Searching for cross-links with other cultural fields (anthroposophy, geobiology) a wider semantic network of meanings emerges, which diminishes the subcultural isolation of the Táltos community.

Healing by hands, healing by spiritual or cosmic energy, chi, prana, ruach, dynameia, and Reiki energy – they are variants of something similar to different ethnocultural backgrounds and belief system. The subtle energies may be subject to scientific enquiry and object of sceptic debate (RASMUSSEN I.L. 1995). The energy healers compete for the same niches. This sometimes may be strengthened, as Reiki masters may warn their novices not to leave for Táltos healing and vice versa. It is ideological attention, to keep the community together, as a great deal of the attendants are only curious people who will never practice the skills they are given.

This sort of distant or bioenergy healing may be embedded in another reinvented tradition. Tagir Abdull al Bulgary from Kiew, Ukraine came to Hungary in 1990. His ethnic background is Volga-Bulgarian. His eclectic arsenal of unconventional medicine consists of acupressure, reflexology, bioenergetics, and ear-acupuncture. His main method – that he also wrote a book about – is energy healing with mental power and hands. He sends the "love-energy" received through the so called "Crown chakra", not by his palmar – chakras, but through his "Heart chakra". He speaks about mixed energy to be given to the patients, which consists of bioenergy of the body in 15%, and the main component:including the psychic energy 70%, and another 15% higher, cosmic energy.

Ethnicity is articulated in his case too. His book about energetic medicine starts with short comprehension of the history of the Volga Bulgars including the relationships with Magyars. In his book he attempts to integrate Bulgarian folk tradition, Muslim healing mixed with the Yoga tradition. Tagir emphasises the importance of integrative framework and the common roots of diverse phenomena, too: «It would be a mistake to separate bioenergetics from acupressure, phytotherapy, because these methods' essence is the same universal energy. The name is different, the method is distinct, but the aim of influencing and tapping the same energy is common».

The cultural conservativism and the adaptive efforts of immigrant Chinese or Vietnamese acupuncturists are different from the healing subculture of Táltos healers, who reconfigure the whole spectrum of alternative medicine in a special "reinvented" tradition. The syncretic eclecticism of Táltos healers has only weak attachment to the mainstream biomedicine, but a wider integration of different fields like folk tradition, religious contents, "Aquarian" mythologies and a wide range of alternative medical practices like homeopathy, spiritual healing, divination, dowsing, massages, reflextherapy. Training and indoctrination of acupuncturists and Táltos healers can be considered as a process of cultural emigration to a sort of alternative or counter-culture with its special cosmology and belief system. Nevertheless their ecclectic medical world has something in common as all of them extend the reality beyond the visible.

Neoshamanist Eclecticism

Tcm needs a shift from the Western professional medical tradition into an Eastern one, while bioenergetic healing itself is an escape from the material world into the invisible energetic and spiritual reality made visible by ideomotoric kinesis reflecting the subjects' unconscious. Perhaps the neoshaman revival movements and circles in Hungary reflect the most radical break away from mainstream biomedicine. Although the revival of shamanism seems the most radical turn, nevertheless this also can be found – as an exceptional healing practice in a Department of Psychiatry of Flór Ferenc Hospital, Kistarcsa in the neighbourhood of Budapest.

Shamanism is not a surviving tradition in the Hungarian folklore of healing, but one can trace back elements of it in the deeper layer of folk customs, narratives, tales, and texts with careful hermeneutic attention. When neoshamanism reached Hungary, it came from the West, and had been brought in by anthropologists like Michael Harner, Jonathan Horwitz and Felicitas Goodman (HOPPÁL M. 1998). It is not surprising that this tradition exerted influence on Hungarian psychologists dealing with pathopsychology of religious practice. The initiator was Harner, but another (ex-) anthropologist, Jonathan Horwitz became the spiritual leader of the group. This "root shamanistic" experience was not absorbed by unconventional medicine, but it became part of official psychiatric healing work applied by two creative psychologist, Orsolya Czaga and Gábor Elekes.

Their group at the National Psychiatric and Neurological Institute operated for three years, then they continued to use techniques of shamanic healing in psychiatric work in outpatient care and, more recently, in a drumming group in the psychiatric ward of the Flór Ferenc Hospital in Kistarcsa. The sessions of the group working in the ward are arranged into three-week intervals, with three or four sessions each week with 6-8 patients. On the basis of Michael Harner's work, the sessions are built on each other systematically, for the sake of the patients' safety, so that they would be properly protected from the uncontrolled invasion of unconscious contents. The applied techniques were shamanic rituals with drum, rattle, song and dance. The verbal and pictorial elaboration also helps to integrate the experience.

Elekes and Czaga eclecticism regarding ancient and modern healing practices is based on the Jungian approach and this is reflected by the integrated therapeutic 'vocabulary and grammar' of healing, as Orsolya Czaga describes this intergrative way of thinking:

> «To handle resistance at the start of the group we use three types of terminology according to the language of shamanism, depth psychology and the everyday language. Further on we mainly use shaman terms and sometimes their psychological equivalents for help».

This "multilingual" approach had been developed in an interdisciplinary department of psychiatry focused on religious pathology. The Jungian interpretation of deep psychological processes offers explanatory models for shamanistic phenomena. Here we meet the process of ecodynamic symbiotism again, where two different medical realities with their metaphors, explanatory models, roles and tools are brought together into a special form of healing. This fusion implies mutual deconstruction and reconstruction of theraputic forms and contents in a Jungian framework. The result is different from the conventional forms of group psychotherapy and differs from the Harnerian "root shamanism" too, because the therapeutic elements are reconfigured offering the above mentioned three discursive levels at the same time. This reconfiguration is crucial because when psychologists adopt "root shamanism", they have to insert their activity to another paradigm, to the clinical framework of psychiatry.

«In the case of psychiatric patients a shaman group can operate safely only in a psychiatric ward, where there's the possibility of biological treatment and intervention (for example, when a patient goes out of the group, he can ask for his medicine, so his anguish cannot cause his disintegration). Sociotherapy is suitable for leading the patient to the ordinary reality, within which he can experience his own new aspects and practical abilities».

The experinces regarding alternative reality of shamanistic healing must be adopted to the paramount reality, the everyday world of patients too.

«During the discussion the therapists try to fill the requirements of the conviction that they are only helpers in the process of changing, because it is the patient's primitive reality that has to be the catalyst of development. Naturally dealing with these spiritual regions requires a great precaution because the deeper and more archaic levels it touches, the more power potential it gains. In addition it's very important that the obtained information should be built into the participant's real life».

The clinical professional responsibility induces critical reflections towards those, out of the clinical paradigm. The psychological dangers come from the inadeqate, sometimes commercial experience.

Patients who were taking part in that kind of course and found their condition getting worse or their disease occurring, in our group, under safety regulations could work well, had positive experience and they could integrate their former experience. As we experienced, this needs much work, as the ego has to be strong and stable. If it isn't, it has to be supported by the leader and social environment temporarily. The ego, a messenger between worlds reworks the experience.

Conclusion

Extending the scope of diversity to the wider environment of medical memes and institutions – one must realise the dynamism, variability or mutability of knowledge, representations, metaphors and explanatory models regarding illness and healing.

The ecosystem of medical memes doesn't constitute a closed system, rather a landscape with fuzzy borders and ecozones. These borders seem to be impermeable between science and the fields of non-science nevertheless postmodern eclecticism may offer hybridization beyond competition, and neutral co-existence. Scientific knowledge systems are in a constant process of interchange in an environment full of challenges of still unexplored ways of healing. Scientific, social, economical, technical aspects are interwoven in interchange of memes of mainstream and unconventional healing. All creative turns in cases of unconventional medicine are strongly attached with shifts of identity of people, migration of people, transitions of social system at macro and micro level. In one phrase: it is based on ecodynamics of memes. People are on the move, as they leave their homeland, profession, worldview and attitudes for another in constant changes. Medical doctors become unconventional healers, biologist acupuncturist turns towards western medical studies. East Chinese and Vietnamese traditional healers come to Hungary to teach and heal. Western anthropologists visit Hungary to bring ancient knowledge and revitalised practice, and clinical psychologists start to shamanize. Engineers leave their theoretical and practical rationalism behind for healing by laying on of the hands, and measuring geopathic radiation. Most of them change their worldview representing a very variable diversity in their alternative, sometimes counter-culture reality.

This multiplicity and eclecticism of ontologies, healing paradigms are welcome from a post-modernist view. Regarding unconventional therapies, the post-modern framework is centred around particular and local, as opposed to universal truths. The new experiences gained by trance states, embodiment of previously unknown sensations open up different realities. The exchange of explanatory models derived from different healing practices may modify the basic concepts of health and illness just as the basic view of human being as pure biological system, spiritual entity, or energetic being with aura, chakras etc. The mixed healing practice helps to deconstruct the monolithic biomedical thinking and/or eliminating the antistructure or counter-culture contents from alternative healing and calls for bridging the gulf between different medical paradigms.

Legitimization can not be imagined without standardization of eclectic or hybridized forms of biomedical and complementary medicine. Standardization from within the mixed medical practice may help this legitimization process (GAMST A. 2004). However orthodox and non-orthodox medicines reflect the same political economic aspects of the social context in which they are located (HAN G.-S. 2002). This creates the postmodern context for multiple realities of different healing with the same economical dynamics. From this viewpoint it is the political economical context and not the ontological content which creates the common framework. On the free market of health and illness it doesn't matter what sort of ontological basis is offered, the economical framework is common, or almost common.The standardization and legitimization offered by biomedical science compete with the standardization and legitimization by market and media shaping consumer behavior along the the routes of the Health Plaza.

Notes

(1) The medical memes may be seen as reproductive units of (culture-bound) medical traditions, be they of biomedical, traditional, or alternative source of medical knowledge like different metaphors, explanatory models and representations of illness and healing.

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2.4 *Other medicines. Which wisdom do they challenge?*

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Introduction

Some students of medical anthropology make generalising statements that any discussion of disease implicitly involves the issue of causality, as though this principle of biomedical ideology would apply to any form of healing. Students of this persuasion also tend to consider medicine and healing as prominently explicable in terms of belief and knowledge, thereby overlooking the importance of bodily dispositions and embodied skills, regardless of whether they are referring to biomedical forms of practice or other ones. Furthermore, they investigate medical knowledge, in particular that of other medicines, with methods that liken it to biomedicine, methods that differ from those for investigating the knowledge of patients and thereby the preconception that practitioners' knowledge is qualitatively different from that of lay persons is reinforced and reproduced. This article critically examines such issues that are grounded in principles of biomedical and, by extension, medical anthropological wisdom, and it shows that an attentive study of other medicines challenges those very principles (1).

The article suggests, first, that narrative analysis, which is now generally used to research on patients' knowledge, could also be applied to the investigation of medical knowledge. Second, awareness that the mood in which medical knowledge is expressed need not always be the descriptive indicative mood that alienates the speaker from his or her object of speech, may open new avenues for understanding the interrelation between text, word, and bodily practice. Third, contrary to the general assumption that knowledge of the illness cause (a cause that temporally precedes the effect) explains treatment choices, there are medical ideologies that emphasize the importance of synchronous signs, and there are thinkers who have long pointed out the importance of the issue of 'risk and redemption' of 'presence' for understanding how healing 'works'. Developments in the history of medical anthropology show that biomedical ideology has had a profound impact on medical anthropologists because we frame our questions in ways that are often guided by preconceptions derived from our own (bio-) medical ideologies. The way other people think and act, and the other forms of medicine they practise, challenge the very foundations of medical anthropological questions and, implicitly, biomedical ideology.

The term 'other medicines', in this article, refers to a wide range of medical knowledge and practice. Anthropologists have long been interested in the medical practice and knowledge of other peoples and investigated 'folk', 'popular', or 'indigenous' (2) forms of medicine and 'traditional medical systems' (3). Some of these medicines are now practised outside their home countries, side by side with biomedicine, and in the process of translocation have been transformed. Together with other non-biomedical forms of therapeutics, they are referred to as 'alternative' (4) and 'complementary' (5) medicines or 'non-conventional therapies' (6). Needless to say, mutual appropriation of practice and knowledge among these forms of medicines is common, and various forms of biomedicine, to various degrees, have modified them and been modified by their continued presence in health care.

The term 'other medicines' furthermore is meant to refer to patients' knowledge of medicine. Regardless of whether the practitioner is a biomedical doctor, a CAM (complementary and alternative medicine) practitioner or a traditional healer, patients' knowledge of medicine is usually regarded as inferior or even as non-existent. However, it would be an oversight for the anthropologist to adopt the ideology of health care providers, and not take seriously the knowledge of patients with regard to medical matters, even if this knowledge is not always as verbalised as that of the practitioners.

By setting the scene in this way, and asking which aspects of medical anthropological 'wisdom' are challenged by the investigation of 'other medicines', the study may appear flawed in two ways. First, the term 'other medicines' lumps a whole range of practices other than biomedical ones together for comparison and contrast. This reiterates a stance that is today questioned for its ethnocentricity. Second, the article uses the term 'biomedicine' (7). This choice is deliberate, since it is precisely some basic features of the ideology of the bio-sciences, rather than the daily practice of the general practitioner, that has had a profound impact on medical anthropological 'wisdom', and will therefore be discussed in this article.

To be sure, the establishment of illness taxonomies, the investigation into illness causation and the exploration of belief for understanding practice represent some of the most valued studies medical anthropologists have undertaken, and this is not questioned here. Nevertheless, the assumptions which guided these endeavours are grounded in insights of biomedicine that more recently have been challenged and should direct the anthropologist's attention towards further aspects of medical practice.

Syntagmatic and paradigmatic temporality: from classifications of disorders to narrative analysis in medical anthropology

Scholarly articles on illness classifications appeared before medical anthropology had become consolidated as a discipline. Frake's (FRAKE C.O. 1961) article on Subanun skin diseases is one of these ethnoscientific undertakings. Although Byron Good criticised Frake's endeavour already in 1977, medical anthropologists continue to publish work that builds on it, not least Christopher Davis in 2000, in his book Death in Abeyance (that begins with nosological taxonomies but goes beyond those, and ends with illness narratives set in local history). Inspired by componential analysis that works with minimal pairs, Frake set up neat hierarchies of skin diseases that obtained their structure from the anthropologists' judicious questioning. Whether a sore was distal or proximate, deep or shallow, were features the astute anthropologist had identified (8). Good emphasized that we need to identify the subjects' own associations, i.e. the connotations of a term like narahatiye qalb (heart distress), and instead of invoking a hierarchy of taxonomic knowledge, he established semantic networks. Semantic networks typically reflected the terms people themselves used, and they highlighted interrelations between these terms. These interrelations were not necessarily causal but associative, and they were often ill-defined and vague, and have therefore remained a useful fieldwork method to the present day (9).

The study of 'other medicines' in the 1970s and 1980s was that of so-called 'folk' and 'traditional' medicines, and their taxonomies. It was emphasized that indigenous medical practice was not merely a hodge-podge of superstitious practices but grounded in knowledge systems that were internally coherent; anthropologists explained that standards and concepts that applied to the biomedical sciences should also be used for accounting for so-called traditional sciences and medicines. Not only biomedicine had disease taxonomies but also other medicines; it was a very timely and worthwhile undertaking, and many medical anthropologists continue to explore those aspects of other medicines, and there still remains much to do.

The preferred topic of studying 'other medicines' has since shifted, however; one speaks of the narrative turn. The last fifteen years have seen a series of studies that centre on patients' narratives, on disabilities, chronic conditions and terminal diseases. However, as Shimazono (SHIMAZONO Y. 2003) emphasizes, narrative analysis in medical anthropology has so far centred on patients' narratives in biomedical settings; it has barely been applied to the study of narrative in the construction of a 'diagnosis of disease', neither in biomedicine nor in so-called traditional medical settings. The medical knowledge of patients is thus analysed within a different paradigm than that of doctors and healers, a paradigm that resides in a different 'temporality'.

Following Paul Ricoeur and Jerome Bruner, Shimazono (SHIMAZONO Y. 2003) stresses that the generation of knowledge through narrative is different from the paradigmatic mode of setting up taxonomies. The narrative mode of knowing takes account of intention and desire, and is interested in context-bound connections. The knowledge of medicine that emerges from narrative analysis is thus contextual and situation-bound as is typical of 'syntagmatic temporality'. This is fundamentally different from the decontextualised paradigmatic knowledge that the natural sciences strive for, and that has been valued in the study of traditional and indigenous, complementary and alternative medicines (by setting up nosological taxonomies, for instance).

If we define the 'other' medicine as the patient's knowledge of medicine, take the method of narrative analysis used for eliciting the patient's knowledge, and apply it to the study of biomedicine and traditional and indigenous, complementary and alternative medicines, we challenge the wisdom on which biomedical, and by extension medical anthropological knowledge, is based: namely, that medical knowledge is primarily based on the paradigmatic mode of knowledge production that leads to the establishment of classificatory schemes of disease.

Needless to say that several medical anthropologists have challenged this wisdom already. Various authors have pointed out the need to take account of a temporality that differs from the one that produces nosological taxonomies. Bibeau (BIBEAU G. 1981) in the early eighties already pointed out that people refer to different morbid stages with different words and that it is problematic to speak in those cases of a single disease entity that progresses through different stages. Farquhar (FARQUHAR J. 1991) emphasized that the category, which in Chinese medicine accounts for a morbid condition, the differentiation pattern (*bianzheng*), is based on a different notion of temporality to that of the biomedical disease concept. Both authors recognised the intrinsically different notions of time that the terminology implied of the disorders they studied, and contrasted those with the paradigmatic mode of knowledge in biomedicine.

One can go a step further and, rather than contrasting the knowledge of patients and practitioners, non-biomedical and biomedical practitioners, highlight how contextual and situation-bound the production of all practitioners' medical knowledge is. Hunter (HUNTER K.M. 1991), for instance, by focusing on biomedical doctors' narrative, and Berg and Mol (BERG M. - MOL A. eds. 1998), by highlighting differences in biomedical domains, have done so with respect to biomedicine. However, while there are studies of medical narrative in historical times (DUDEN B. 1991 [1987], FURTH C. 1999), narrative analysis, apart from being applied to rather formulaic case histories (e.g. FARQUHAR J. 1991, 1994, SCHEID V. 2002), has rarely been applied to the study of contemporary traditional and indigenous medical knowledge; Shimazono (SHIMAZONO Y. 2003) stresses this (10).

Elegant Theory and Messy Practice, and the Relevance of Embodied Skills

At about the same time as there was a turn towards narrative analysis, with its emphasis on interview culture and the spoken word, medical anthropologists have started to stress non-verbal aspects in the medical encounter. Particularly authors who come from the phenomenological perspective that builds on M. Merleau-Ponty's writings have set out to investigate the aesthetics of healing and have emphasized how music, rhythm, odours, and bodily movement can become important for the therapeutic process (e.g. CSORDAS T.J. 2002, DESJARLAIS R. 1992, 1996, LADERMAN C. 1991, ROSEMAN M. 1991; LADERMAN C. - ROSEMAN M. eds. 1996, and also JACKSON M. 1996, DEVISH R. 1990, and HONKASALO M. this volume, among others). They have explored emotionality and aesthetic sensibilities rather than engaging in a detailed study of the meanings of the texts that are sung. Their study of other medicines thus draws attention away from the intellectually grasped contents of the texts used in medical practice towards the importance of bodily dispositions during the medical encounter.

These authors can be understood implicitly to have challenged the aspect of biomedical ideology, and also much medical anthropological investigation, which derives from the belief that 'theory' describes the processes in question accurately, and that inaccuracies between theory and practice arise from medical practice being messy. The interrelation between medical theory and medical practice, as known from biomedicine, is often taken as a prototype for how text and practice are thought to interrelate. This is so particularly in the analysis of so-called 'traditional' medicines and CAM. Those often comprise an important body of texts, considered to capture the workings of the universe and of medical knowledge, and they tend to be treated as medical 'theories'. The question that arises then is whether by treating them as 'theories', one distorts their intrinsic relatedness to medical practice (11).

As pointed out elsewhere (HSU E. 1999: 233), texts in biomedical theory are descriptive and their formulation requires the author to be distanced and alienated from his or her subject. Accuracy and un-ambiguity of the meanings of the terms are highly valued qualities of a scientific text. There is, however, always a 'gap' between biomedical theory and biomedical practice. Texts in knowledge traditions other than biomedicine need not always be descriptive, and consequently the interrelation between the author and his or her subject of investigation need not be as alienated from each other as in biomedicine. To be sure, these texts are insightful and contain knowledge about the body and the world, as any 'theory' does, but the relation the practitioner has to text and practice, need not necessarily be the same as that of an alienated bio-scientist to the world (pp. 105-127). The canonical texts in Chinese medicine may well have a proscriptive aspect, and they may well have been written in another mood than the indicative, perhaps in an optative or conjunctive mood (pp. 210-217). If a text is proscriptive, the relation between medical text and medical practice differs from that between a descriptive medical theory and medical practice. The notorious 'gap' between theory and practice disappears.

Some practitioners may claim that in Chinese medicine a differentiation pattern (*bianzheng*) provides a description of reality. They are right but only to a certain extent: differentiation patterns do not only pertain to describe reality, they also contain proscriptive information for adequate treatment selection (12). Moreover, the flowery language that one finds in these texts may have a different effect on those who recite them than merely providing a detached description of 'reality'. The study of the texts of other medicines thus inspires the medical anthropologist to think about the significance of texts for medical practice, and to rethink the relationship between medical text and medical practice. There is always a 'gap' between descriptive biomedical theory and practice, the epistemology being that medical theory is elegant and the real world messy, but such an epistemology has a very specific purpose in the biosciences, does it do justice to the relation between word and deed in other medicines? (13)

Needless to say the above authors, particularly in the context of spiritualist and shamanic healing performances, have proposed that emphasis on somatic modes of attention and embodied skills. Investigation of medicines with textual traditions would suggest that it might be fruitful to transfer their insights to a wider range of medical 'theory' and practice. In this way, familiarity with other medicines challenges this particular biomedical, and medical anthropological, wisdom.

Notions of Causality, and the Choice of Adequate Therapeutic Intervention

The third biomedical, and also medical anthropological, 'wisdom' that illness causation explains adequate choice of treatment would seem more difficult to challenge since many 'other medicines' do refer to illness 'causes', and some refer to notions of illness causation that predate biomedicine (14). One has to think carefully about what is meant by 'cause', and also how thinking about illness 'causes' has coloured medical anthropological writing. The ideas presented below suggest that it is the biomedical ideology of illness causation that influenced anthropologists, and it is the usefulness of that ideology for understanding other medicines that is questioned here.

Illness causation was a theme already dealt with by W. H. R. Rivers and E. E. Evans-Pritchard. Rivers (RIVERS W. H. R. 1924: 48) stressed that the medical practices of other peoples were a 'logical consequence' of their beliefs about the causation of disease. He was convinced that these beliefs were wrong but was empathetic when he said:

> «The practices of these peoples in relation to disease are not a medley of disconnected and meaningless customs, but are inspired by definite ideas concerning the causation of disease. Their modes of treatment follow directly from their ideas concerning aetiology and pathology».

Beliefs about illness causation, Rivers maintained, explained unfamiliar therapeutic interventions. He was interested in invariant relations between belief and therapeutic practice. Evans-Pritchard (EVANS-PRITCHARD E. E. 1937: 69-70), by contrast, in his explanation of witchcraft among the Azande, deals with causal reasoning in another way. In the context of discussing causality, he addresses the questions "why me? Why now?", which ask for answers that do not point to invariant relations of causation but to particular personal intentions:

> «Now why should these particular people have been sitting under the particular granary at the particular moment when it collapsed? That it should

> collapse is easily intelligible, but why should it collapse at the particular moment when these people were sitting beneath it? ... We say that the granary collapsed because its supports were eaten by the termites. That is the cause that explains the collapse of the granary. We also say that people were sitting under it at the time when it collapsed. To our minds the only relationship between these two independently caused facts is their coincidence in time and space. We have no explanation of why the two chains of causation intersected at a certain time and in a certain place».

Thus, Rivers suggested transposing the notion of illness causation as relevant in biomedicine into other cultural contexts, and he emphasized that there was an invariant relation between belief and medical practice that was 'logical', 'causal', and 'rational'. Evans-Pritchard, by contrast, was interested in sequences of events for which the biosciences provide no causal explanation, and his discussion of causality elaborated on 'coincidence'. The two invoked 'causality' for explaining rather different aspects of other medicines. Yet both had an understanding of causation as given in the modern natural sciences.

Causal reasoning in medicine is closely related to the question: what counts as evidence in diagnosis? Practitioners are confronted with everyday life problems; yet in their explanation often allude to variables outside everyday life experience and perception (LEWIS G. 1975: 223). What goes beyond immediate perception is considered a cause, and to a certain extent, one can say that medical anthropologists have been quick to link evidence in diagnosis to 'causal explanation' in much the same way as biomedical practitioners conceive of biological processes as the result of cause-effect relations. In biomedicine, a pathological condition has a pathogenesis, and treatment that goes beyond the alleviation of the momentarily perceived symptom, is meant to deal with the cause of the disease. Biomedical treatment differentiates between symptom alleviation (towards which it considers T/CAM to be oriented) and treatment of a causative agent. T/CAM by contrast, often accuses biomedical treatment to be body – and symptom – oriented, and also claims to treat the cause of the illness (e.g. UNSCHULD P. U. 1992).

To reconcile these viewpoints, medical anthropologists have pointed out at least two problems that surround talk of causality. First, there are different levels of causation. One may speak of proximate and ultimate causes (SINDZINGRE N. - ZEMPLENI A. 1981) and, in addition, discern further levels and qualities of causation. An effect may be produced by multiple causes, which are not mutually exclusive. Whereas causative agents in biomedicine are often micro-organisms or degenerative biological processes, T/CAM may find causative agents in variables like hot and cold, spirit loss or indulgent behaviour, which are often directly linked to the social, religious, moral, political and ecological environment. In other words, the level of causation invoked and the quality of causative agents may differ (which is not to exclude the possibility that both invoke the same variable, just in a different vocabulary). Many medical anthropologists have emphasized this.

Secondly, causal reasoning is considered an aspect of rationality, and it is treatment that is grounded in rational thought or 'logical thinking' that acquires legitimacy. Causality, rationality, and legitimation of treatment are thus inextricably linked to each other. This makes any kind of detached study into questions of illness causation difficult because treatment directed at the cause of the illness is considered the only legitimate one. If T/CAM practitioners were to deny that their medical practice is directed at treating the cause of the illness and deny that they are interested in questions of causation, they would deny themselves their claim to the legitimacy of their treatment, its coherence and internal consistency.

In the light of Rivers' understanding that beliefs of causation explained treatment procedures, that causal reasoning was evidence of other peoples' rationality and their treatment's legitimacy, one can understand why an empathetic anthropologist would wish to use the notion of cause in a wide sense. There are, however, reasons to challenge the biomedical as well as the general medical anthropological wisdom that investigation of illness causation is as important as generally assumed. In other words, the study of other medicines would suggest that, rather than widening the notions of 'cause' and 'causation', it might be useful to narrow its sense down, and demonstrate that issues other than the illness cause are important in peoples' management of illness and disability. Pool (POOL R. 1994) has long questioned the ethnographer's preoccupation with illness causation. From a pragmatic sociological viewpoint, maintaining social relations, for instance, may be just as important (NICHTER M. 1996, 2002, WHYTE S. R. – HARDING A. – VAN DER GEEST S. 2003). This article, however, sets out to show that there are medical ideologies which do not consider illness causes the most relevant aspect of the illness event for determining adequate treatment.

Evidence in diagnosis need not, by definition, be linked to causal explanation, and what counts as evidence in diagnosis need not always stand in a Humean cause-effect relation to the problems presented, where causes temporally precede the effect. Evidence may be found in signs that are synchronous to the complaint. Naturally, one may say these signs are indicative of causes. However, there are signs that people do not consider indicative of causes, and they cannot be viewed as causes that precede effects because they are synchronous. These ‘synchronous signs’, rather than ideas about the illness cause, may be the most relevant factors for determining adequate treatment. I will demonstrate this by taking recourse to a study of an ancient text, rather than interviewing respondents today (who certainly would not be eager to find that their medical reasoning was not causal).

In a formulary Chinese text of the second century BC, diagnosis was not dependent primarily on establishing the illness cause. In my understanding of that text, the doctor differentiated between the following three aspects of the illness: the name of the illness, the cause of the illness, and the quality of the illness. He himself did not speak of name, cause, and quality of illness, however. These are words of my choice. What I call the name of the illness was introduced by the recurrent phrase: “I said” (which followed an introductory phrase of saying that he had examined the ill person); what I call the cause of the illness, is perhaps better paraphrased as that form of behaviour for which the patient is to blame, and it was introduced by the standard phrase: “The illness was contracted by”... (e.g. alcoholic beverages); and what I call the quality of the disease was introduced by the standard phrase: “the reason I recognised it was that...” (e.g. the pulse was slippery). My analysis demonstrated that while the names of the illness varied in each of the twenty-five cases that were recorded in this text, in almost half of the cases the cause of the illness was attributed to indulgence in sex and wine. In other words, the cause of the illness could not have been the determining factor for establishing the twenty-five different diagnoses (Hsu E. 2001a). Instead, I found that the quality of the illness regularly correlated with the name of the illness (Hsu E. 2001b).

The analysis of this ancient text of a traditional medicine is relevant to the question of what wisdom other medicines challenge in that it points out that the cause of the illness need not always be known to chose an adequate treatment strategy. In this ancient text, it was not the cause of the illness but its quality that was relevant for determining the name of the condition, and to a certain extent also the treatment strategy (15). The quality of the illness was not claimed to be established by means of investigating the pathogenesis of the patient, and identifying a cause for the illness in the past history of the patient. Rather, it was claimed necessary to feel the pulse and observe the complexion, to search for signs that were synchronous. To be sure, this was only an ideology. One may object that in reality, while the doctor takes the pulse, he or she also speaks to the patient, and the patient reveals her illness history and that, ultimately, even the doctor who claims to know the condition from the feeling of the pulse, actually knows it from listening to the patient's narrative. The point I wish to make is that there are medical ideologies that challenge the biomedical ideology that knowing the illness cause is the most important factor for determining adequate treatment. This challenges the biomedical, and medical anthropological, wisdom that knowing the cause of the illness is essential for delivering treatment.

One need not go into the analysis of an ancient text to emphasize that according to some medical teachings the cause of the illness is unimportant for the selection of adequate treatment. As already mentioned, in modern TCM it is not the diagnosis of a disease but pattern differentiation (bianzheng) that is essential for establishing adequate treatment (FARQUHAR J. 1994: 154-169). This process of pattern differentiation ideally involves four different diagnostic methods: looking, listening, smelling and feeling (the pulse); the patterns that a doctor diagnoses are not disease entities but patterns of the patient's condition in the moment when he or she is diagnosed; they are expected to be different according to constitution, age, gender, etc. of the patient, and differ from one moment in time to another. The point about pattern differentiation that I wish to stress is that it takes account of the condition of the patient at the very moment of diagnosis; doctors are not preoccupied with finding the cause of the illness, this is not a matter of interest, but rather qualities of colour in the face, pulse, and many others that the patient can communicate to the doctor, the frequency of urinating, the quality of the stools, and the like, are matters of concern.

I have spoken to TCM doctors who claimed that the cause of the illness is intrinsically given through these qualities of the illness condition, and they emphasized that the cause of the illness is contained in these signs. Eager to present their medicine as scientific, they were quick to attribute this to causal reasoning. One teacher who taught me was, however, very explicit to the contrary. He said that if a woman was diagnosed with a wind-cold-common-cold (fenghan ganmao), it was not because she had exposed herself to a draft or heavy winds the day before, but that signs on her tongue and her pulse at the time he made the diagnosis were relevant. The woman may have thought it was the cold and wind she had experienced the day before that caused her to have a wind-cold-common-cold, but a TCM doctor made his diagnosis on the basis of synchronous signs (fieldwork notes 1988-89). In this way, Chinese medical pattern differentiation challenges our wisdom that for treatment to be effective one has to know the cause of the illness.

As Lewis (LEWIS G. 1995: 559-560) puts it: «The anthropologist's dilemma is the choice between being too active or too passive. How does one encourage people to express thoughts, which are silent or implicit, without distorting them with a foreign style of questioning?» An anthropologist's «method of question and answer might give unwonted clarity and direction to the representation of causal understanding in another culture» (*ibidem*: 559) (16). It is precisely this aspect surrounding the investigation of illness causation that leads anthropologists and their respondents into directions that are given by biomedical ideology but may not be important in the cultures in question.

It may be that spirits are invisible, but are they really only known through the perceived 'effects' anthropologists consider them to effect? Is it not the framework of causal reasoning that makes spirits 'invisible agents' that produce 'effects' that can be perceived? This framework suggests that the visible world, contingent as it appears, can be explained by principles ruling the invisible world. It is a credo of the natural scientist, formulated in an ocular metaphor, which has been adopted by many medical anthropologists in their study of other medicines. However, if someone says of an illness, it 'is' a spirit, does the person mean that it is 'caused' by the spirit or that it 'is' the spirit? The latter would presuppose an ontology different to our own.

Once we admit that other medicines are challenging the 'wisdom' intrinsic to our own ontology, which is grounded in the same ontology as the biosciences, new avenues for studying illness and healing open up. This is a point Ernesto de Martino has long made. The three aspects of medical anthropological wisdom discussed above – the preoccupation with illness taxonomies, the emphasis on medical theory, and the focus on illness causation – all have been guided by the assumption that biomedicine and other medicines are primarily concerned with 'knowing'. In de Martino's words, however,

> «Magic is not primarily concerned with 'knowing' the world, nor with changing it, but aspires to guarantee the world to which the being may make itself present». (DE MARTINO E. 1988 [1948]: 107)

It is likely that the centrality of illness causation in biomedical reasoning led to its centrality in medical anthropological research, and anthropologists, who granted their subjects rationality, widened the concept of cause to include aspects of medical reasoning that are perhaps not always best described as 'causal'. To be sure, it would be simplistic to state that other medicines and magic are not concerned with 'knowing'. However, as de Martino points out, the aspect of other medicines that most interested him, so-called 'primitive magic', was importantly concerned with the «risk and redemption of presence» (*ibidem*: 92). In this way, illness and its treatment become an issue of an existential drama concerned with the mastery and consolidation of «the elementary being-in-the-world or presence of the individual» (*ibidem*: 150). It is the 'reality of presence' that is a problem, presence being «something to be aimed for, a task, a drama, a problem» (*ibidem*: 147).

Rather than likening medicine to the sciences, as biomedical ideology does, and as medical anthropologists have done with regard to other medicines by emphasizing their paradigmatic taxonomies, theories, and ideas about causation, treatment of illness can be concerned primarily with the self, its being-in-the-world, and its 'presence' in this world. De Martino stresses:

> «Here we find ourselves faced with a limitation that is characteristic of the historic consciousness of our own civilization [...] so our guaranteed and fixed presence is considered (still within the limitations of our historical consciousness) as the model for every possible historical presence: it is felt that the presence, in every historical and cultural world, must follow this model, and that, in no civilization, can the reality of presence become a problem or a self-established reality». (DE MARTINO E. 1988 [1948]: 147)

De Martino opposed 'the historic consciousness of our civilisation' to 'the cultural world of magic', our taken for granted of the self, on the one hand, and the drama surrounding the struggle of the presence of the self, on the other. This opposition allowed him to flesh out the peculiarities of what he called 'primitive magic'. However, in the meantime, medical anthropologists have repeatedly stressed that such oppositions between modern and magical, between us and them, tend to mystify rather than clarify the issues at stake.

With this in mind, let us return to the question: other medicines – which wisdom do they challenge? Not only does the attentive study of other medicines highlight the bias intrinsic to the investigation of patients' narratives (rather than practitioners' narratives), theories (rather than bodily dispositions and embodied skills), and illness causation (rather than questions surrounding the issue of 'presence'), but it also shows up that this bias of medical anthropological inquiry reproduces and reinforces biomedical ideology. Furthermore, the observation that the establishment of 'presence' is central to some forms of healing and that there are other medicines, like Chinese medicine, that stress the importance of 'synchronous signs' for diagnostic purposes, may alert the medical anthropologist to the possibility that these dimensions of wisdom in other medicines may also be constitutive to the various forms of biomedical practice, in spite of ideological claims to the contrary.

Notes

(1) I would like to thank the editorial committee of this volume for their valuable comments on the draft presented in the panel 'Spreading medical ideas', at the MAAH conference in Perugia, Italy, 24-28th Sept 2003. An early version of this article was presented in the panel 'Challenging medical wisdom', at the BAAS in Salford, UK, 8-12th Sept 2003.

(2) The terms 'folk' and 'popular' medicine were common particularly in early writings, though they continue to be used often for local forms of medical knowledge and practice. More recently, researchers refer to 'indigenous' medical practice particularly in the context of intellectual property rights and ethnopharmacology, where the indigenous knowledge of flora, fauna, and minerals is researched. The term 'indigenous' medicine thus often alludes to the medical knowledge of small-scale societies.

(3) Paradoxically, the term 'traditional' as in 'traditional medicines' is often used to designate those forms of medicine that recently have been revived , and in the process of revival have been transformed and 'modernised', such as Traditional Chinese Medicine (TCM) in China or the medicine of 'traditional' herbalists in Africa.

(4) Adherents of 'alternative' medicine in the seventies and eighties stressed the need for refashioning life in another way than late capitalism demanded, and they were often motivated by ideas of decentralisation, ecological and environmentally thoughtful living.

(5) From the eighties and nineties on, adherents of 'complementary' medicine often came from within the medical profession, as the belief waned that biomedicine can solve all health problems. It was recognised that non-biomedical treatment can effect changes that biomedicine validates. The discourse that dominates CAM today is motivated by the endeavour to validate non-biomedical treatment as 'complementary' to biomedicine.

(6) The term 'non-conventional therapies' is now increasingly used to refer to CAM, and also to practices that could be described as 'folk' or 'popular'. The term singles biomedicine out as the medicine that has become the conventional form of medicine, and thus alludes to the differential institutional setting of conventional and non-conventional forms of medicine. The term is mainly used in Europe and North America, and some but not all of these non-conventional therapies may have existed historically before biomedicine became firmly established.

(7) Frankenberg (FRANKENBERG R. 1993) has criticised the use of the term 'biomedicine' because bio- alludes to the ideology of general practitioners rather than to their daily practice. It is the ideology that is discussed in this article.

(8) Davis (DAVIS C.O. 2000) is careful to provide taxonomies based on the criteria of her subjects.

(9) Kleinman's (KLEINMAN A. 1980) explanatory models (EM) built on Good's (GOOD B. 1977) semantic network approach, though Kleinman structured EMs into four distinctive knowledge domains – illness causes and treatment, symptoms and social problems (see diagram p. 108) – which were modelled on biomedical wisdom that patients and practitioners of other medicines do not necessarily share.

(10) Indeed, advocates of traditional and indigenous medicines emphasize scientific aspects, i.e. the paradigmatic mode of knowledge production; narrative analysis does not fit their programme.

(11) Farquhar (FARQUHAR J. 1994), by calling her book *Knowing Practice,* points in this direction, although the book investigates texts. As has been variously remarked, Pierre Bourdieu's definition of *habitus* is singularly disembodied.

(12) To a certain extent, differentiation patterns (*bianzheng*) can be regarded as 'illness taskonomies' in the sense of Nichter (NICHTER M. 1996: 120).

(13) A dynamic tension between word and deed is also given, for instance, by ironic situations and statements (LAMBEK M. 2003). Statements made in an 'ironic mood' would contrast with proscriptive ones in that they defy intentionality.

(14) In the Middle Ages, Aristotle's four causes were central to causal explanation, and also applicable to medicine: the material, formal, final, and efficient cause. Lloyd (LLOYD G. E. R. 1995: 538) explains: «The matter corresponds to what a thing is made of, the form to the characteristic fea-

tures that make it the thing it is, the final cause is its function or the good it serves, and the efficient selects what brings it about», and points out: «Of these four, only the efficient cause looks like a cause in any ordinary English sense».

(15) The study in question only demonstrates that the quality of the disorder determined its name. Since the treatments the doctor applied were more varied than the repeatedly named cause of wine and sex, it is reasonable to assume that the quality of the disorder played a larger role for determining the treatment than did the cause of the disorder.

(16) Lewis (Lewis G. 1995) points out arbitrary distinctions between what an anthropologist calls 'description' and 'interpretation' (the anthropologist writes about burning a leg with scalding water in terms of a 'description', while strange connections between coincidences are mentioned in the rubric of 'illness causation'). It comes as no surprise then that the investigation of 'illness causation' is often related to public health efforts at overcoming 'mistaken' beliefs and attempts at changing peoples' behaviour.

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3.

Patients narratives, power and distress
Narraciones de los pacientes, poder y enfermedad
Narrazioni dei pazienti, potere e malattia

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3.1 *Agency and hegemony in the patient-physician encounter. Use of coat and other devices in the construction of general practitioners' therapeutic space*

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Notwithstanding the common stereotypes spread at a "common sense" level (1) by a large and heterogeneous literature on this theme, medical anthropology disposes today of a theoretical-critical knowledge to affirm that the patient-physician relationship is never a merely one to one relationship and never assumes a pure technical character.

Even when the outpatient space is shared by a single physician and his patient, it's something much more complex than a simple meeting between two individuals. Through both their voices a huge chorus is actually voiced: the therapeutic space is indeed fuelled by dynamics which have origin in each of the cultural universes that every patient and every physician transversally bring. I'm not only referring to the obviously different (being elaborated inside specific and different contexts) representations concerning illness in general as well as everyone of its histories. I'm speaking also about a more generalized and constant dialogue, often implicit, established at different levels between each of the actors and the social structure, its various forms, subjects and institutions. Health and illness social meanings project the patient-physician interaction in the setting of a collective drama, a performance in which both the actors – although in different ways – express sometimes belonging and membership, sometimes refusal, uneasiness, alienation: «both these bodily expressions exist in a dialectic relationship, expressing the tensions between belonging and alienation which occur everywhere in the social life» (2) (SCHEPER-HUGHES N. 2000 [1994]: 285). As every social sphere in which concrete people act, the therapeutic encounter can also be read as a place in which sense and dissent meanings are produced. Or, to say it with Gramsci's words, as one of the places in which the hegemonic dynamics take form.

The hegemonic institutional pressure is indeed put on the patients bodies as well as the physicians', through apparently opposite processes which in practice seem to be aimed to grant conformity and agreement. Already in the fifties, Parsons recognized the strategic importance of the institutionalization of doctors and patients roles in order to guarantee the continuity of social system. To elaborate behavioural structures with intensely positive values means to regulate and coordinate people's answer to the fundamental problems of life, which are potentially threatening for the established order (Parsons T. 1965 [1951], Seppilli T. - Guaitini Abbozzo G. 1974 [1973]). Nevertheless, the over simplification of Parsons' discourse about the relationship between patient and physicians (actually rich in critical elements) had a share in the feeding and reinforcing of the physicians' image as exclusively "power" holder, contrasting the patients' representation as exclusively victims of such a power. That is still the tone currently used by a certain medical anthropology to define the patient-physician relationship: «the physician today is an essentially new breed of professional whose scientific body of knowledge and professional freedom place him in a class of his own: he has obtained unrivalled power to control his own practice and the affairs which impinge upon it and the patient, depersonalised by medical technology, is increasingly being reduced to a mere raw material» (Senah K.A. 2002: 45).

The latest critic medical anthropology's considerations on the body as metonymy, of illness as resistance and illness behaviours as attitudes of social criticism, crumble this stereotype, giving the possibility of a different reading of Parsons' message itself. On one hand, indeed, if we want to talk of "roles" for the patient as well as for the physician, we ought to talk about an identical – but two-sided – device of social control: the aim is in fact, in both the cases, conformity. On the other hand, the observation of clinical practice and the study of therapeutic itineraries have pointed out the great agency power patients actually possess (Ainsworth-Vaughn N. 1998).

But what I would like to propose, here, is a further point of reflection: the physician's position is as ambiguous as the patients', and the game between "endured" and exerted power is played in a very similar way by both, even though with different modalities. In both the cases what is performed is the drama of the individual assertion of the subject and the resistance to the hegemonic forms, the medical institution's in particular. To this end, each actor uses the instruments he has: these are often paradoxically the same – but sometimes used in a "subversive" way – supplied by hegemony in order to control them, to confirm and delimit their position on the social scene.

The space of the therapeutic encounter represents to the patient the opportunity to reaffirm – even to the doctor, identified as the medical authority tout court – the right to self-management of his own body. For the physician (3), it represents the place where he can put in field a neverending confrontation/clash with medical institution and the professional "identity" it has stringed together for him. In other words, the therapeutic encounter represents for the physician the place where he can continuously act to claim his own way of being a "doctor". That's why it is reductive to show as being only in opposition the patient-physician relationship: sometimes allies, sometimes adversaries, each one's challenge is launched far beyond the consulting-room's limits. The rhetorical strategy which represents these roles as in contrast, one against the other, seems therefore to respond to the will to cancel out and render innocuous the disruptive drive of such a challenge.

The concept of "negotiation" too, if read in this key, acquires wider and more complex features: it is not just a kind of "tug of war" between two people bringing different cultural values. It is actually like an arena in which each of them uses the other's presence to affirm his own subjectivity on the social scene, in the ways which become by and by most available and fitting.

The rhetorical and performative tools with which this game is played are many, but I would like to dwell here upon those performed by physicians, and in particular by the general practitioners I worked with during the period of my PhD, finished last springtime (April 28, 2003).

The store with which every single physician constructs his own therapeutic space and, within this, his own relationship with every single patient, is made from a set of tools and ways to manage such tools; from different ways to occupy spaces; from rhetorics of verbal and non verbal communication, and so on. All these elements seem to be acquired during the training period, embodied through the exposure of the aspirant doctors to the medical institution's hegemony. I refer here again above all to Nancy Scheper-Hughes and particularly to the way she critically revisited the concept of embodiment: she distempered the passivity features of the subject to the social structure with which this concept was charged in the 80s by social and symbolic anthropology. What is to stress now is no more only the violence of institutions on the individual body, but the incessant struggle between hegemony and the bodies' subversives skills to re-manipulate hegemonic meanings in a critical key referring to the dominant system (4).

In that sense, the most powerful tools – that is to say the most "ambiguous" ones and therefore, paradoxically, the most malleable by subjects – are the "identity based" ones. In the medical sphere the most "evident" one is the white coat: «les formes d'identités qui sont marquées ou portées sur le corps [...] semblent plus faciles à maintenir que les autres formes d'identité, parce qu'elles sont définies comme internes à la personne et donc plus stables» (GAGNÉ N. 2001: 105). The practical function of the coat (however dubious, in a non-aseptic environment) seems indeed clearly secondary to a certain number of "semantic" functions that distinguish it as a sort of "position marker". The main symbolic function officially assigned to the white coat seems to be the construction, for the coming doctors, of a special identity fitting with the specific "biomedical" way of managing health and illness, epistemologically grounded on oppositions and dualisms, on separation: separation between technique and emotion, between rules and creativity, between scientific rigour and humanization, between what can be dominate and what is uncertain. Lastly, between obedience and resistance.

The coat is therefore one of the elements to which is assigned the task of safeguarding these limits: however, what cannot be controlled is the way each individual will act with it once he has "incorporated" it. The ambiguity every symbolic form brings – due to the frailty of the link connecting significant and significance – makes the coat a very powerful semantic tool, and therefore a privileged one in the dialogue with the social system. One can choose to wear it or not: the conformity or socially critical message is not necessarily communicated by the former or the latter action, but by the meaning one assigns to either choice, each time it should occur.

> «Just wearing the white coat makes you feel like another person!! There are some rituals, mm? The coat, measuring blood pressure, wearing the stethoscope round your neck... the first blood-test, the first intravenous injection, the first time you look on the microscope at your first blood smear... you feel like a real doctor!! You stop feeling like a student and you start to feel like a doctor!» [doctor D., 50 years old].

The coat identifies, it certifies, it exposes, it hides, it protects, it reassures: from being a hegemonic taming tool it becomes a raw material used in the sense attribution process, in the relationships of force determination, in both physical and metaphoric relational spaces connotation. Shortly, in the social relationships construction. To this aim, as a bricoleur, every physician uses the available rhetorical and performative tools to represent, to mean, to mark, to differentiate his own way of “doing medicine”: «the bricoleur, facing a task, uses the materials he has at hand giving them another meaning, if I can say so, in respect of the one they had at first» (LÉVI-STRAUSS C. 1990: 155) (5). The repertory is bounded, strongly marked in hegemonic sense (the hegemonic power is inherent to the white coat itself, not only in the way the physician uses it), but a certain variability margin is always found out and “exploited”. Nevertheless, this operation always occurs and acquires a proper meaning in the dialectical relationship with the individuals introduced in the consulting-room in the role of patients, acting such a role equally as actively and strategically:

> «[I] never [wear it]! [...] My patients appreciate that, otherwise they wouldn’t come, that’s obvious, isn’t it? Anyway, the choice is reciprocal... doctor D., who always wears a white coat, probably has the kind of patient typologically different from mine. This selection takes place with passing time, do you get me?» [doctor F., 48 years old].

It sometimes concerns strategies, sometimes tactics (DE CERTEAU M. 2001 [1990]), which enliven that complex strengths’ field that is the therapeutic encounter. A field in which different “knowledge” and therefore different “powers” are facing, comparing, undergoing continuous decoding and recoding processes, with the aim of establishing the position coordinates of those present in that specific field of action. Every physician seems to manipulate at will the semantic area of an object which therefore assumes a clear function of interfacial mediator at various levels: between the individual and his perception of his own way of being a doctor; between the “physician” and his “patients”; between the physician as a “professional” and the medical institution which he belongs. What is needed is to single out, each time, the discursive sphere opened by the act of wearing it in that particular moment and in that specific situation. Therefore re-connecting it to the general hegemonic biomedical discourse with which it is however in a constantly dialectical relationship.

It is also interesting to notice, for instance, that even the physician who usually received patients in the consulting-room in “civilian clothes”, reserved the possibility to wear the white coat in those situations in which the kind of intervention requested could be interpreted as more “invasive” from a relational point of view: for instance, during an inspection of the auditory duct or an auscultation of breast and shoulders. Actually, in those occasions in which although only a slightly bodily “compromise” was requested, a sort of “violation” of people’s physical intimacy (which means also the physician’s own physical intimacy) comes into play. To reduce, then, the destabilising impact provoked by physical contact among extraneous people, it seems necessary, on one hand, a sort of "legitimacy to proceed", attributed to the white coat's power to underline medical "identity". On the other hand, at the same time, a real defensive action seems to be needed, and it is supplied by the "estranging" power of the coat (Cozzi D. - Nigris D. 1996: 311-320). It is due just to this estranging character if some physicians choose not to wear it at all, convinced that making medicine inevitably means – even if in the limits of a correct hygienic prophylaxis – to have direct physical contact with the patient:

> «normally I don't wear it, because I think the coat creates distance. So, if I have to do a dressing I go over there and I put on my white coat, but if I have to stay here measuring blood pressure, auscultating a breast, palpating a stomach, I don't get dirty if I leave my normal clothes on! [...] the white coat is for not getting dirty: it is not for seeing who the doctor is, because it is evident that I am the doctor! Therefore I don't need the white uniform to be recognized!» [doctor D., 50 years old].

However, in many cases the way in which the coat is used seems to communicate a precise message: when it is to welcome the patient in the consulting-room, to make him feel really at ease and to establish an informal and empathic relationship with him, the absence of the white uniform ("official" symbol of professional, and therefore of detachment and differentiation) is fundamental. When instead "acting" on the patient's body, it is necessary to call upon specific technical competences for the exercise of which the emotional component is of great disturbance, since it creates a sharing space with the patient that weakens the "power" – that is to say the "identity" – of the physician.

The white coat, better than other medical tools, seems able to represent what we could define the epistemological core of biomedical knowledge, the element which founds and legitimates the power of the ones practicing such a knowledge: the hierarchical opposition between technique and emotion. Forcing the separation between rationality and sensibility, between "mind" and "body", such assumption can be seen as one of the most violent of medical training: by admitting as its own specific field exclusively the first of the dilemma's two horns, it violates the consubstantial unity of the human body and it ratifies such a division with the indisputable mark of science. But clinical practice constitutes for every single physician the occasion not really to cancel, but at least to re-discuss such limits: in a continuum going from the exclusive and rigid selection of the technical element, to its refusal in the perspective of a totally emotional empathy, the white coat is often used as position marker, each time outlining the therapeutic space.

It is very frequent, for instance, among physicians who have personally experienced a dramatic illness, the choice to wear the white coat as little as possible, above all while treating patients with the most compromised and emotionally involving illness histories. Nevertheless, in many cases it remains hanging up well in view, as a reminder that it is not its absence but its having being removed, the element to which the physician entrust his message. The message is always twofold: it communicates intimate sharing to the patient, whereas it is strongly critical towards medical hegemony. It denounces the conflict that a certain way of managing emotions, handed down during medical training, generates in those applying medicine to "real" bodies, to those that someone would define mindful bodies (SCHEPER-HUGHES N. - LOCK M. 1987). It seems, indeed, that the sufferance embodied in oneself or in one's own family is one of the most powerful elements in the breaking up of a central biomedical device: that which biomedical system assigns the control of destabilising risks introduced by the emotional element. The choice of hanging up the white coat in these cases is the declaration that there is an attempt in progress for its reinstatement.

Nevertheless, the recent pressures towards a managerial organisation of sanitary institutions and the resulting tendency to transform health into a commercial and marketable product, have introduced – not only in Italy – elements of further complexity. In the perspective of a more general calibration in a neo-laissez-faire sense of the politics of a large part of the highly industrialized countries, in fact, the role of patient tends to be more and more compared to that of a client consumer. Competitiveness becomes the exchange currency for the management of the resources and capital also in the sanitary field. Every "weak" element ends up to render less spendable – in the terms of consumers "pleasure" – the sanitary "product."

So, the same pressures insisting from "above" on the promotion of a "humanization" of medicine and "patient-physician relationship", seem to result deeply and strategically marked in that sense. In other words, one can be more competitive if the formula of the correct patient-physician relationship is found: once the necessary calculations comparing costs and benefits are made, the best strategy seems to be that of the revitalization of general practice, to which all responsibilities regarding of relationships' "humanization" can be delegated. Here therefore the blooming of training courses, seminars and stages to "teach" physicians (above all general practitioners) to "understand" their own patients. But for many of them the strategy is unmasked:

> «They "technicized" also the human element... now they say we must be "human", they pretend to teach us this too! It's becoming foolish...» [lady

> doctor M., 51 years old, during a training course on "patient-physician relationship"].

If the hegemonic pressure goes toward the "technical" construction of "non-technical" physicians, that is to say toward the production of "humanized" physicians, more pleasing to the consumers' public, it is not rare to notice in some physicians lesser or more greatly aware attitudes of deep criticism and refusal of such manipulation. Also in these cases, the physician assigns his own message in a certain way of organizing spaces and technical tools: if the risk is a sort of "lowering" of the general practitioner's role into a simple "entertainer" accompanying the patients to the places where the "true medicine" (the specialist and hyper-technological one) is practised, the exhibition and manipulation of white coat and other diagnostic tools, such as the electronic measurer of diabetes and other blood values, seem to be used as a reminder that the general practitioner is always however an authoritative "scientist" and a highly competent physician. The same message seems to be assigned to the identity claims of "category" in play for the construction of a specific institutional role for general practitioners.

Paradoxically, one seems to express an analogous claim of autonomy also when appropriating some over simplification (general practitioner = friendly physician). Herzfeld, for instance, emphasizes how the stereotype is never a simple "prejudice", but rather a real weapon of power, a tool used to hide specific advantages and strategies: «the resort to stereotypes is in fact inevitably connected to situations in which "identities" are at the stake, since their production allows to people grasping them to develop self-justification strategies» (HERZFELD M. 1992: 67) (6).

> «The effort we have been making in the past years has been just to give a connotation, an image and a role, tasks and functions, to the general practitioners that can be codified and recognized, do you understand? Because what is important for us is that even Universities recognize this...» [doctor G., 52 years old].

In conclusion, we could say that biomedical knowledge founds its own hegemony also on the construction of some devices in which it condenses its more salient features, in order to reproduce and strengthen them throughout their inoculation in the bodies of the coming doctors and – according to other strategies that it was impossible to discuss here – in those of the patients. But it would seem that both patients and physicians learn equally well to make good use of "ways out", that is to say tactics of alternative manipulation of the acquired tools, thanks to which they can "perform" in a dialectical way a proper autonomous dialogue with medical institutions and, in general, with the social order.

A system always has the necessity, to preserve its own setting and internal order, to control centrifugal forces: for this reason containment devices seem to be put in action which, although powerful and effective (the white coat is a good example), acquire ambiguous outlines because they can constantly be overturned and used in a critical way against the system itself (above all when the tactics adopted by physicians are combined with those effected by patients). All this seems to be actually put into play in the midst of the therapeutic encounter, which therefore assumes the shape of a privileged space in which medicine really becomes "creative", that is to say "vital" and then "human."

Notes

(1) The reference is Gramsci's notion of the whole widespread opinions people has about life's matters (GRAMSCI A. 1975 [1929-1935]).

(2) The translation in English is mine: I worked with the Italian version of the book, so I readapted here a provisional translation that is not correspondent to the original edition. For the complete, correct citation, see the bibliographic references.

(3) Here I refer above all to general practitioners, which most of others are founding their own professional specificity on profound, wide and lasting relationships with their patients.

(4) We must to stress that on the basis of a certain reading of concepts like "embodiment", "agency", and so on, it is evident as United States' anthropology has received as well – profitably but lately – Gramsci's teachings.

(5) Translation is mine (see note 2).

(6) Translation is mine (see note 2).

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3.2 *Illness as embodied cultural practice. Investigating Cfs/Me in the UK*

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> «The incarnate body (in contrast to the merely biological) is the living site of a contested hegemony of power».
> R.J. Frankenberg (1992: XVIII).

Introduction

This paper is based on research undertaken in 1998 on chronic fatigue in the UK. At that time sufferers and their organizations were engaged in a fierce battle to affirm the organic nature of their affliction against the dominant psychiatric interpretation sanctioned by the medical establishment as the proper way to diagnosing and treating a condition that had increasingly come to medical and public attention during the past 15 to 20 years.

The different medical categories crafted to define such an affliction, namely Chronic Fatigue Syndrome and Myalgic Encephalomyelitis (1), represent very different processes of constructing its nature: the former interpreting sufferers' complaints as symptoms of a psychological condition; whereas the latter referring to the same set of signs as the outcome of an organic condition of complex aetiology.

We can list Cfs/Me among those controversial illnesses, whose characteristic is always a very hot debate over their nature as 'real' medical conditions (Singer M. *et al.* 1984, Cooper L. 1997).

Neurasthenia, Myalgic Encephalomyelitis and Chronic Fatigue Syndrome

Conditions marked by symptoms similar to those of Cfs/Me are not new in our own and other societies medical history. Historical accounts of Cfs/Me (Demitrack M. - Abbey S. 1994, Shorter E. 1993, Ware N. - Kleinman A. 1992, Wessely S. 1991, 1994b) usually start with its parallelism with neurasthenia. Neurasthenia came to be established as a medical category at the end of 1800 by the American neurologist George Beard (1869, 1880, 1881). He revived the term to describe a set of symptoms marked by lassitude, fatigability and mental impairment, a condition supposed to affect mainly the female population of the social upper class. Beard described the condition as a neurological disease of uncertain origin, occurring along with other morbid episodes involving emotional distress (2).

However, at the turn of the century, a new line of reasoning emerged in the medical field: neurasthenia was not meant anymore to be a neurological disorder of unknown aetiology, but rather a psychological one (3). In accounting for the relationships between neurasthenia and CFS, Norma Ware and Arthur Kleinman (WARE N. - KLEINMAN A. 1992: 205) claim that both conditions have witnessed «a shift in thinking from the observation of depression-as-symptom to the positing of depression-as-cause». In this regard the conceptual histories of the two illnesses are similar.

The case of neurasthenia condenses many of the arguments that have been animating the debate on CFS/ME today, and it summarises the sort of polarisation we face today between organicist and psychiatric interpretations. During the research I have come across different views of the relationship between neurasthenia and CFS/ME: on the one hand their parallelism was taken, especially in the medical literature, as evidence of the psychological origin of the condition; on the other hand, patients' groups and associations referred to Beard's understanding of neurasthenia as a precursor of ME, to state that the latter is a complex organic condition that has been around for some time: these historical reviews can be conceived of as different strategies to sustain the legitimacy of the proposed interpretation.

We now need to look at the processes that brought the categories of ME and CFS to existance. All the historical reconstruction of the definitions of CFS and ME look at a series of famous epidemics that have been spreading in several parts of the world during the first half of the XX century, the most famous ones being those of: Los Angeles Country General Hospital (USA), Akureyri (Iceland), Adelaide (Australia), New York State (USA), Middlesex Hospital of London (UK), Rockville (Maryland, USA), Addington Hospital (Durban, South Africa), Florida Community of Punta Gorda (USA), Royal Free Hospital of London (UK), Lake Tahoe in Nevada (USA) (4).

The category of Benign Myalgic Encephalitis emerged in an editorial of the Lancet in 1956 under the title of "A New Clinical Entity" (*Editorial* 1956: 789) precisely to explain these epidemic outbreaks of uncertain aetiology. The label was meant to be no more than a symptomatic description of the condition which occurred during the epidemic at the Royal Free Hospital in 1955: 'Benign', referring to the fact that nobody died; 'Myalgic', to describe the diffuse muscle pains suffered by the patients; and 'Encephalitis', to refer to symptoms believed to be the outcome of a brain infection (ARONOWITZ R. 1992: 160). However, such an infective interpretation was challenged few years later by McEvedy and colleagues (MCEVEDY C. - BEARD A.W. 1970a, 1970b), who re-analysed the case notes of the Royal Free Hospital (MEDICAL STAFF OF THE ROYAL FREE HOSPITAL 1957), proposing a much different interpretation: that of mass hysteria (5).

The viral hypothesis emerged again in the USA when a conference was held in 1985 under the auspices of the National Institute of Allergic and Infectious Diseases on the role of the Epstein-Barr virus as possible cause of an epidemic outbreak in Nevada (Incline village on the shore of Lake Thaoe). Moreover at that time it became clear that the condition from epidemic was becoming more and more episodic with an increasing incidence on the general population (6). After few years another conference took place in 1988 supported by the Centers for Disease Control (Atlanta, USA), as the Epstein-Barr virus could not be fully satisfactory as an explanation: this conference led to the first official definition of 'Chronic Fatigue Syndrome' (HOLMES G. *et al.* 1988) (7). The main point of the definition presented by the CDC is that a diagnosis of CFS can be made only after the systematic exclusion of any other known condition capable of producing the same symptoms (including psychiatric disorders) (8).

In reaction to the CDC criteria another conference was organised in Oxford (UK) at Green College in 1990, where another set of criteria, the so called 'Oxford Criteria', was presented. The UK definition proposed to distinguish between two broad syndromes: CFS and Post-Infective Fatigue Syndrome. Despite the fact that the new criteria still emphasise the need of excluding certain psychiatric conditions, their authors state: «other psychiatric disorders (including depressive illness, anxiety disorders, and Hyperventilation syndrome) are not necessarily reasons for exclusion» (SHARPE M. *et al.* 1991). The British definition of the affliction paved the way to the psychiatric interpretation of the condition.

The reaction of UK sufferers and their organizations (ME Association, Action for ME, and Westcare) led to the set up of a National Task Force, whose outcome was a Report produced in 1994, addressed and commissioned by the Department of Health, with the declared aims of providing information about the condition, encouraging research about it, educating public and professionals about the existence of the condition and improving services for patients (*Report From The National Task Force* 1994: 8-

10). Very significantly, the Report adopts the term 'syndromes', distinguishing between ME, Cfs, and Post Viral Fatigue Syndrome (Pvfs), a choice that shows patients' interests and concerns in distinguishing between suspected psychiatric conditions and what they believe to be organic ones, namely ME and Pvfs.

The National Task Report was presented to the Chief Medical Officer who forwarded it to the Medical Royal Colleges to receive feedback. The feedback did come, but in the form of a counter-report presented by the Royal Colleges of Physicians, Psychiatrists and General Practitioners as a reaction to the political activity of the patients' Organisations. The Royal Colleges Report (1996) proposed to drop the term ME in favour of that of Cfs on the basis that ME implies a link to encephalomyelitis that is believed by the Royal Colleges to be a pathological process absent in the condition; secondly the term ME was seen as implying a single diagnostic entity, described by the Royal Colleges not only as unproved but as unlikely to be present at all; and finally because ME dismisses the psychological dimensions regarded as central by the Royal Colleges. In assessing the Royal Colleges Report the Lancet stated: «Psychiatry has won the day for now» (*Editorial* 1996: 971).

Patients' Organisations complained that all the evidence supporting the organic nature of the condition had been progressively removed by the official definitions (9): their reaction took the form of a petition that led to a meeting in March 1998 with the Chief Medical Officer who made the promise to re-consider the issue further with the Royal Colleges. In fact, patients protested that their voices were muted by the professional interests of the psychiatric medical sector. Thisconcern appears justified as it is reflected by the services available on the UK National Health Service, all psychologically oriented (10).

Body Politics and Historical Forms of Embodiment

My aim so far has been to show how the process of defining medical knowledge can be looked at in terms of a socio-political process by which several groups engage in a struggle for the definition of the nature of the illness. To a great extent the status of categories such as Cfs and ME depends on the outcome of a struggle between different groups and forms of knowledge (Cooper L. 1997) (11).

In the definition of the nature of this affliction what is at stake is a struggle over who has the right to define its reality, according to which frame of reference and which interests. Simon Wessely explains why the struggle has been so fierce: «these arguments create passions because what is at stake is the issue of legitimacy: what constitutes an acceptable disease, and what is legitimate suffering, deserving of support and sympathy?» (Wessely S. 1994a: 34).

According to Ware (Ware N. 1993, 1994), at the core of the process of delegitimisation of the Cfs/Me experience is the mind-body dichotomy, setting the scene for a polarisation between organic and psychiatric aetiology, reflected in the opposition between real and non-real illnesses. In fact, the two interpretative lines which emerged through the debate construct the condition in such a way that the psychiatric explanation has been seen by patients as a denial of the existence of the condition itself, in so far as it relies precisely on the non-existence of organic evidence. A specific rhetoric of reality has been informing the debate, a rhetoric based on the biomedical definition of the body as a measure of truth and criterion of reality (Quaranta I. 1998).

However, if we look at medical categories not as interpretations of a given reality but as practical devices for its enactment, we may conclude that there is no single reality out there, independent from our interpretative practices (12). Such an anthropological approach necessarily entail a reframing of the questions to pose, no longer in terms of 'are ME and Cfs real?', but rather in terms of 'how are they made and become real in people's existence?', and the answer is neither just rooted in the intimate personal experience of sufferers alone, nor solely in the medical construction of an objectified body, but it must be searched for in the interconnections between socio-political processes, historical horizons of meanings and practices and the lived experience. My aim here is precisely to explore this process of interconnections between subjective, political and historical processes.

As we have shown medical categories, as well as cultural categories in general, are socially produced, and represent historical discursive and practical devices to meaningfully construct the body and its dys-states of being. Being social to the core medical categories entail specific values, as Allan Young (Young A. 1982: 271) claimed: «Symbols of healing are simultaneously symbols of power. Specific views of the social order are embedded in medical beliefs, where they are often encoded in aetiologies and beliefs about the sources of healing power». These reflections lead us to consider the issue of the body politics in terms of how bodies are made, how their states of being are conceived of. However, what I wish to stress here is that we should integrate such a focus on 'how bodies are made' with a careful examination of 'what bodies do' in the specific context of illness, in general, and of Cfs/Me, specifically. These two analytic concerns are far from being independent, as I intend to show.

In order to state immediately the theoretical background of my argument I will look at what bodies do through the experience of illness, conceiving of the latter in terms of a bodily practice, as a specific arena of production of culture and experience: willy-nilly, illness experience produces something, e.g. a different subjectivity, a different engagement in the world, a different configuration of intersubjective relationships, a different lifeworld, in a nutshell a different process of being-in-the-world.

What I want to argue is that we should look at illness as a human product that must be investigated in terms of its manifold processes of production (how it is produced and what it does produce). However, I believe that illness can be appreciated as a cultural practice only if we look at the relationship between experience and representation in constitutive and dynamic terms: as Kleinman, Das and Lock have suggested, cultural representations of suffering shape it as a from of social experience (Kleinman A. - Das V. - Lock M. 1997: XI-XII). If this is true for experience it is also true for the body: as Michel Feher pointed out, «the history of the human body is not so much the history of its representations as of its modes of construction. For the history of its representations always refers to a real body considered to be "without history"» (Feher M. 1989: 11). Historical images of illness and the body, then, emerge as practical and symbolic means for their construction, so much so that we may talk of them in terms of historical and social processes. It is through such historical and social images that we live ourselves as positive presence in a meaningful world (13).

Nevertheless the body is not a mere product of history and society, as it is also the lived ground of existence: bodies are constituted in and by practices (Mol A. 2002) and discourses (Young A. 1995) as well as they are lived sites of discourses and practices (Csordas T.J. 1990, Good B.J. 1994). In this guise, I believe we must reject any assumption of a holistic-integral form of embodiment that is primary to any historically subjective experience of it. Instead of an integral or autonomous body, we should look at the body as a process that is historical and social as well as it is personal. We should therefore talk of historical forms of embodiment rather than embodiment as such.

What I am calling for here is the need to combine an anthropology from the body (Csordas T. 1994: XI) with an anthropology of the body: the former concerned with 'what the body does', whereas the latter looks at 'what is done to the body' The two approaches, in fact, have the potential to be reductionist if not combined with each other. An anthropology from the body has the potential to show the active role of the body in producing culture and experience, but it runs the risk of positioning the body as a transcendent force devoid of history, whereas if we combine such a focus with an anthropology of the body we can counteract this tendency «by revealing that the body is always-already engaged in a specific social situation by means of techniques or rule governed practices which are historically and geographically contingent » (Crossley N. 1995: 43-4). I believe that only when we combine these two analytical focuses, illness can emerge as a process that is personal as well historical, produced as well as productive.

It is with this aim that I now move on to the examination of sufferers' account of their affliction, trying to show how their experiences are historical as much as they are personal, subjective as much as objectified in forms knowledge, subversive as well as embedded in power relationship, socially produced as well as active producers.

Experience, History and Power: Illness as Embodied Cultural Practice

> «Sickness is more than just an unfortunate brush with nature. It is more than something that "just happens" to people. Sickness is something that humans do in uniquely original and creative ways. Illness is a form of body praxis, of bodily action».
> N. Scheper-Hughes (1994: 232).

Chronic illness can be seen as a form of ontological assault (Garro L. 1992: 103) in the sense that it undermines the assumptions on which our daily existence rests. If the work of culture is precisely that of grounding ourselves in a meaningful world as positive presence, chronic illness represents a crisis in such a process, a crisis that calls for a re-integration. In the case of Cfs/Me this process must be looked at in the context of the general debate I have reconstructed above: in fact, as Ware (Ware N. 1992) and Cooper (Cooper L. 1997) show, the very 'nature' of Cfs/Me as an illegitimate illness adds another burden to the suffering involved in the condition.

The narrative reconstructions of the affliction tends to biographically locate its onset in concomitance with a flu-like illness, whose problematic nature emerges from the time-scale dimension involved in the persistence of the symptoms: they don't fade away as our embodied memory would expect them to do, and doctors as well as other actors (such as relatives, friends, colleagues, etc.) are incapable of understanding what is going on.

The devastation of the symptoms is described as an overwhelming experience: general fatigability, memory losses, difficulty in concentrating, sore throat, swollen glands, muscles pain, joints pain, sleep disturbances, food allergies, digestion problems, pain in the eyes, exhaustion, dizziness, are some of the symptoms usually listed by sufferers (14). To describe how these symptoms enter their existence, informants usually talk of their impact on everyday life in relation to the most proximate activities:

> «We can say that I am in bed nearly all the time, not quite all the time, and I only go out in a cab or a car because I cannot walk as far as the bus stop, and I cannot stand at the bus stop for more than five minutes, and I have a wheelchair, because I couldn't walk from the front door to the car. And if I talk for long, for instance ten minutes at the phone, I am going to be exhausted and I will have to lay down, and if I stand up for half an hour I have to lay down. And I am too tired to have more than one person to talk to me, if I have too many people there I would be exhausted quicker. I can just about to walk to the bathroom then I would wash part of myself, and going back to bed, and then wash the second part. It sounds ridiculous. ... but there seem to be no light at the end of the tunnel» Jane (40 years old, at the time of the interview affected for 4 years) (15).

> «Generally the accepted view of the [medical] establishment is that people with ME will respond to exercise and cognitive behaviour therapy, but as I was reading the other day, people with ME are living at their limits just by living, just by walking form one room to another, they really haven't got any reserve to do exercise programs» Kiran (48, affected for 9 years).

> «When I got ill it was really quite hard work even to lift the spoon to my mouth. If I went to the lavatory I had to decide if I had the energy to get there, it was extraordinary, I was amazed, with what brain I had I was amazed» Sally (66, affected for 11 years).

What we are facing here is the very impossibility of taking for granted everyday life and existence, which is the most proximate manifestation of the ontological assault chronic illness represents. The world itself ceases to be 'obvious': every single action requires decision and negotiation, a negotiation which is often represented in relation to the body. The latter leaves its realm of silence to start 'being present' with its demanding voice, a voice that, if ignored, leads to punishment. The body is charged with an intentionality of its own, and such an intentionality represents the very revolution involved in bodily symptoms:

> «Normally if you haven't got ME your body works and most of the things you do are automatic: you walk or you do things, whereas if you are suffering for ME you are always aware that some part of you physically can't do things. You get always information from your body to your mind telling you

> look this isn't right, you can't do it. When you are well everything is relaxed and feels as it should be» Kiran.
>
> «Q- How has the relationship with your body changed through ME?
>
> A- It's very mixed, well sometimes I'm angry with it because it's not doing what I want it to do. What I've done is to become very much more in contact with it, I listen to it all the time now, and this is very hard to tell because it's such a weird disease, I think perhaps there are not that many diseases where if you don't obey your symptoms you can be given a very hard time sometimes, whereas, oh what shall I say, I was in a theatre once and I was an actor and "the show must go on", whatever happens you do the show, and all actors despite how sick they are they manage to do the show, regardless. Now with this disease you can't manage to do it regardless, it simply doesn't let you» Sally.

These narratives testify of the "inescapable embodiment" (TOOMBS S. K. 1992: 134) the illness brings about. The 'ill' body leaves the realm of absence and silence to be problematized as the explicit focus of concern. It is in this sense that Drew Leder (LEDER D. 1990) uses the expression of dys-appearance. As he claims, the body as a ground of experience is always characterised by absence in so far as it tends to recede from direct experience. When it does appear «the body appears as a thematic focus of attention, but precisely in a dys state – dys is from the Greek prefix signifying 'bad', 'hard' or 'ill', and is found in English words such as 'dysfunctional'» (LEDER D. 1990: 84). The body emerges as an alien presence «that exerts upon us a telic demand» (LEDER D. 1990: 73), that is both hermeneutical and pragmatic (LEDER D. 1990: 78), in the sense that it engenders a practical and symbolic struggle against dissolution (MURPHY R. F. 1987: 223).

The body then can be seen at the very centre of the process of dissolution of the lifeworld as an active player, imposing a practice of listening to it and to its commands never experienced before. Sufferers' accounts invite us to look at bodily distress in phenomenological terms, meaning that what is being called into question through illness is the very process of being-in-the-world. Loss of confidence in the body is very much related to the lack of control over one's own life:

> «Sometimes I'm hardly sure that I'm there at all, it's as though there are rust and cobwebs that have covered me over, and there is just this little flicker of flame that I know it's me who's trying to get through [...] Sometimes I feel I've lost the proper ability to be a wife, a mother, a friend, a worker a person» Sally.

Illness brings to light the process of being in its 'negative' fashion, and in this sense illness cannot be seen as an 'event' interrupting the processual flow of existence, but rather it must be looked at as a 'change' in the embodied process of being-in-the-world. Illness is itself a process, whose peculiarity lays in the rupture it engenders regarding the previous pre-existing relationships between body, self and society. The body leaves its silence and calls for a re-orientation of our being-in-the-world, and illness can be seen as a different existential mode of being-in-the-world (16).

Chronic illness imposes a re-negotiation with the world, ourselves, others and therefore it can be seen not only as culturally performed, but also as performing reality, a reality of a different order, that is not commonsensical anymore, forcefully reflexive, that imposes ongoing negotiations, a reality that is not ontologically given but that must be objectified every time consciously: in a nutshell, we can claim that the work of culture leans out of the inchoate to the window of awareness through the illness experience.

In this fashion we can appreciate illness as a form of cultural practice, a bodily one, that produces a re-positioning of a different self in a renewed world: the experience of illness does not just require a different 'culture', it produces a different 'culture', a different process of being-in-the-world. What I am concerned with here is an anthropology from the body (Csordas T.J. 1994: XI), an anthropology focused on the active role played by the lived body in the culture process, in general, and in illness experience, in particular. Obviously we cannot confine such an active and productive role of the body to chronic illness, as it is the very ground of constructing and constituting ourselves in our daily existence: however, to be specific to illness experience is the fact that such a process becomes explicit, as sufferers make clear in talking of their affliction. Moreover, my argument is that such a focus cannot be divorced from an anthropology of the body, i.e. an inquiry concerned with the ways in and through which bodies are culturally patterned and informed by social practices and discourses. When we combine the two concerns then illness can emerge as an embodied cultural practice.

Having earlier on discussed the medical construction of the body, I now move on to explore the images of the body articulated by and through sufferers' narratives, in order to show how we must take into account the dynamic and constitutive relationships between subjective experience and processes of objectification of the body.

The narratives produced during the research can be seen as one of the many ways sufferers come to 'objectify' their experience, bringing-into-being discourses to give meaning to their existence. In sufferers' production of cultural discourses biomedicine comes out, from all the narratives, as a general overarching horizon of meanings to refer to in order to make sense of their problems. In accounting for the onset and cause of illness all the informants referred to one form or another of organic problem (virus, immune-deficiency, neurological dysfunction etc.). Biomedicine sets the scene for the understanding of the illness. The deep pervasiveness of the biomedical discourses must be seen in its broader socio-cultural context: the very biomedical definition of the body rests upon wider assumptions about reality and knowledge, notions that are at the very core of an 'embodied anthropology' people share in their everyday interactions with each other and with the world (17).

Sufferers appropriate biomedical discourses and concepts in a creative way in order to make sense of their experiences: in analysing their accounts to emerge as central in almost all of them is the role of the immune system as an image around which a narrative construction can take place (Good B. J. 1994). If every illness episode comes to question the social order in some way or another, and if every interpretation about it is not just a social one, but brings into account the social, it is with the rhetoric of the immune system that such a link becomes explicit in its fullness:

> «Q- How do you think that your life at that time affected your illness?
>
> A- [...] ME is an immune deficiency disease. My immune system was lowered by the amount of stress I had a couple of years before I got ill. I was struggling to keep my work going [...] and this struggle was very undermining, plus at home things weren't going that well either. All these things lowered my immune system and I had been extremely strong and active for many years and then when this virus came along I wasn't able to resist it, and it got hold of me, also because I didn't give myself time to recover. I think that it is the immune system that is deficient and a virus then can act in a different way from what a virus usually does» Zelda (69, now recovered after 10 years of suffering).
>
> «Q- Do you think there is any special link between ME and contemporary society?
>
> A- I think there are two things: one is that there is a lot of pollution in the atmosphere and that lowers your immune system and makes you more vulnerable, and so there are more people get ill than used to be as a result of that, also there are a lot of stressors in society, and that lower the immune system too. The other thing is the pesticides that are used on crops and food, some people get ME or something similar to ME just from the pesticides, if they live in an area where a lot of spraying is done on the country, and their symptoms are almost identical to ME. So I think in this way modern society has made it more prevalent than it used to be» Alan (43, affected for 8 years).
>
> «Q- Why do you think you've got ME?
>
> A- I don't really know 'cause we don't know what the cause is yet. I think that I don't think it's one thing. I don't think it's one virus. I think it's many factors and I think a lot of it is environmental. [...] And although I think the infection is the final trigger, I think that other things in our environment

> weaken the immune system [...] And the sorts of things which weaken the immune system I think are too much use of antibiotics... it dys-regulates everything. The contraceptive pill and Hormone Replacement Therapy, again they are unnatural things in the body which upset the natural balance of the immune system. Also things like emission from cars, pesticides – they're all around us now; it's in the water, it's in the food. The hormones in food. Pesticides you just can't avoid from pet products to gardening products to things we find in our food. And all these things together, all these modern things, have a downside which is to weaken the immune system.[...] vaccinations is another trigger as well. If you have an awful lot of vaccinations again it upsets the natural immunity. So yeah, I don't really know the answer» Carla (26, affected for 4 years).

> «I was always busy never stopped. I had worked hard, played hard, holidayed hard. You know I didn't have a weekend at home, or put my feet up, or lie on a beach It might be part of the problem, that I got ill and I had nothing left to fight. All my immune system was tired» Veronica (34, affected for 9 years).

When asked about their life before the onset of the illness, about the reasons why they have became ill, about the relationships between ME and society, etc. the informants refer to the immune system as a general meaningful landscape to organise and express their views. They usually describe themselves as very busy people, driven by multiple commitments, overactive, and always rushing to keep up with a stressful life.

It is relevant here to stress the historical-bound character of the representations sufferers elaborate in their accounts, by focusing on the symbolic dimensions of the immune system, seen as a metaphorical device to place personal experience of illness and its onset in a wider moral and social context. Emily Martin shows how the imagery of the body and of its boundaries has changed in post-industrial societies: from a passive object to be guarded from outer intruders, to a permeable and open one, active and flexible in its adjusting to internal and environmental threats. In such a new image of the body the immune system is seen as playing a central role as the very measure of health. In Martin's words: «What we see emerging through the immunologists' eyes by the late twentieth century, then, is a body that actively relates to the world, that actively selects from a cornucopia of continually produced new antibodies that keep the body healthy and enable it to meet every new challenge» (MARTIN E. 1994: 37). Within such an open field (the body) the immune system plays the role of distinguishing between self and nonself, as Martin puts it: «The notion that the immune system maintains a clear boundary between self and nonself is often accompanied by a conception of the nonself world as foreign and hostile» (MARTIN E. 1994: 53). The body is seen as a constant blur open to the interaction with the external world, a world whose potential negativity is controlled by the immune system. The immune system is the one that pays for all the risks we go through, all the stressors we live by, the lifestyle we carry on. Stress at home and at work, our habits, environmental pollution, pesticides, water, food, vaccinations, antibiotics, etc. lower our immune system and the infection is just the final trigger. The biomedical discourse presented by the informants broaden its features and becomes a way to account for the entire economy of life and for its relations with the social world.

Patients' narratives point our attention to the fact that through their experience of illness a different understanding of life and society has emerged, an understanding that comes to be fully articulated through the metaphor of the immune system: the latter constitutes an imaginative field in which people readily explore their ideas about the body and society. From sufferers' accounts, in fact, society becomes an active player, potentially menacing, a context within which individuals are constantly at risk. Bodily surface disappear and the social is in the flesh. The body, in other words, becomes a landscape where personal life histories and social forces come to play their part. Society, medicine and technology emerge from the narratives as potentially dangerous, and their outcomes as un-predictable.

Related to such historical images of body and society is a specific conceptualisation of the self. Giddens talk of 'the self' in high modernity as a project «to be reflexively made» (GIDDENS A. 1991: 3), a project in which the notion of lifestyle appears as fundamental. In the age of high-modernity in fact no-one escapes (GIDDENS A. 1991: 124) the risks produced at the personal and institutional level, that is to say that the individual has to choose his/her behaviour and lifestyle to build up a narrative project of the self capable of sustaining his/her identity The risk the body is exposed to are transformed in the very risk of the self as vulnerable and incapable to resist, unless through a proper lifestyle. This is the only means the individual is left with in order to balance the difficulties of living in a risk culture (GIDDENS A. 1991: 182). Lifestyle becomes the only means to monitor a situation of institutionalised risk over which the individual has little control (GIDDENS A. 1991: 192) (18). To ground these considerations in the ethnographic material presented I wish to pay closer attention to the symptom of fatigue. Again the immune system works as the master metaphor adopted by sufferers: the lowering of its defences is experienced as a lack of energy because of which the body is not able to recover from an infection that in normal situations would not represent a threat:

> «That's why people don't get better, because they haven't got the energy to ... and when they get a little energy they use it all up, that means not to use all your energy if you want to get better and heal» Zelda.

Specific notions of time and society are central in such an economy of energy informants refer to:

> «I think that one of the problem with modern life, if you think back to the 19th century when medical technology was zero how did people get better, they convalesced. The concept of taking 6 months off was perfectly acceptable, because there was nothing else they could do, they let the body heal itself, and we've lost this concept of convalescence, it is unacceptable to be ill in the modern life, people are under a lot of pressure, jobs need to be done, we have so many options around to enjoy ourselves, fulfilment is important, we feel we are entitled to have an interesting life, we travel, we go to the cinema, we want to go out to eat, you know, we've got all these options that somebody in the 19th century didn't have, and therefore the idea of taking time off is unacceptable, so we lost this concept of convalescence, and part of the reason for that I think is because in so many areas medicine now has technology: you give someone a pill and they get better after a week two weeks four weeks you know, and therefore it's instant solutions isn't it, nothing takes very long, and then medicine comes up against something where it can do nothing, but they've lost the concept of convalescence because for most things you don't need it anymore, you just take a pill and you go home for a few days and you get better, instant solution.
>
> Q- How do you think your relationship with your body has changed.
>
> A- Well I think you learn to listen to your body much more, because I think part of the unacceptability of being ill in modern life is that people push themselves because they think they can't let people down, and if they've got aches and pain they just keep going, and you don't listen to your body. With ME you begin to learn when your body says it had enough, instead of ignoring it and keep going» Tom (55, now recovered after many years of suffering).

Again, the experience of illness can be seen as an embodied process of culture production: a different view of society, self and the body emerges from the experience of illness. Society becomes an agent in the production of illness, the body as the very source of healing, and the self as a vulnerable agent that in order to survive must be put in touch with the body. What is at stake in such a process is a form of embodied knowledge, in the sense that the body is at the very core of this process of meaning production. In this regard Tom's account articulates a clear critique of the role of medicine and society in relation to illness. Illness is seen as unacceptable in relation to the modern pace of living, and medicine is conceptualised as driven by the very same assumption at the core of modern living, and as such is demystified and put back in a critical understanding. Here we can appreciate the symbolism of fatigue as expressing a form of distress in relation to the implicit dominant values at the core of 'modern life' with their stress on fulfilment through personal satisfaction at work and in social life. The symbolism of fatigue refers to the felt need for a different configuration between individual and society. As Ware writes: «Chronic fatigue syndrome served as the catalyst for a radical lifestyle transformation in which 'perpetual motion' was replaced by relaxation and rest [...] The result was the re-assertion of control, the choice of a more manageable and healthier way of living which deliberately placed personal well-being at the centre of conversion» (WARE N. 1993: 67). As already stated, willy-nilly, illness experience produces a different configuration of the relationships between body, self and society, and as such it is a productive process.

Moreover Tom's narrative points our attention to a view of the body as an active player in the process of gaining recover. Such a process of recover must be based on the very ability to rest, i.e. a way of resisting the pressure of the modern way of living that tends to interfere with the very possibility of regaining health: in contemporary society the body is not given the time it needs to heal itself. The strategies of pacing and resting comes out as necessary to allow such a process of self-healing, implying the need to adopt alternative and reflexive lifestyles:

> «What most people do, is that they constantly overdo it, and then they relapse and they rest, and that's the boom or bust problem: I feel well, I go crazy, I overdo it, collapse and I go to bed, I feel better, I overdo it, I collapse... so it's like this, up and down. And the sensible way to stop that happening is to be pacing, which is about learning your limitations, remaining within them, gradually increasing your activity but listening to your body» Carla.

The body does not just loose its boundaries, but it even becomes an incarnate source of knowledge we must learn to understand in order to be aware of what we can do, and when, which is to say also who we can, and have to be. The symptom of fatigue, the causal link found in relation to the pace of modern life, the change in lifestyle brought about by the condition, all suggest a form of distancing from the dominant values, showing how bodily symptoms come to be articulated in narratives as expression of social distress, as the very embodiment of such a distress.

Good or Bad Attachments

The dissolution of the lifeworld implies a search for meanings, and biomedicine works as a meaningful landscape to walk through for such an endeavour. Biomedicine emerges then as the 'automatic' source of possible answers to the problems engendered by illness. The concept of hegemony here is particularly useful: biomedicine is hegemonic not because it is the dominant medical system in society, but because its dominance is generally accepted by people as the appropriate means to deal with their problems (FRANKENBERG R.J. 1988). People refer to biomedical practioners, not because they are victims of mystification, but rather because not to do so would not make sense to them. Therefore the concept of biomedical hegemony helps us to re-think the relations between culture, individual and society in embodied terms (19).

The concept of medicalization must be re-considered as well: in medicalizing their illness ME sufferers are not victims of the dominant process of mystification of the social nature of their problems, but rather they look for meanings capable to sustain their being-in-the-world, meanings they have embodied and rely upon to be able to successfully objectify the experience of dissolution engendered by illness (20). In their auto-medicalization patients are making a clear political statement that is 'positive' in so far as it is related to their need to be-in-the-world in meaningful terms. Contrary to a certain definition of medicalization (CONRAD P. 1992), here it is really a form of resisting a definition of reality felt by sufferers as oppressing, i.e. the psychiatric one with its stigma on personal responsibility (21) Auto-medicalization, as Mark Nichter has shown (NICHTER M. 1998), can be looked at, in certain contexts, as a form of agency rather than as a form of mystification, though enmeshed within the hegemonic dichotomy between mind and body.

Here we need to look at medicalization in terms of a politics of symptoms attribution, meaning that there is a political dimension (related to the politics of truth and reality entailed by the debate about the condition) in the need of affirming sufferers' presence in the world, which is the need to affirm the reality of the experience of illness: the politics of truth and reality enter the existential process of being-in-the-world, i.e. power mingles with the waves of intimate experience. It should be clear by now how reductive it can be to oppose hegemony and resistance in terms of processes of objectification and subjective experience, rather than attending to the contextual, fragmented and contradictory, though constitutive, dynamic inter-relationships between them. I am arguing that we should overcome the opposition between illness and disease, between subjective experience and objectified bodies, and instead conceive of their performance as being in continuous relation and tension with one another as well as mingling with each other in the existential process of being a person, whether ill or healthy, within specific historical horizons of discourses and practices.

The affirmation of the reality of the affliction through the dominant biomedical rhetoric is in fact an integral part of their highly existential symbolic struggle against the dissolution engendered by this chronic illness and its socio-political context. In following Joost van Loon (VAN LOON J. 1998), I believe that any opposition between subjective embodiment and objectified bodies makes little sense, as this is a question to be asked ethnographically and not so much in (?)oppositive terms but rather as different forms in which the practical constitution of the body takes place in the life and socio-cultural world of the subjects. As he claims: «the issue of body-politics is not one between autonomous versus attached bodies, but between good or bad attachments. Whereas good attachments are identified as those which allow for a process of 'learning to be affected' – a transformation of subjectivity – bad attachments lead to isolation, irresponsiveness and an inability to counteract upon (alleviate) suffering» (VAN LOON J. 1998: 11). In the case under discussion, then, medicalization works as a good attachment for ME sufferers. In sustaining the organic nature of their affliction, they resist the process of delegitimization they claim to be caused by the psychiatric interpretation (BROOM D. - WOODWARD R. 1996, COOPER L. 1997, WARE N. 1992).

We must therefore socially locate cultural discourses and consider medicalization (in this particular instance) as the means through which sufferers come to appropriate a political rhetoric whose social value is extremely powerful in defining truth and reality. The powerful biomedical objectification of the body is appropriated by sufferers to ground their subjective need to affirm the reality of their suffering in the context of the medical and public debate surrounding the definition of the affliction.

Conclusion

As I hope to have shown, the several levels I have investigated in this study about CFS/ME are far from being independent. Acknowledging that the body as historical process is at the very core of our existence, we come to realise that bodily states of being are themselves socio-cultural practices. In these terms the very 'nature' of illness is re-framed: no longer is it simply the outcome either of an organic entity, or of a psychological and social distress, but rather a meaningful domain in its own right.

An anthropology of the historical forms of embodiment can help us to gain an understanding not only of the processual nature of experience and culture, but also of the power relations inscribed in them. To assume that the body is at the very centre of anthropological inquiry does not imply any kind of reductionism. It rather allows us not to mystify subjective experience as the mere result of social processes, and at the same time it sheds light on the socio-political dimensions of our most intimate experiences. In this sense anthropology is not to be seen as a form of advocacy for the powerless, as my experience in this research has taught me: «the natives can speak for themselves» (FRANKENBERG R.J. 1995). It rather takes the form of a critical discourse, whose aim is not that of de-mystifying social reality (22), but rather of grounding general questions in specific contexts while giving general relevance to specific issues, such as the ones raised by ME sufferers. In doing so anthropology is a negotiated form of knowledge that can produce alternative categories capable of showing us the relativity of our taken-for-grantedness, and therefore of orienting possible alternative ways of conceiving of reality and ourselves.

However, such a task must be accomplished by looking at the multifold processes of production involved in illness: in asking general questions such as "how illness is produced and what it produces", in the specific context of the public and personal aspects of CFS/ME, we may give sufferers' voices a theoretical framework to rethink capital issues such as the relationships between experience and representation, between medically objectified bodies and subjective experience, between lay and scientific knowledge, and in doing so force ourselves to deeply investigate their mutual, yet fragmented and highly contextual dynamic interdependence. However, we must avoid the adoption of an a-historical view of embodiment: by looking at it as a product we must investigate its processes of social and historical production. In this fashion bodies emerge as constituted in and by practices and discourses as well as lived sites of discourses and practices.

To conclude we can argue that illness experience emerges as a bodily practice, a creative process, and as such it is a cultural yet specific existential mode of being-in-the-world that is produced as well as producing, enacted as well as enacting, traversed by power relations as well as active in negotiating the terms of its relationship within a historically constituted world. Once we recognise the constitutive relationship between representation and experience, bodily states of being (in health as well as in illness) emerge as cultural practices and as a specific domain of production of meaning and experience.

Notes

(1) In this paper I will use the acronyms of Cfs and ME. They will be used together when I discuss the condition in general terms, otherwise I will use the label preferred by the actors I am referring to.

(2) He called the condition the 'American nervousness' and hypothesised that it was typical only of the 'civilised world' Beard's argument about the cultural-boundedness of neurasthenia was based on the changing social organisation of western countries with its demands for brain work. Quite tellingly the Greek etymology of the term refers to a 'lack of nerves strength'.

(3) Regarding the historical precursors of Cfs, Shorter claims that it is not possible to assume neurasthenia as having a one-to-one coincidence with Cfs, in fact the former was used as a diagnostic tool in many different contexts and implying different meanings: as a synonym of general nervousness, as the male equivalent of hysteria, as a synonym for depression, as a diagnosis for idiopathic fatigue. Moreover he claims that many 19th century sufferers from fatigue did not receive a diagnosis of neurasthenia: «It is thus evident that great caution is indicated before assuming an even rough equivalency between neurasthenia and chronic fatigue» (Shorter E. 1993: 12).

(4) For a detailed discussion of these epidemics see Quaranta (Quaranta I. 1998, 1999).

(5) They proposed to drop the term of ME and to adopt (following the analogy with Anorexia Nervosa) that of Myalgia Nervosa (1970b: 15).Their argument was based on the absence of any organic evidence, and on the majority of the female population affected by the epidemic, that took place in strict circumstances, as they argue it is always the case in mass hysteria. Such a line of reasoning was picked up by Elaine Showalter (1997) in sustaining that Cfs can be looked at as a postmodern form of mass hysteria in which patients refer to their symptoms as organic ones to avoid the stigma of psychiatric illness.

(6) Many scholars arguing for the psychiatric interpretation of the condition tend to look at this shift from epidemic to sporadic cases as the outcome of a process of sufferers' self-diagnosis, fostered by the attention given by the media and the press to the condition (Wessely S. - Hotopf M. - Sharpe M. 1998). Simon Wessely (Wessely S. 1994a: 27) points out that the link between the first epidemics and the contemporary sporadic cases is mainly historical, in so far as the two conditions seem to share very little: epidemic ME was in fact contagious, acute, with evident neurological signs, whereas Cfs seem today to be non-contagious, sporadic, and with no neurological signs.

(7) The guidelines proposed by Holmes *et al.* (Holmes G. *et al.* 1988) pointed out the need to fulfil a set of criteria in order to assess the condition. These criteria are divided in major and minor criteria (and the latter in 'symptoms criteria' and 'physical ones'). Patients must fulfil the two major criteria («1. New onset of persistent or relapsing, debilitating fatigue or easy fatigability in a person who has no previous history of similar symptoms, that does not resolve with bedrest, and that is severe enough to reduce or impair average daily activity below 50% of the patient's premorbid activity level for a period of at least 6 months. 2. Other clinical conditions that may produce similar symptoms must be excluded by thorough evaluation, based on history, physical examination, and appropriate laboratory findings...» [Holmes G. *et al* 1988: 388]), plus 6 or more of the 11 symptoms criteria and 2 or more of the 3 physical ones, or 8 or more of the 11 symptom criteria. The symptoms criteria list: mild fever, sore throat, painful lymph nodes, muscle weakness, myalgia, generalised fatigue, headaches, neurological complaints, sleep disturbance, etc. The new "working case definition" is described by Aronowitz as a «Chinese menu approach to diagnosis» (Aronowitz R. 1992: 163).

(8) Many reactions to this definition arose both from patients' groups and medical professionals, the main problem for patients being the perception that the shift from an etiologic (Epstein-Barr) to a symptomatic (Cfs) definition could enforce the legitimacy of the psychiatric interpretation: as a patient wrote in a letter to the editor of the Journal where the definition was published: «a patient diagnosed with a disease must live with its label and with lay persons' understanding of that label...This new name, instead of affirming the infectious nature of the illness, reinforces its psychiatric nature» (Annals of Internal Medicine 1988: 166). As far as the medical sector was concerned the main problems were related to the exclusion criteria and the multiple somatic

symptoms required. In fact the combination of the two criteria came out to be contradictory in so far as, by the one hand, researchers have shown that psychiatric illnesses are present in over half of the cases diagnosed as CFS (according to the proposed new criteria), rising the issue of how to establish a clear boundary (MATTHEWS D. - LANE T. - MANU P. 1988, MANU P. - LANE T. - MATTHEWS D. 1988). On the other hand, it is the very definition requiring multiple somatic symptoms that leads to an overrepresentation of somatoform psychiatric illnesses (KATON W. - RUSSO J. 1992). Moreover the new definition seems to be overlapping with that of other conditions such as fibromyalgia rising further issues in the problem of tracing boundaries. Finally the list of conditions to be excluded, and the laboratory tests required in order to do so, made the definition impossible to adopt in practical and economic terms (DEMITRACK M. - ABBEY S. 1994). In response to these problems other definitions have been produced (SCHLUEDERBERG A. *et al.* 1992, FUKUDA K. *et al.* 1994) trying to reduce the list of physical symptoms in order to avoid the overrepresentation of psychiatric illness.

(9) Such evidences tend to frame the condition in terms of entero, retro and Herpes viruses, immune, neurological and endocrinological dysfunction, chemical sensitivity and environmental pollution, allergies, and so on (see KELLNER R. 1991: 32-5 for a detailed review).

(10) These services included anti-depressant trials, Cognitive-Behaviour Therapy and Graded Exercise Therapy. According to the patients' organisations these treatment options are based on a psychiatric understanding of the condition that tend to dismiss their claims that there is the need to distinguish between different kinds of Chronic Fatigue, in which ME must be kept as a useful definition for those cases that are not affected by primary psychiatric disorders, and that present abnormal muscle and mental fatigability according to a variable pattern swinging between remissions and relapses.

(11) It is significant that after the end of my fieldwork ME was accepted as an official diagnostic category by the NHS. Such a success, as Ronald Littlewood has pointed out (LITTLEWOOD R. 2002, 2003), has been obtained thanks to the patients' activist groups, that is through a struggle fought mainly in the extra-scientific arena, showing the active role of social and political relations in shaping medical knowledge and practices (SMITH B. 1981).

(12) Since the body and its diseases are not given outside such practices, we may agree with Annemarie Mol (MOL A. 2002) that bodies ontology is multiple: «Realism no longer entails a submission to medical doctors if "the real" isn't mapped onto the singular virtual objects they talk about, but is, instead, taken to coincide with the multiplicity of objects they practically perform» (MOL A. 1998: 162). Such a theoretical standpoint reveals how ontologies are not to be seen as transcendent but rather they must be viewed as brought about in practice.

(13) In adopting the concept of 'presence' I am referring to the work of Ernesto de Martino (DE MARTINO E. 1995) and his reading of the Heiddeggerian *Dasein* in cultural and historical terms. In de Martino's work this is not something given once and for good, but it is conceptualised in its processual 'nature' in which cultural institutions work in its constitution and maintenance against the risk of not being: i.e., the very crisis of presence.

(14) During the interviews sufferers refused to consider the symptom of fatigue as appropriate to describe the kind of exhaustion they experience. They tend to look at it as the most visible symptom to others, but just as the peak of the iceberg in relation to their illness experience.

(15) All informants' names have been changed to safeguard their privacy.

(16) Murphy and colleagues use the concept of liminality to describe the lives of disabled people as stuck «dramatised in a rite of passage frozen in its liminal stage» (MURPHY R.F. *et al.* 1988: 241). However liminality is probably better understood as a process of re-negotiating meanings and roles, i.e. lives, in different terms. Such a process leaves behind the taken for grantedness of everyday commonsense and requires a new positioning of people in the world.

(17) However it is misleading to talk of biomedicine as a monolithic institution and a given set of theories and practices. As Hahn and Gaines' collection (HAHN R. - GAINES A. eds. 1985), as well as Lock and Gordon's one (LOCK M. - GORDON D. eds. 1988), show, medical knowledge and practice is made up of numerous sub-specialities, interest groups, and individuals who bring a variety of perspectives to their work. Moreover its knowledge cannot be seen as being the exclusive posses-

sion of the medical profession, as if the boundaries between expert and lay actors were closed and clearly marked, but it is rather spread within society and appropriated in many different ways both by lay and experts actors (ARKSEY H. 1994, MARTIN E. 1994).

(18) Our choices are the only way we can manage the potential dangers spread in society, a situation that leads Emily Martin to conceive of the self in terms of an «empowered powerlessness» (MARTIN E. 1994: 122): when the individual feels responsible for everything and powerless at the same time, in so far as the very possibility of controlling and managing the enormity of factors at stake in one's own health becomes overwhelming. The self comes to be trapped between the contradiction of «universal agency and helplessness» (p. 135).

(19) The body, in fact, is not a marginal element in the process of challenging and consolidating the social order and its 'givenness' By the one hand it is in fact through its inscription in the body that knowledge and the social order become hegemonic: in entering the lived experience, they disappear from awareness. It is through such a process of embodiment that the dominant order becomes 'natural', and the socio-political processes that sustain it come to be obscured in the immediacy of the lived experience. By the other hand bodily distress articulates a form of dys-ease with the social. Both these processes are performed in the depths of our intimate existence. The process of embodiment therefore can be seen as producing as much as it is hiding. Meanings perform their embodied rituals of producing humans, and at the same time they cover the process they perform (QUARANTA I. 2001).

(20) This does not mean that power, mystification, social control, depoliticization and medicalization are not useful concepts. Indeed they are, but they must be re-located within the process of embodiment (i.e. the process of coming-into-being of culture, society, and experience), and within specific socio-historical and ethnographic contexts.

(21) Broom and Woodward (BROOM D. - WOODWARD R. 1996), Ware (WARE N. 1992) and Cooper (COOPER L. 1997) all argue that in sustaining the organic nature of the illness sufferers resist the process of deligitimation they claim to be caused by the psychiatric interpretation.

(22) Allan Young, in criticising Taussig (TAUSSIG M. 1980), already expressed doubts about such a theoretical position: «How can Taussig or any anthropologist be sure that his own ideas are correctly demystified [...] all knowledge of society and sickness is socially determined, and [...] anthropologists cannot legitimately claim access to demystified facts» (YOUNG A. 1982: 276-277).

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3.3 *"Dogs don't bite the hand that feeds them": managing distress in the changing rural landscape of South West Finland*

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On a sunny afternoon on the island of Koppars I was discussing with a young farmer Peter, his father Bengt, and Christian, their neighbour, about the changes that have taken place since Finland joined the European Union in 1995. They were stating that Natura (1) has taken the land of the small farmers of the area, but not of the rich ones, and many of those on the "hitlist" took it even, cut down their forest, their security for leaner times. The tone of the conversation, the bitterness and frustration hidden behind the words is an ample indication of what is going on in the idyllic landscape bathing in the golden rays of the setting sun. This is a region of Finland where farms have traditionally been larger and wealthier than elsewhere in the country and the climatic conditions are the most suited for the cultivation of grains, vegetables, sugar beets and apples. This is not the first time that "land has been taken" in the history of the island. It is just that the previous appropriation, the so called "colonisation process", to accommodate refugee families (2) after the Winter and Continuation Wars was perhaps easier to comprehend, on a moral level. Here people are proud of their history and it is seen in the landscape in prim farmhouses, well-groomed gardens, healthy, green fields punctuated by islands of forests with the glittering sea just beyond the tree tops. This is a beautiful place by all accounts, a place where people have their roots firmly planted, their dreams and wishes invested in the fields and in the forests, now brutally wrested from them, because that undefined entity, Natura, wants it. It almost conjures up an image of a beast, an island dinosaur, greedily grazing on both saplings and majestic pine trees, like offerings given to the mighty god, the EU. This God is not content with scattered parcels of forest land, it also wants to safeguard the purity of the billowing fields. From its position in the skies its watching eye observes what its subjects do. It has the sneaky suspicion that some of these subjects aren't filling out the documents, decreed in the royal regulations, in the appropriate way, that some are working in a way which damages the purity of the land. So it sends out its inspectors, with tape measures, scales, handbooks and testing equipment. They try to enter the prim farm houses, even hope for the typical gesture of local hospitality: a cup of coffee and a sandwich. These subjects have their own way of putting up a fight, of trying to hold onto to the land, plant their feet as deeply as they can into its fertile soil and not allow these outsiders, the 'foreign' into the sanctity of the what they cherish the most: the home. (Field diary 30.05.02)

Although this may sound like an account from a fairy tale book or some obscure rural legend, the main story line surfaced in conversations I had with farmers living in an idyllic corner of south west Finland. During a year long field work period I entered the lives of these individuals struggling to hold on to a way of life becoming ever more restricted in the "narrowing space" of what constitutes farming in Finland today. This fable truly has a moral undercurrent which can be fully grasped only if we look at the symbolic and historical texts that lie behind these statements of resistance and the expressions of distress that these squeezed life conditions give rise to. Finnish farmers have witnessed a decline of farming in Finland in the years following European Union membership characterised by rising production costs, plunging production prices and changes in the grant system making it increasingly difficult for small holder farmers to survive in a system based on a market-based model of profits and efficacy.

The sense of distress felt by farmers is born out of the disenfranchisement brought about through the process of "bureaucrats in Brussels" viewing rural landscapes as a de-spatialised cultural concept (GRAY J. 2000, CREED G. - CHING B. 1997), as something "out there" to be controlled, rather than as a lived reality (JACKSON M. 1996). To the farmers the meaning of the landscape comes from the practical engagement they have with it over generations and the deep-seated emotional stake they have in its maintenance. Farmers also express worry over their dependence on an agricultural grant system that they cannot control. It is a system based on a perception of productivity that is at odds with farmers' concept of "good farming practice" and one that reserves itself the right to place economic sanctions on individuals thought to misuse arable land. It appropriates land as a means of protecting the environment. Farmers are subject to the surveillance activities of the national and EU level inspectors (here I mean the anonymous people within the bureaucracy who are responsible for the development of the Common Agricultural Policy) represented both by bureaucrats physically carrying out inspections on the farms and by EU-wide surveillance activities through satellite imaging (3). Farmer's discourse about "the bureaucrats controlling their lives in Brussels" serves as a metaphorical framework for expressing feelings of uncertainty about the future and fears about losing their means of livelihood and, thus, also their homes.

This paper explores the sense of uncertainty and distress felt by farmers through their discourse on the control over farming practices enacted by the European Union. I ask what are the central values of farming life that are under threat. What is going on between the main actors; the farmers and the "controlling bureaucrats"? How is the moral clash regarding "good farming practice" connected to these symbols? I argue that farmer's experiences of surveillance and control of farming, which has followed in the wake of Finland joining the European Union, and their sense of distress, are directly linked to changing perceptions of agricultural production. As rural landscapes become de-spatialised, emptied of the meanings connected to life-as-lived, farmers increasingly feel that their knowledge and practices are not respected. Despite the pressures they face in the present situation, farmers remain in place. By enduring and silently living through these difficulties, they create their own forms of resistance that incorporate uncertainty into the web of their lives in a manner that makes it possible for them to cope with their changing situation in life.

I begin by briefly describing the social context of farming in Finland from the post-war years until the present day situation, tracing the historical background of the development of the Finnish welfare state and the rapid urbanisation process that unfolded alongside it. Second I define the central concepts used in this paper; distress, risk, and uncertainty. This is followed by a presentation of ethnographic data in the form of interview excerpts used to illustrate farmers' views of surveillance, control and bureaucracy.

The Social and Historical Context of Farming

When I asked my informants when they felt the village was most "alive" they remembered the 1950's when local farms expanded and the mechanisation of farming was at its peak. People had not yet started moving to the cities and basic services were available like shops, schools, post offices, black smiths and tailors. The years following the Winter and Continuation Wars (1944 and onwards) were a time of reconstruction, hope and enthusiasm over the common project of re-building the nation. The settlement and land reform activities of post-war rural Finland were extremely significant milestones in Finnish recent history. A tenth of the Finnish population had to be resettled on land either donated by the government or colonised from large land owners, which turned Finnish agriculture into a mode of livelihood primarily based on small holdings (4). Finland was the only OECD member state where small holding farming was practiced on a large scale (ALESTALO M. 1980: 117). The most common form of agriculture was dairy farming combined with forestry, the exception being southern Finland where grains and sugar beet production was more predominant. Small holdings consisted of both arable and forest land (GRANBERG L. 1992: 53-54). Forest ownership, in the context of Finland is an integral part of farming in Finland and is seen as an important form of investment, a kind of farm-based savings account to be used in leaner times for vital investments connected to the maintenance of the farm. Forestry activities shaped the structure of Finnish agriculture at a time when Finnish export in wood was a significant source of income for a government burdened with war payments (5). In the west and south of the country most forests are privately owned and many forest owners today live in the urban centres but retain country cottages.

The 1950's was also a time period characterised by major structural changes in farming and forestry due to mechanisation; use of fertilisers, pesticides and new, more effective species that increased yields; industrialisation, and; the construction of the welfare state which offered educational opportunities and service sector jobs. At this time over a third of the labour force worked within agriculture and forestry, a situation that the other Nordic countries experienced in 1930 (GRANBERG L. 1992: 58). Prior to the Winter and Continuation wars Finland was a 'peasant state' and the welfare state project made a late breakthrough from the 40's onward as a result (GRANBERG L. 1999: 315). A shift in focus has occurred in agricultural policy making since the 50s and onwards. The policy climate has moved from settlement activities to income policy. When the old peasant society dissolved a new dependence on governmental activities was created. The impact of agrarian interests encouraged the development of universal coverage of social insurance to include entrepreneurs and farmers who were not wage earners in the technical sense (GRANBERG L. 1999: 313). In the second half of the 1960s a migration wave from the rural areas to the growth centres of the south and industries in Sweden cajoled the youth to leave the countryside and join the ranks of the wage earners. Many women left to educate themselves and men joined the rapidly growing construction sector. During this same time period and continuing into the 1970's the government started curtailing agricultural production, removing the heavy subsidising of small holdings, "packaging of fields" (6) and also integrating farmers into the national income structure. The number of farms decreased with a third between the years 1964 and 1980. The change in policy climate has been drastic and rapid. In a period of twenty years the welfare state went from supporting small holders to stringent regulatory measures to force them out of production and to expand the scale and production capacity of Finnish farms (*ibidem*: 57).

The development of new forms of livelihood in the rural areas and specialisation of production has been characteristic from the 1980's onward as well as the tendency for farmers to turn to part-time farming and supplement their income through especially women's off-farm wage labour. Public sector jobs, also in the rural areas, were created as a result of the growth of the welfare state (*ibidem*: 59). Rigorous policies to curb agricultural production were in continuous use in the 1990s which weakened farmers' financial security and increased their sense of vulnerability, deepening further in 1995 when Finland joined the European Union. The situation has been particularly grave in the southern parts of the country where production prices dropped drastically. The number of farms in the municipalities under study has decreased by 25-35% since 1995 (Mela 2004).

Farming is in a vicious cycle of subsidies which it is hard to break out of. The cost of land is constantly rising, making it ever more difficult for young farmers to inherit. Farmers try to increase their income by increasing their yields through the use of more fertilisers, leading to a growing environmental problem and, with it, a growing need for subsidies and regulations to protect the environment (Granberg L. 1992: 61). With its peripheral location, on a European scale, and harsh climatic conditions affecting the size of yields, it is impossible for Finland to compete with the cheap, mass produced agricultural products of South and Central Europe. It is little wonder that Finnish farmers are concerned about their future and embittered over the control regimes they have been placed under and the lack of political leverage they feel they have in influencing the outcome of EU level negotiations. Farmers feel that the government, including the agrarian party, has betrayed them by supporting European Union membership, nor do they defend farmers' right to produce in a morally acceptable way. Recent changes in the grant system of the Common agricultural Policy (Cap) has meant that farmers are no longer compensated for their work input through the price of the product, but, rather through the number of hectares under cultivation or let to lie fallow to protect the environment (7).

One cannot judge the outcomes of negotiations between the government of Finland and the EU commission, nor how long the decided upon regulations will apply.

Dealing with Distress

Farmers are presently faced with a form of unpredictability different from what characterises farming in general – that of the whims of the climatic conditions – because it is controlled by decision makers beyond the boundaries of the Finnish nation and by national decision makers that, farmers feel, have betrayed them and their way of life. Not knowing the future, causes distress, which locally is expressed as worry, anxiety, sorrow and enduring silently. Bearing suffering is what I understand as an idiom of distress. It is a culturally and socially constructed way of expressing, explaining and identifying discomfort or anxiety, a way of understanding and being in the world (NICHTER M. 1981, PARSONS C. D. F. 1984, PARSONS C. D. F. - WAKELEY P. 1991). It is intimately connected to what Arthur Kleinman (has termed local moral worlds, in other words, what matters most and that which threatens the things that are at stake for individuals. What matters most points to what is dangerous because different social constructions of the human condition make people's life worlds change The infrapolitics of everyday social life is affected by political, social and cultural transformation happening beyond the local sphere, but it is at the micro level that the moral engages and inspires people to act (KLEINMAN A. 1999: 29). To Kleinman, suffering is social in a number of senses; firstly in the interindividual mode by having an effect on social relationships; secondly, as a collective experience as a triangulation of cultural meanings, collective behaviour and subjective responses; and lastly, by being reduced and objectified by professional discourses into bureaucratic categories (*ibidem*: 32-33).

Farmers seldom express their suffering verbally other than as criticism directed towards the European Union and talk on the central values of farming life. I heard many discussions around country house kitchen tables about the memories of hard labour involved in building drainage pipes, clearing the forest or harvesting work carried out around the clock. Farmers have been socialised into working hard since childhood and they expect an equally high working morale from their own children. So, how do they deal with this uncertainty of an unforeseen inspection or financial insecurity? I posit that distress is not only an issue of passively being in the world, but also of adjusting to life conditions that make it burdensome and challenging to live. To me it can also be understood as an adjustment style (RADLEY A. 1989, 1994, BURY M. 1991), a life pattern that is intertwined with the personal biography. As such, it is about social performance, actively engaging with the surrounding world, producing on the land and maintaining the land. The ethos of production is part of a farmer's backbone, a habitual stance towards life. It is the meaning of life, especially in a culture characterised by a "cult of work" (APO S. - EHRNROOTH J. 1996) and it is about the historical memory of the necessity of food security in the post-war years. Individuals tend to devise ways of making sense of the unexpected in many different contexts and localities from the witchcraft practices of the Azande (EVANS-PRITCHARD E. E. 1937) to the Ugandan farmers studied by Susan Reynolds Whyte (WHYTE S. 1997). They have a pragmatic stance towards life and seek to deal with uncertainty, to create some form of safety net to protect them from a 'precarious and perilous' world, rather than helplessly accept the facts (DEWEY J. 1957 [1922], JACKSON M. 1989: 15).

The idea of risk is, according to Mary Douglas, a central construct of our times (1986). We are obsessed with managing the threat of the unexpected. In an increasingly secularised world control of the unforeseen has shifted into the hands of individual actors, which is particularly prominent in medical discourse. Unexpected events are seen as risk-producing and as something normatively negative (LOCK M. 1998, GIFFORD S. 1986 , FRANKENBERG R. 1993, KAUFERT P. - O'NEIL J. 1993, MARTINEZ R. G. - CHAVEZ L. R. - HUBBEL F. A. 1997) or disordering (BECKER G. 1997). Associating risk with disorder, danger and threats distances it from an engagement with the things that are at stake (VAIL J. - WHEELOCK J. - HILL M. 1999).

Margaret Lock reminds us that «The break with divinatory practices prevalent before the development of modern science is not complete, because the idea of risk retains not only uncertainty about the future, but also permits the creation of a moral discourse» (LOCK M. 1998: 10). In order to understand how people deal with moral discourses beyond simply that of health risks to include the totality of social experience and moral worlds that people live in, we need to consider the socially mediated, shared cultural meanings that shape people's actions. In the case of farmers of south west Finland the idea of uncertainty is a deeply moral one because at its core lies the clash between "good" farming and "regulation adapted" farming. Their resistance to the new regulations imposed by the EU is about continuing to act, to produce because abandoning the land implies more uncertainty than remaining on it. Leaving is a contingent act because it is a moral breach against the legacy left to them by their ancestors - land requires continuity. For most farmers it is the only job they know how to do and for those near retirement age (50 years and older) the options are restricted in terms of finding other employment. "Good" farming makes sense because it respects the knowledge of past generations and it is embedded in local micro environments. Leaving fields to lie fallow and following other environmental measures, being forced to fill out complicated grant application forms and being subjected to inspection of their work is senseless, according to farmers.

What lies at the core of this clash is differing concepts of knowledge and land use. The practice of de-spatialisation of rural landscapes, which is part of the process of bureaucratic control, makes the forests and the fields of the south west into objects of spectator knowledge (DEWEY J. 1957 [1922]). They become phenomena to be viewed, as objects of distanced reflexive knowledge, rather than places moulded through purposive action and lived realities (JACKSON M. 1996). The absurd regulations of the EU and the burdensome bureaucracy involved will eventually cause the system to fall apart by itself, farmers reason. This is their hope for the future and their belief in the possibility of improvement. Spectator knowledge is based on being and understanding reality from the stand point of given truths. Practice based knowledge, on the other hand, deals with the changing, the particular, the contingent, the unexpected (DEWEY J. 1957 [1922]). Although most farmers in the south west are educated as either agronomists or agrologists (8), much of the knowledge they base their farming practices on is of a practical nature. It is a matter of combining knowledge on the suitability of crops for the type of land you have, knowing when to sow and harvest, engaging in preventive practices to minimise the spread of weeds and plant pests, predicting what types of crops are most likely to fetch a high price on the market. It is a complicated web of taking chances, using available resources, making investments and pure luck. The practice of living with uncertainty is a form of knowledge one can only get from experience and from oral information passed down from one generation to the next. Land to a producer is invested with so much more that just financial means. It contains the memories and knowledge of past generations, memories of the own labour put into it, love, caring and concern, skills that are particular to the locality of the land. To a "controlling bureaucrat" the land is viewed as a production unit meant to produce maximum yields and to be cultivated according to general, EU wide regulations and concepts of rurality.

The Common Agricultural Policy created a morally charged image of rurality linking material production and moral reproduction. John Gray explains that in the era of rural fundamentalism within the Common Agricultural policy «Family farming sustains not just rural society, but society as whole characterised by the ideal of stability, justice and equality» (GRAY J. 2000: 60). Specific mechanisms for preserving rural localities were implemented such as the problem of overproduction leading to decreasing the number of people engaged in farming, counter acting low income levels in the farming sector, price support schemes and providing improvement and development grants. The result of the agricultural policies of the 1990s has lead to rurality being separated from agriculture. A shift occurs from agricultural to rural development policy where rural space no longer is primarily for agricultural production, but a location for consumption and, thus, the importance of farming has become marginalised in rural regions (GRAY J. 2000: 61-68).

Enduring Injustice

I will start with an interview excerpt of Christian, a man in his early forties whose father was a small holder farmer and left him with a farm of 50 hectares (arable and forest land). He talks about the appropriation of his forest which was on the "hitlist" and his reasoning about how local people deal with the moral dilemma of being dependent on an entity far removed from the context of their every day life, the European Union. He explains to me what he thinks of the EU administered environmental protection programme Natura 2000. He answers in a neutral tone, punctuated, at times, by a tone of incredulity:

> «The idea is good and one should protect nature. It's not an issue of that. There is a lot of good with it, but they could have done it differently. First they should have gone to the landowners and told them that this is what you have that is valuable, a few years earlier and tell them they are interested in buying that area of land and then start discussing how this will be done. Instead of the way it happened now. It came to the municipality. [...] It went via the municipality or was put up on the bulletin board there that my forest would be taken. It didn't even come to me at my home. [...] They should have discxussed with the land and forest owners. Now they (the landowners) became afraid of what this was all about. Then they took it even. They cut down their forest, most of them or many who had anything to cut. [...] I think the main thing for Natura was to get the hectares. There came demands from the EU to the government of Finland that the total areas of Finland were to be certain percentages. And then the most important was that they got the hectares. Now it's like this that the government has very many hectares of its own forest. They should have started picking from there first, that which is worth saving, that they own themselves. And then they would have gone out and picked from private people and done it in a neater way. None of this bureaucrat business, this authority business» (Christian 05.06.02).

Christian did not bother to protest although the government five years back took 14 hectares of his land because “there were some protected flowers in the forest”. Nor did he resort to any drastic measures. He removed a few trees that were overgrown and left the rest because they were too small to fell. When I ask him if he considered protesting against the decision he replies in a matter-of-fact voice that it is pointless to start processing against the government because they will take the forest from him anyway and, in the meantime, he can do nothing with it. I ask if he later received any explanation as to why the landowners on the “hitlist” did not receive any information personally from the government, to their own homes about the appropriation decision. To this Christian laconically comments that;

> «The government does not need to explain why. The government is a person who does not need to apologise. At that time there were many debates in the paper. Now it’s silent. Now it’s not that important. They have not done anything with the forests. Actually the government couldn’t give a damn about the forests, but just wanted to show the EU that they could amass the hectares. They are like little kids looking up to those that decide and want to please them, but this is no new thing. This was taking place already at the time of the Swedish colonisation» (Field diary 05.09.03).

Christian confirms the idea that local farmers have a tendency to accept without protest. He does not think farmers want to organise themselves to oppose the regulations;

> «Because it is so easy to buy people and this is what EU is doing now all the time. Why would you oppose something that you get paid for? Nor does the dog bite the hand that feeds it. It is EU that is now feeding the farmers».

Buying people is facilitated by the carelessness and indifference, a kind of apathy that has affected farmers who have struggled through a multitude of policy changes within a short span of recent history (see section below). The loathing of authority has its roots in an age-old lauding of the self-sufficient and free farmer, which is now constantly in the line of fire as Finnish agriculture has entered the EU era. In Finland a strong work ethic is central to people’s notion of self and people are measured against the quality and quantity of the work they do (ROBERTS F. 1982, 1989, SILVASTI T. 2001). It is not uncommon for farmers to feel that they do not want to be dependent on the state, like the unemployed or social welfare receivers in the cities. But they are undeniably caught in a moral dilemma; they do not want to be dependent on a system beyond their control, but cannot survive on the income they make in farming, not even with the aid of subsidies. Controlling bureaucrats used to live close to the producers. They were national decision makers and negotiators who presently cooperate with bureaucrats and decision makers governing at both a geographical and moral distance from the Finnish farmer.

Christian's consternation over the government's need to please and obey the European Union, can, as he himself mentions, be traced back to a history of conquest. (please refer to the section below) An array of themes emerge in the sarcastically bitter story of Christian, but the main point is the conflict caused by a difference in interests and, above all, experience of acting with the landscape and differing concepts of land use and nature protection. These land and forest owners are the landscape that they are being demanded to give up. So, in effect, giving up land is giving up part of yourself and your history.

Non-Recognition of Practice Based Knowledge

Christian calls for an open discussion between landowners and the government as opposed to the impersonal and, he deems, underhanded way the information was communicated to him. The government was going to chop off a piece of his home, his inheritance and could not even tell it to him face-to-face. The manner of communication increased the sense of distance between those in control and those forced to subjugate themselves to the will of the EU. The whole issue of inspections, of the distant gaze of the bureaucrats is about the invasion of the home and also an invasion of bodies through the work conducted in the home, cultivating land, tending to forests.

So, why this reference to the value of the land in the interview excerpt? Landowners want recognition of the work and care they have put into maintaining the forest and the landscape, in general. The forests and the fields look the way they do because they have been moulded into that shape by the actions of landowners and it is a constant process of care. The landscape has to be maintained and nurtured to prevent Nature from encroaching on it. This value is also inscribed with the work of generations past and, as such, represents an important ancestral heritage. Forests are called reserve banks, pruned and tidied to last for generations, as a legacy for your children and as a source of income if one should need to invest to improve the productivity of the farm. In the past, forest income enabled farmers to mechanise agriculture. In the current situation of rising production costs and falling product prices, as well as a rising price of land, income generation gains an increasingly important role. Financial security is vital in a situation of growing uncertainty about the future. Forests provide local people with many other goods like fire wood, construction materials, berries, mushrooms and meat from hunting as well as a production site for home made vodka. These gathering activities are tied to both a cultural heritage of being “forest people” who view the forest as a source of safety, peace and sacredness (9) and to the idea of self-sufficiency (10).

Uncertainty about the future and the vulnerability caused by government control causes fear and fear, in turn, causes distress. Some locals on the “hitlist” decided to take to drastic measures and destroy what they had built up. It was their only way of protesting against a system they felt was unjust. The irony of the whole situation is that senseless and inexplicable demonstrations of power and control caused destruction instead of protection. Some landowners destroyed nature because it was wrested from them. They felt that their concept of nature protection was neither recognised nor respected (11). Local people also question how long the appropriated land will remain as protected areas or what the government will actually do with the areas. They suspect that before long the project will be abandoned and perhaps the land will be sold off to strangers or investors who lack an emotional engagement with the land.

Christian’s demands for neatness in the manner of appropriation points to a need for respecting what is private and part of the home. The farmers I interviewed see the home in terms of a totality, an unbroken whole or wholeness consisting of the buildings, garden, fields and forests of a farm. It is both a place to live, to live out social relations and a place of work (12).

Bureaucracy and Control

The freedom and autonomy of the Finnish farmer is part of an ancient cultural script of managing on your own, of being self-sufficient, of practicing self-control and of the cult of work (13) (Apo S. - Ehrnrooth J. 1996: 31). The most commonly mentioned positive feature of farming as a profession is freedom. Another local farmer, Rikard, who has 150 hectares under cultivation (100 hectares rented land and 50 of his own land) talks about the loss of this freedom because of increased control and demands of compliance;

> «What has driven us even more into the ground has been since EU membership. Now we no longer are independent. We are totally dependent on our subsidies. Half of my income comes through subsidies. It is not motivating to produce any more. The ones who are effective and try to produce more and of better quality do not gain anything from it. You often just have higher costs. We are reaching a limit where so called pseudo-farming is entering

> the system. One is not as exact any more, people are careless and do not invest an input in the same way (as before) [...] Many farmers make their cultivation plans based on what they get subsidies for and not on what they can produce of high quality. That is what makes it less interesting to be a farmer today. We are constantly watched, we constantly have to write what we are doing all the time and there are lots of regulations. I find that we somehow have the same system you had in Russia before.(How does it feel to be watched all the time?) It feels unpleasant. You find it is strange that you can't work freely and care for your farm in the best possible way without constantly submitting reports on what you are doing. Dependence on a subsidy is not motivating. [...] You have to accept the system if you want to be a farmer. If you don't accept it you have to stop immediately. There are no choices. [...] We are members of EU and totally dependent on them. It is Brussels that governs us» (Rikard 08.11.02).

His worry about carelessness due to a lack of motivation, previously based on the desire to produce a lot (of grains, produce) and of high quality, relates back to the idea of untidiness. A tidy landscape communicates to viewers a vision of a moral order and bears witness to the fact that the individuals who work the land are decent and hard working. A tidy landscape is invested with emotional value and the memory of physical labour.

Rikard's comment on how the regulated system of farming today reminds him of the Kolchos system of the Sovjet era indicates a fear of the eastern threat. The territory of Finland has been invaded and its people subjugated to the regulations and decrees of invading powers (14). This has happened in very recent history at the time of the Winter and Continuation Wars when the Sovjetunion threatened to, once again, take over Finland. A small country fought a giant and won. It is a moral master narrative that Finns seldom forget. This also implies that we are a people used to bearing suffering, to endure in silence. But these sacrifices have produced something of great value – the national home, the independent state of Finland.

Some farmers simply just get on with work although they lack motivation due to the new regulations. Silja believes farmers should get their pay from the work they conduct on their land;

> Silja:«[...] Then there is this thing that they say that it makes no difference what you sow any more…you do not get any money from the fields. Whats the point of doing anything? It is a big thing for Finland that we go and do a thing like this. You should get that salary there from fields and not from a counter [in the welfare office]. The whole idea of it is lost! But it still has to be cared for according to good practice»
>
> Interviewer: «What does it mean?»
>
> Silja: «The same as before. That's what its based on»

> Interviewer: «But if there isn't anything that gives you motivation then where should it come from?»
>
> Silja: «But you have to work anyways. Care for it in the same way as before. According to good practice» (Silja 28.07.03).

Another local couple, Maija and Lasse, who own a large farm of around 100 hectares of arable land explain to me why farmers find farm inspections and the filling out of grant application to be burdensome. Built into the system is a practice which contradicts their moral perception of "good farming practice" and according to which the goal of inspections is to find 'guilty' farmers.

> Lasse: «[…] filling out the forms, bureaucracy […] this is something I shouldn't be dealing with as a farmer. I should be on my field or in the barn working. Whether I have filled in [the forms] in the right way and whether it follows what I have done outside [on the fields] and additionally it should follow the regulations».
>
> Maija: «And then there is this that even though you haven't done anything consciously in another way than what is required in the regulations you are punished for it. This is a heavy thing«
>
> Interviewer: «What about the inspections?»
>
> Lasse: «It depends a bit on the grant type, but its about five or ten percent of farms that are inspected. [...] If you have a farm that has done some kind of mistake a year ago then you are blacklisted. Then you are inspected, inspected, inspected».
>
> Maija: «Then it is so cunning this thing about making mistake or doing it in the right way. Here nearby there is a farm that had filled in the papers in such a way that it benefited the EU, but still it wasn't the right way so it had to be corrected and first then you got the grant when he corrected it. These are such small things and so unnecessary. It does not impact positively nor negatively on the end result, but you can be punished and that is very negative, but for the EU it is of no consequence».
>
> Lasse: «The whole system is built up in such a way that in the EU they say that five percent of the farms make some mistakes and if they do not find them [the mistakes] they have done their job poorly. Then the EU comes and inspects our national inspectors. Then they get in trouble and they have to find five percent of mistake makers among our farmers, because that amount is statistically found there in continental Europe. If many mistakes are found there then just as many should be found here in Finland».
>
> Maija: «The Finnish morale is so high»
>
> Lasse: «extremely few [farmers] really try to act irresponsibly. Mistakes happen because this system is so complicated» (Maija and Lasse 25.06.02).

The control system does to make a differentiation between those producers who have misreported with intent and those who have done it by mistake. Honesty is a deeply ingrained virtue in Finnish society and being indirectly accused of cheating is experienced as an insult.

Coping Through Politics

Some farmers develop political means of dealing with the dire conditions of farming today. Roy tells me that because he actively engages in a producers' organisation, which brings him knowledge and the opportunity to meet producers from both Finland and abroad, he has hope for the future and the strength to continue farming (15). He believes that the bad aspects of the system, such as the senseless regulations, will be gradually removed. The opportunity to express opinions, and in this way influence agricultural policy, also is a form of insurance for the future:

> «What helps me is that [...] if some thing is bad you don't have to wait for a very long time for a change to come [...] In many things you can have an idea that it will not last in the long run so I will put up with it as long as it lasts because I know it will be better then [...] It gives me strength to move on. No matter what I stand it a bit better because [I am active in a producers organisation] and in this way I am closer to decision making. What I say carries a bit further» (Roy 23.07.02).

Christian, Rikard, Roy, Silja, Lasse and Maija demonstrate a pragmatic stance towards life in their opinions on the control regime they have been subjected to since European Union membership. They know a country cannot survive without producing its own food and they believe in the solidarity of the Finnish consumer. Finns want to eat pure food produced in Finland, they reason.

Engaging Uncertainty

Many producers complain about the binding nature of their work. They seldom have holidays or visit their relatives and friends. Although many of them find their work is senseless, due to the low economic compensation they receive for it, they stay in place (16). As one of the ethnographic examples shows, farmers in the area of my field study do not actively protest against the appropriation and surveillance activities. They live with the constant risk of being inspected or having their land taken, but stay on the land. This idea of enduring distress and the anxiety caused by an uncertain future is something that I want to link directly with what I term as purposive suffering, "good" suffering. By patiently enduring difficult times in life farmers' produce continuity. They have through the ages suffered in their own way and seen this suffering as part of their life. Life in harsh weather conditions, where large parts of the arable land has been cleared from the forest has required many sacrifices that have produced concrete results. It has also required certain forms of risk management in the form of investments and savings. For farmers it is natural to think that the importance of producing food makes their suffering meaningful, valuable and honourable. It is a form of suffering the produces a "good" landscape, as opposed to a de-spatialised, objectified landscape characteristic of the EU perspective. The production of "good farming practice" is mainly about social performance. It is not theorised or even discussed that much. It is just done through engaged practice and it is communicated among farmers through action, a knowing-by-doing.

Concepts of risk assume that contingency is a threat to individual experience or social order, but if we broaden our scope to consider life as a whole, as a web of social relations and performances we will notice that individual actors and local communities engage contingency as a normatively neutral aspect of life, belonging to the idea of life as lived. Individuals engage with indeterminacies as a way of indicating their relation to others and the world (WHYTE S. 1997, MALABY T. 2002). Similarly, enduring the uncertainties of farming life, the whims of nature, price fluctuations and, now the shifting agricultural grant policies of the European Union is embedded in the web of life for farmers. Farmers devise their own ways of making sense of the unexpected by being actors that engage contingency as a part of the totality of life.

Notes

(1) NATURA 2000 is the environmental programme of the European Union whose main goal is to create the European ecological network (of special areas of conservation), and to integrate nature protection requirements into other EU policies such as agriculture, regional development and transport. It includes policies to prevent the destruction of natural habitats and landscapes. (European Commission 2004)

(2) After the Winter War (1939-1940) and the Continuation War (1941-1944) local families were required to give up land to the refugees. By making the land into a commercial venture landowners could avoid relinquishing land. Some of the first extensive apple orchards were established on the island as a result.

(3) The practice of satellite imaging and farm inspections was introduced in Finland as a result of European Union membership. Inspections were carried out on a minimal scale before when farmers' income was based on selling their produce (it was integrated into the price of the product). The compensation system changed with European Union membership shifting to grants being based on the number of hectares under cultivation and/or number of fields left to lie fallow for environmental reasons. The regulatory system of the EU stipulates that inspections are a prerequisite for receiving grants (European Commission regulation no. 3508/92 and no. 3887/92).

(4) Settlement activities have been practiced since the 1500's. After the civil war a law was passed to give crofters the right to buy the property they cultivated and a fund was set up to provide

them with loans. A total of 277000 hectares of arable land was lost after the Winter War and Continuation War and 460000 refugees needed land. 40% of this land was appropriated from large land owners. Settlement activities continued until the 60's. A total of 100 000 new small holder farms were established as a result of these resettlement activities (Alestalo M. 1980: 117).

(5) Because Finland sided with the Germans in the last stages of WW II, as a means of regaining land lost to the Russians, they had to pay war payments to the Sovjetunion. According to a peace treaty signed in Paris 1947 between Finland and the U.S.S.R. 300 million gold dollars (amounting to an estimated $570 million in 1952) was to be paid by Finland to the Sovjet Union in reparations. The debt was paid off 1947-52 (Jutikkala E. - Pirinen K. 2002).

(6) The law regarding the packing of fields, i.e. included compensation paid to farmers if they packaged their field either by not producing on it or by planting forest on the land or forced them to pay the government if they cleared field land from the forest.was introduced in 1969 (Korkiasaari J. 2000: 140). During the 1980's additional regulatory measures were taken. A series of 15 laws and regulations were stipulated to curb production, this (*Raivausta on säännetty palkkioin ja rangaistuksin* 2000).

(7) The compensation system consist of many different types of grants; a national grant, the national component of the LFA grant (Less Favoured Nation) and a Cap grant (Common Agricultural Policy) (Ministry of Agriculture 2004).

(8) On the island of Koppars an agricultural school was established in 1906 (Sagalunds Museum 2004). Most local, Swedish-speaking farmers have received their basic education in agriculture from there and some have attended continued education at an agricultural college in the town of Turku.

(9) In pre-Christian times people worshipped sacred groves in the forest. The intimate relationship between people and trees in Finland is still strong (Kovalainen R. - Seppo S. 1997).

(10) Following the First World War the food security dropped to 40% and there was hunger in Finland because grains could not be imported (*Raivausta on säännetty palkkioin ja rangaistuksin* 2000). Food scarcity was also a feature of the later wars years (1939-40 & 1941-44).

(11) The Natura 2000 network in Finland was criticised for a lack of transparency in the preparation stage. In the southwest of Finland the conflict between private landowners and the Government of Finland was the most visible because of the large percentage of private land in the area and the intensity of land use for cultivation. Also arable land was demanded by Natura. Landowners that did complain against the appropriation decisions feared that Natura would compromise agricultural activities in an already hardening competitive climate within agriculture (Oksanen A. 2003).

(12) This has been confirmed by other recent studies conducted on Finnish farmers (Silvasti T. 2001: 272).

(13) The rationality of the Finnish farmer was based on self-control, long-term planning and managing risks. The harsh climatic conditions and short growing season required farmers to have very broad-based knowledge of cultivation, food preservation and building (Apo S. - Ehrnrooth J. 1996: 29-30).

(14) Swedish colonisation of Finnish territory began as early as 500 A.D. and around 800 A.D. it became an important trading route for the Vikings. The first crusades from Sweden to Finland took place in the 1100's. The Swedish control over Finland ended 1808 when Finland became part of the Russian empire until independence in 1917 (Jutikkala E. - Pirinen K. 2002, Allart E. - Stark C. 1981).

(15) Roy is also a board member of the municipal council.

(16) The income structure of farmers has lagged behind the general income development trend in Finland. The reduction of the grant amounts and the market and production cost situation does not promise any improvements in terms of the income level (Ministry of Agriculture and Foresty 2003).

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3.4 *Making continuities. Agency,* presenza *and secular life in Finnish North Karelia*

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Introduction

In my ongoing research in North Karelia (1) (Honkasalo M.-L. 2003a, 2003b, Honkasalo M.-L. - Hinkkanen R. 2001), which is an area of endemic heart disease, the uncertainty of life and how to deal with it was central to everyday life theories about disease. An interesting detail in the fieldwork – one that constitutes this article's main point of departure – included an emic notion of uncertainty; when we were talking about heart disease, some of my informants said that they had not gotten it yet (en ole saanut sitä vielä). The verb "saada" in Finnish means literally to receive or to obtain, so the sentence has a rather strong meaning. To receive, to obtain, a heart attack? It was something we often laughed about – how was it that we received a heart attack? But the inclusion of yet was something that forced me to reflect further on the issue. Did they see illnesses as something that was part and parcel of life, one of its essential constituents? Did they think that disease and illness were somewhere waiting for them? Or were they like objects, lurking somewhere along the path of life, waiting for people to come along and bump into them?

In the contingency of life, the informants' control and safety systems were often embedded in the endemic morbidity and mortality. So many things in society were unsafe, but there was a pattern of certainty which remained almost unchanged through the years, as long as one could remember. At some phase of life, they knew, people became ill, "got" a heart disease and somehow, after a period of time, died from it. The informants knew well the disease and how it progressed, and they had seen so many people suffering and dying from it, that it was accepted as a part of society. This knowledge contributed to the foundation of a certain trust in a kind of biological certainty within their bodies. People knew that this way of dying might also be theirs, and this constituted certain knowledge, secure like blood in the veins. In the midst of life's contingency, this knowledge allowed them to see their end, the manner in which they would die. This is how a model of a good death was created, understood and shared in the cultural context, as a death legitimised within the symbolic universe of one's culture (Berger P.L. - Luckmann T. 1966).

In the context of modern life, extensive social and cultural changes such as the impact of increasing globalisation and, more locally, the problem of uncertainty as an aspect of social experience and the fall of the welfare state have assumed an increasing importance. Illness is an area where fragility and the unpredictability of life are of great importance in ontological, experiential, inter-subjective, social and political senses, often conceptualised as suffering in medical anthropology. In this article, my focus is on how people try to find roots and continuity in the contingency of life, and how they make sense of diseases and death in the context of an emptying social and cultural periphery of Finnish North Karelia (2). Within the theoretical context of la crisi della presenza (de Martino E. 1958, 1959) (3). I shall focus on especially women's agency, on their micro-level attempts to retain a grip and a hold on a world which seems to be falling apart. This holding on seems to happen through adjustment of concepts of time and space accordingly, by acting in everyday life and by memorising the shared past. De Martino has done his work in the ritual context of folk religious life and I try to rethink his theory in order to understand some problems in modern secular (4) life.

Suffering, Contingency, and La crisi della presenza

What has taken place is the fact of losing and losing again ... nobody can really stand this. Last year they took away our post office and now they say they are going to stop the snow ploughing in this area. We get about 80 centimeters of snow every winter, how does one live here (if public services are abandoned)? ... Quite a lot of people die here, every year. Now there are about five houses left, out of tens that used to be inhabited. They die of heart attacks, mostly men. How is it possible? Last Christmas eve a man from the neighborhood died all of a sudden; he suffered from a cerebral hemorrhage. Where do the diseases come from? What are they? Is it so that life is so tight (ahasta) here, especially living alone, and if one is forced into that kind of a situation? One perhaps does not have any other way than to pray, and ask whether He allows suffering, or would He give comfort?" (a woman in a distant village in July 2001, the distance from the village where she lives is 40 kilometers from the municipality's center)

What was this "ahas" (tight/narrow), what did it mean? In the Finnish language, the term has a double meaning. In addition to 'tight/narrow/cramped', in a verb form it has a connotation with anxiety, "ahistaa", to be anxious. I have tried to understand the meaning of "ahas" in relation to its opposite, 'full/rich', 'voluminous', something which is animated, filled with life. Once life was full, indeed, the women (5) said, but it was in the past, when all the villagers were working together, "when we used to do things together", when the village was still whole and thus living. Within one's "full life" bloomed vivacity and animation of being-in-the world. But, it was said, this wholeness existed in the past, it was something that had taken place for a long time ago. The opposite of this 'full' would then be empty, deficient and lacking. And this was the way that the women in the village defined their life when it is "ahasta".

But could not full life also be tight, "ahas", in the meaning of being cramped when there were too many people around, too many children, relatives, too much work and worries? It really was so, the women said, but "ahas" which makes them anxious now is different. Somehow the living space has now diminished, the borders of life are closer to each other, and everything is more limited and strict in that sense. It is precisely this kind of "ahas" which makes them anxious. And now, when half of the population has moved away, the area is emptier and life is more fragile, and thus the possibilities to hold on to one's world are scantier.

Suffering, Passion and Agency

The emic notion "ahas" can be conceptually opened up through the concept of suffering. In the discussions of medical anthropology, suffering is defined by the limits of meaning giving ability, as a situation of enduring something which is unbearable (KLEINMAN A. 1995). It is the dark side of the experience of living at the edge of significance, it is «the result of processes of resistance [...] to the lived flow of experience» (*ibidem*: 174). In the Anglo-Saxon anthropological literature, the concept of suffering has two meanings. It is 1) the phenomenological content of an unbearable situation in local moral worlds and 2) a cultural category that brings into a single space an assemblage of human problems that have their origins and consequences in the devastating social circumstances (KLEINMAN A. - DAS V. - LOCK M. 1996). In the core of suffering is uncertainty of life. Uncertainty is regarded as a more or less ontological content of suffering (KLEINMAN A.

1995: 125-126). Kleinman thinks that people meet uncertainty as “a dark side of experience” in situations with distress, afflictions, and when they are living at the edge of their abilities for social action and defence.

The perspectives which are opened up by the notion of suffering, illuminate the question of the boundaries and ties between the world and the self. In order to avoid the threat of contingency, human beings create bonds with the world and each other in inter-subjective interactions, or in “the works of culture” (OBEYESEKEYRE G. 1985). They can be social structures, such as institutions, but also ties and bundles which human beings create in their everyday interactions. What Kleinman means with suffering, echoes the phenomenological thought of a relationship between the bodily subject and the world as being constituted by intentional threads. We are attached to the world by bundles of threads and so is the world to us (MERLEAU-PONTY M. 1962: XIII). In this article, I focus on the ties and bundles which human beings create.

In the Anglo-Saxon way of understanding suffering, enduring, almost passion are much at issue. I would go further in the theorizing of suffering and think about how are the bundles and ties inter-subjectively shaped and re-shaped in the social situations? How do people act in order to create the ties? Precisely here comes also the question of agency that has to be taken seriously in the context of suffering. People act in order to shape the ties, the grip on the world, and in the situations of threatening uncertainty, make inter-subjective efforts to hold on.

The contribution of Ernesto de Martino’s theory of the *crisi della presenza* (DE MARTINO E. 1958, 1959) and human agency is crucial here. According to de Martino, some natural and structural circumstances may render life extremely precarious and threatening, and in this kind of situation the individual may be in a constant danger of losing her or his presence, la presenza, her or his ability to be an active agent in the world and in history. With the term la crisi della presenza he means a situation which is characterized through a threatening loss of historical agency (6), a risk of not being in the world, or not being here (7). I interpret de Martino and his thinking of agency as having a grip on the world. The grip is not something already there but is made and re-made continuously in the intersubjective interaction in the human world. For de Martino, in a world where one’s presenza is not decided and guaranteed once and for all, one is always in the process of constituting and maintaining oneself as such, while the world itself is entangled with the drama.

De Martino is especially interested in the healing rituals and magic. Instead of sliding into a mere passivity, magic gives vehicles for agency, to intervention, and translation of passivity into activity, thus introducing the shaping power of culture (DE MARTINO E. 1958). I think that for ethnographic research in modern secular society, and for the study of human suffering, the importance of de Martino lies here. For him, to act in the human world, is the core of human existence, its essere-agito-da (DE MARTINO E. 1959: 98). I let him speak for himself: «Esserci nel mondo, cioe mantenersi come presenza individuale nella società e nella storia, significa agire come potenza di decisione e di scelta secondo valori, operando e rioperando sempre di nuovo il mai definitivo distacco dalla immediatezza della mera vitalità naturale e innalzandosi alla vita culturale: lo smarrirsi di questa potenza, il venir meno alla stessa interiore possibilità di esercitarla, costituisce un rischio radicale che rispetto alla presenza impegnata a resistere senza successo all'attentato si configura come esperienza di essere-agito-da, dove l'esser-agito coinvolge la totalità della personalità e delle potenze operative che la fondano e la mantengono» (*ibidem*: 98).

Having conducted ethnographical studies in post-war Southern Italy, and as a historian of religion, de Martino has been interested in understanding folk religion and magic as cultural techniques (8) as a series of means whereby people try to hold on to their fragile world which is falling in to pieces because of adversities of subalternity: poverty, distress, continuous losses and the power of all negative. Trained in the Gramscian way of thinking about culture, de Martino's main interests have been in people's "molecular" ways of maintaining a grip on the world, i.e. of various minimal everyday practices that they invented when the situation seemed hopeless. Some of them were present in the healing or bereavement rituals of the rural countryside; some in magic. The notion of ritual – and magic – includes the task of reconstituting and consolidating the jeopardized presenza; as cultural acts, magic intervenes and reintroduces the shaping power of culture. For de Martino, culture is practicing, doing and acting, and attributing shape and meaning to the flux of life, creating value out of what passes away despite or against us, so that we "risk passing with what passes", «ed invece di far passare cio che passa [...] noi rischiamo di passare con cio che passa» (DE MARTINO E. 1958: 18).

La Crisi *and Agency in Secular Modern Culture*

To apply de Martino's thoughts into a study of contemporary culture in the North opens up important conceptual insights into experiences of life at its margins, or into social conditions where the individuals' grip on their world is loosening. When I have tried to think la crisi della presenza and the ways of having a hold on one's everyday life world, I have needed conceptual widening in terms of intersubjectivity and agency.

In the focus of this article is "minimal agency" of the women in my ethnography. With the term I mean a kind of everyday agency which is ethnographically seemingly small and "minimal" but has intentions of holding on a world in place and ascertaining the grip on it. Women's practical repetetive agency was minimal only in relation to its immense ends – which I think are to keep the own and the family's hold on the world. This reminds the aims of ritual practice which situates the individual in an imagined place and spans historical time.

Women's agency was characterized by repetition, practical quotidian acting, without a visible aim to change anything, rather to maintain the living situation, to hold it as it were. This kind of agency was realized in everyday life, in women's repetetive activities: women were cooking, cleaning, baking, knitting, they were doing something all the time. I have called tentatively "minimal" this kind of agency because it was minimal as perceived ethnographically and in relation to the symbolic ends of the activity. How can this kind of agency be conceptualized as agency at all? In social theory, there is a heavy Weberian burden with an idea of rational agency and choice. The question of agency has been approached mainly as a kind of rational acting aiming at a change of social situation. In my research, the North Karelian mothers had earlier taken part in various social activities within the area, they had build the Finnish civil society together with the men, and they had been engaged in abundant and splendid handicraft in various settings. Now they – the most of my informants were elderly women, mothers in grandmother years – regarded political activity as something that was no longer important in their life, "muttei ollu ennee niihe aika". In their research of everyday routines and actions, some authors have a conceptual perspective of resistance, some call a corresponding agency as "culture of contest" (LOMBARDI SATRIANI L. 1974, SCOTT J. 1985). In my study this kind of conceptualization did not fit because it was difficult for me to find in it contents or themes against authority and other power systems. I can not open up women's agency in my ethnography with any theory of rational choice – nor with its dichotomous opposite, habitual agency with its boring task to maintain the present situation (see e.g. ALEXANDER J. 1982). I insist that there is something more than maintaining that is at issue. Or perhaps to maintain would be better understood in a different, not conservative, meaning.

In Finland, the sociologist Eeva Jokinen (JOKINEN E. 1996) has studied mothers' writing and diary keeping as agency of meaning-making, of significative agency. By writing their diaries, the mothers at home with small children were continuously acting in order to set up their world and simultaneously keeping themselves there. In this article, I am interested in both practical acting and meaning-making, and I would ask which kind of agency is possible when the life situation is defined more or less by enduring the unendurable?

In their phenomenological theory of agency Berger and Luckmann (BERGER P.L. - LUCKMANN T. 1966) write of habitual agency and in somewhat other tradition Giddens (GIDDENS A. 1984) of agency as a stream of actual or contemplated causal interventions of corporeal beings in the on-going process of events-in-the-world. Agency for Giddens is a continuos flow of conduct (GIDDENS A. 1979: 55). Close to this kind of theorizing comes also Bourdieu with his concept of habitus and his purpose to join social structure and individual agency, the bodily and the mental in human action. Also Hannah Arendt's (ARENDT H. 1958) phenomenological theory of agency would offer a possibility for rethinking "minimal agency" as a human agency. Arendt thinks of human agency as something that includes in its core the ability to begin new processes – the kinds of processes that end up with unexpected end products and results. For Arendt, agency is surprising in several ways, it is more grand and immense than the actor her/himself is able to plan. The capacity of human action means that s/he is able to do something which is not planned in advance, something improbable. Arendt refers to intersubjectivity as something that is a precondition and product for agency. In the intersubjective space between human beings arise their specific and worldly interests.

I think that women's agency in North Karelia is to be understood in the context of ahas, in the contested site between remaining, enduring, and attempting to hold on. With the help of de Martino's and Arendt's phenomenological thoughts of agency, my aim is to ask what type of an agency is possible in a fragile world, in a social situation where the society does not hold on its people.

"Minimal Agency". Retaining Grips, Making Continuities

What was "minimally" acted upon? In addition to household activities at home or in groups, such as the type of activities women did when they were picking berries or mushrooms in autumn, or washing carpets during early summers, I would like to call "minimal agency" also the activities within meaning making. Women were memorizing the shared past in the village, they were taking care of the ancestors by carefully cherishing the family pictures on the drawers.

Building Continuities

Attachment to place is central in forming and maintaining coherence of self and identity. According to de Martino, what characterizes la crisi della presenza, are the social circumstances under which the self is not given but must fight tenaciously to establish a presence (see Di Nola A. 1998). To have a hold on one's self means attempting to retain attachments to both places and persons and to balance the two. A central place and symbol in this meaning is home. It lies in the border area, containing both place and family; it is "a localizable idea", as Mary Douglas (Douglas M. 1991) puts it. According to her, «home is a kind of place, which acquires meaning through practice; and as such, it forms part of the everyday process of the creation of the self». Metaphorically, when women in my field work characterized their self, they talked about their home. And, ethnographically, I observed their homes and listened to their stories in search for what was at issue with the problem of the self and identity. The home was a meaningful symbol of a good life, a whole self, which essentially meant the whole life with one's family. But, the tension aroused in the present situation because of the diasporic situation. The children were no longer living in North Karelia but in Southern Finland, and the mothers had the home in the village without possibilities to move.

In women's stories in the village, their self was not, however, a notion referring to an autonomous entity – as it is conceptualized in the contemporary western literature – bounded with one's skin, but something that extended from the narrator towards her family – with the children now living in southern Finland. Rather, the "maternal" self could be understood as something perceived as constituted by the contextual features of social interactions in diverse situations. It included the bonds with the family, now fragmented and scattered around in other, far-away areas of Finland.

Generally, they used to talk in a plural form and referred to themselves as a core person of the family. The family was an unit which gathered up everything and from which everything begun. Sometimes the pronoun we did not extend to include all the children living in Southern Finland or in Sweden and it made the mothers worry, kept them waking during the nights.

The diaspora, tearing apart of the family, also made the home and the motherhood different, somehow strange, anomalous, longing, and lacking, diminished.

The more uncertainty, the more important became the relationships between the relatives and within the families. The villagers had various ways of maintaining ties with their families – with phone calls, holiday visits, photographs, continuous gift-making, memorizing etc. – but there was a threat of loss which was present at all moments. Through these acts, relatives and neighbors were symbolically present, but they were not there. The threat of losing the ties that bound them together was a threat to the unraveling of the self.

The women, especially mothers, also remember in a plural form (PASSERINI L. 1996: 1). I used to sit with the women and look at the family albums, talking and listening to the remembrances. It was a way how families remember (HALBWACHS M. 1981) but it seemed to me that in my field, within the families, the mothers were the actors.

The albums usually contained photos of the common past of the family and the village. The photos touchingly described and in-einender the two bases of identity - the family was mainly pictured in the village landscape, in the home yard. But in addition to the multiple albums, there were, in almost every home, photos of relatives on the armadios, chests of drawers. There were wedding photos of the children, multi-colored school photos of the grandchildren and several black and white photos of the deceased family members, of those men who were killed in the wars. They were there to look at, to be remembered, but they were also taking part in the social life of the family. The persons in the photos were lively present in the discussions, the mothers often referred to their activities. The pictures extended and empowered the family relations and kinship at two levels. The wedding photos, as well as photos of the baptismal ceremories and of grandchildren more generally, tied together the family members. But the pictures of the deceased relatives bound the living members to those in the other world, tuonpuoleinen. For the Greek Orthodox people, the Holy Icon on the home wall is not only a picture but also represents a window to eternity. Only a part of the villagers were Orthodox but I think that in every home the pictures on the walls and on the chests were used to twine ties between the two worlds.

It seems that what described as the ways of acting today, compared to those that are held in their memories, constitutes a difference that opens up a gap for grief.

In the accounts, the older informants turned their intentionality toward the past, toward the time when everything was better because everybody was there. From the perspective of social bonds, I think that what actually took place in remembering, was a process of re-membering . Missing the sons, daughters and grandchildren as well as neighbors was an imaginary re-membering of the social institution of kinship and the social groups that once were there in the village and in the once lively Karelian area.

Making Sense of Illnesses

Within an endemic area, heart disease seems to be something almost structural. It was not unusual to describe the family and the relatives in terms of heart diseases. Almost every one had some kind of personal experience of heart disease, in the form of one's own, or of the older or younger generation. The heart disease was something that was signified as joining the family members together.

It was usual that the informants presented themselves by family photographs. When I came in, we talked about who was who in the photos on the shelf of the drawer. There were often two kinds of photos, the older ones framed with decorated frames, the oldest being from the 40's of 50's; and the new ones, the color pictures of the grandchildren. Both past, present and future of the family was portrayed, as was the position of the informant in the midst.

Some of the persons in the older photos were killed in the war. Some had heart diseases, some something else. The deaths were not necessarily violent, not connected to the war, the diseases made the deaths more commonplace. Once I made an interview with a woman who introduced herself by a photo of her daughter. The woman starts to talk of her own heart disease, then of her daughter's, who died more than twenty years ago. "We have the same disease", she says. They share also the reasons of the disease. They are tied with each other by the disease, it is something that still binds them together. And separates.

The heart diseases run in families, it was often said. Not seldom I heard stories where disease was related to values, especially to hard-working as a core value of Finnish masculinity. The ability to work hard was related to the strength and power of the body - and a consequent heart disease. Thus the way of dying of heart disease was a sign of a good citizenship. In one family the ways of dying shaped a pattern. They were associated with the hot-tempered, strong and sometimes, if boozed, violent men.

"A big man dies in a big way," it was said, and an informant counted several relatives from different generations, all of whom had died of heart attack. All of them in the midst of hard agricultural work, the only exception was an uncle who had died on a Sunday morning when he was helping his wife in the household work, hanging up the curtains on the window. The disease contributed to a shaping of an identity which in this case was a continuation of strength.

The theories which were in use in order to make sense with the heart diseases, were shaped of the elements and discourses of five wide domains. Firstly, a crucial etiology among the informants was uttered as social and historical circumstances, notably the jälkeenjääneisyys, being behind of development, of the North Karelian area. People said that the factors causing the almost endemic morbidity and mortality were past and current social conditions, recurrent wars which had decreased the resistance towards diseases; the life in the border area, "being lotless" (osaton), shortly the themes which described various losses. These reasons for illnesses (generally, because people did not "know" heart diseases) were also uttered in the old folk poems and incantations which were gathered from the area in early 1900th century (HONKASALO M.-L. 2003). 2) one's fate, destiny, was an other theme at issue. People told that the destiny of the North Karelians was to get heart disease and die of it. Interestingly, the current rise of the results in genetic research which an emphasis on genes as an important causal factor behind (every) disease, were translated in the area into discourses of destiny.

Even though continuities were an important theme in the theories, emphasis on alterity was not unknown. Among people who were evacuated from Karelia after the Second World War, I heard an "ethnic" theory. One Russian Orthodox informant who was born in the "Eastern villages" of the municipality and evacuated from there to North Karelia with his family after The Second World War, said to me that "the heart diseases are "diseases of the Finns". Even though he and his family had always been Finns, he made a sharp ethnic distinction here between the Karelians and the Finnish. "We did not know them (heart diseases) there in Porajärvi (the name of the village where he was born and grown). In addition to this "ethnicity" issue he used religion as his theoretical background. According to several Orthodox informants, their religion had three impacts on their proposed lower heart disease morbidity. People I talked to, were not active in the parish but their religiosity was in several ways embedded in their everyday life. One importance of Orthodox religion was the meaning of hope and trust, which they thought was more prominent among them.The second was a more intense social interaction and networking among Orthodox people; this made them healthier. The lively interaction really was the case – in addition to religiosity, it had to do with the social minority position of people. The third was diet. Among orthodox people, fish was used more than among the Lutherans. Previously, every Friday and Wednesday were fasting days; fish was also served on the days of some saints. Currently, this was not the case, perhaps only among the elderly.

de Martino and Modern Society

Back to my starting point of the meanings of certainty and a good death within an endemic area, to the vignette my field research in North Karelia, the de Martinian idea of the meaning-making of illnesses reveals domains of suffering, where the issue is having a hold on one's world. My question has been, is it possible to study modern complex secular society and culture with theoretical instruments that were once developed for research of rural and religious life in Southern Europe? In order to understand the possibilities of secular agency, I started to conceptualize my ethnographic data in terms of de Martino's theory, i.e. by focusing my view on people's micro-level attempts to retain their grip on the world .They seemed to do this by adjusting their concepts of time and space accordingly, by acting in everyday life, by memorizing the shared past, and by creating continuity and rootedness.

According to de Martino (DE MARTINO E. 1955: 21) religion renders politics and techniques for presenza. They do not originate from the Other world but from society and people's historical and social presence within it. With the help of political and technical aims people construct cultural forms and weave their suffering into their history. The aims are dependent on cultural rules which the society recognize and apply. The myths give possibility for fantasy for example in the situations where one is in danger of losing her/his presence. In order to make the myths purposeful, people add to these parts of other myths and rites that perhaps are losing their original religious meaning or that currently, possibly draw their power from totally other institutions, such as work, or, regarding interpretations of illnesses, from biomedicine. The de Martinian concept of agency is loosely rooted in society and tightly in religion and this is the reason why the application of the de Martinian theory into interpretation of current society does not succeed without difficulties.

In social theory, the concept of agency is dichotomous; it refers either to rational agency or, as its opposite, the residual category of habitual agency.

The dichotomy is value-laden, because only the rational acts constitute genuine agency, referring to social change. Also in feminist research, habitual agency is, for the most, portrayed as something repressive with conservative inertia, not having to do with social or cultural innovations. Women are linked with repetition in a broad area of social studies and this is something the feminist studies have tried to problematize (see e.g. FELSKI R. 2000). Behind this link lie several factors, such as the supposed closer connection of women with "biological nature" with its rhythms, with pre-industrial time or, as in Marxist studies of everyday life – with consumption. However, there are scholars in the field of everyday life studies who regard repetetive, habitual acts as creative, having an aim to hold the world in place (see SMITH D. 1987, GARDINER M. 2000). According to Felski, it is a mistake to see habitual acts solely as intrinsically reactionary; repetitions and habitual acts in everyday life constitute an essential part of our embeddedness in everyday life and our existence as social beings. This comes close to Giddens' (GIDDENS A. 1991: 39-40) way of thinking of routine. I think that the point which is closest to de Martino's way of conceptualizing agency is in the following thought of Giddens. Routine, according to Giddens (*ibidem*: 39), helps to «constitute a formed framework for existence by cultivating a sense of 'being', and its separation from non-being, which is elemental to ontological security». Might the relationship of "minimal agency" to ritual be expressed in the parallel symbolic aims and powers?

By habitual acts Berger and Luckmann (BERGER P. L. - LUCKMANN T. 1966: 66-67) point to the grounds of all human activity. By habitualization it is possible to create the first ingredients of new structures, sites and possibilities. Habitualization precedes thus any institutionalization. This is precisely what their predecessors have been thinking; William James (JAMES W. 1950 [1890]: I, 121) has called habit as a source of power of society. According to him: «Habit is the enormous fly-wheel of society., it is the most precarious conservative agent. It alone is what keeps us all within the bounds of ordinance [...]. It alone prevents the hardest and most repulsive walks of life from being deserted by those brought up to tread therein». In the pragmatist tradition, C. S. Peirce takes the furthest step and regards habit as «the logical development of your germinal nature», as a requisite of thinking and learning. Peirce emphasizes that habit and thought shall not be put asunder because they are the two sides of human action. Agency is not some discrete individual actions but a pattern where habit plays the most significant role. (PEIRCE C. S. 1982: 5, 487; see KILPINEN E. 2000).

In all above ways of conceptualizing routine or repetetive agency one thing is missing which is clearly thematized in Arendt's thoughts of agency. Even though pragmatists, such as Peirce and James, write of reflexivity of habitual agency, they do not explicate the content of innovative content of human agency, as does Arendt. For her, natality is the metaphor of this unexpectedness. As in birth, also in agency something which is new comes up like a miracle: "Action has the closest connection with the human condition of natality; the new beginning inherent in birth can make itself in the world only because the newcomer possesses the capacity of beginning something anew, that is, for acting" (ARENDT H. 1958: 9).

The ingredients which the mothers used for the grounds of their minimal agency, originated from their immediate life and world view. The means of holding on to the world were powerful because their significance originated in a well-known, shared and a together interpreted world. In this sense they remind of de Martino's ideas of shared symbols and myths with which people construct new wholes in the threatening situation of crisis della presenza. I think that natality lies in the mothers capacity to shape firm grips of these ingredients of their everyday life. And that social order is coming along also tomorrow, is precisely the unexpected and miracle-like thing for my ethnographer's mind.

Notes

(1) The research project "Expressions of Suffering – Ethnographies of Illness Experience in Contemporary Finnish Contexts" (funded by The Academy of Finland 1999-2004) studies illness experiences and their representations as cultural questions. This interdisciplinary research project that I am in charge of is based on cooperation of altogether nine scholars (see our web page http://medanthro.kaapeli.fi and for more details also HONKASALO M.-L. - UTRIAINEN T. - LEPPO A. eds. 2004).

(2) I conducted my ethnographic field work in North Karelia, in the easternmost part of Finland. It is a social and cultural periphery, constructed by historical layers of political acts. It has always differed from the more affluent parts of the country in terms of non-wealth, unemployment rate etc. – and also morbidity and mortality rates of various illnesses, notably heart diseases and depression but also of violent death. According to some historians (e.g. TURPEINEN O. 1986) and health researchers (KANNISTO V. 1947), people in North Karelia have died earlier than in other parts of the country, as long as there are available reliable statistics. Thus the "eastern excess in mortality" (KOSKINEN S. 1994) – which is about 50% among middle-aged men with respect to mortality in heart diseases, and % in connection with suicide and violent death more generally – is embedded in the "Eastern question" of our country, as I would like to call it. Through centuries, the eastern parts have been more or less influenced by the Russian empire and the western parts have had more intense interaction with Sweden. The numerous repeating wars between the two empires were carried out in the eastern areas of Finland. After the wars, the areas were times ceded to Russia, times to Sweden; in 1809 the whole country was ceded to Russia. Religion was distributed from Russia to the eastern areas in the form of Russian Orthodoxy, and from Sweden to the western areas of Finland first in the form of Roman Catholicism and, later in the 16th century in the Lutheran variation. Depending on

who won the war, often one of the consequences would have been the mass re-baptizing of the population (Björn I. 1991, Hämynen T. 1993). Sometimes the Lutheran Finns were forced to convert to the Orthodox religion, sometimes they did not find any other possibility than to give their consent to the Lutheran church. Several of them fled, and many died. Through such means, continuous wars caused poverty as well as a loss of homes and identities. Consequently, western Finland has developed more in peace and thus has become wealthier, and it still is partly inhabited by a Swedish-speaking minority. Source of livelihood has differentiated historically between East and West. The eastern parts of the country have established agriculture through kaskiviljely... which has not been the case in the western areas. Since centuries, the eastern parts have relied on forest work and agriculture in small farms. Up to the 1960s, Finnish forest industry as well as paper and pulp industry had made use of technology which was based on the semi-manual work of the lumberjacks in the forests. At that time, the North Karelian area was able to support tens of thousands of lumberjacks who were working in the forests during the winter times, and in the small agriculture during the summers. From the beginning of the 1960s, due to technological changes in the machinery of forest work, the economic system, based on a combination of small-scale agriculture and forest work, did not provide enough income for the resident families. A great transforming move was thereby initiated, and from the end of the 1960s, over 40% of the residents of the rural municipalities eventually moved to the town of the local area, or to the cities of the southern and western parts of the country, or to Sweden. Consequently, what followed, can be defined as *diaspora*. This is a term which was introduced already in 1964 by a local teacher and writer, Siiri Mekri, in the local newsletter *Pogostan Sanomat.* She explicitly compares the Jewish diaspora with the present situation of people who "still go on moving to other parts of Finland" (1964: 8). She started to organize a column for people who had moved out of the municipality, collected their writings, poems, and photos from their family reunions and so on. The column became extremely popular. Her way of participating as an active editor of the column was in accordance with how people generally act in diaspora: they maintain memories, images and myths of the original homeland (Safran S. 1991). In the 1960s and 1970s the newsletter contained several stories where North Karelian people living in the southern Finland wrote about their roots and their longing for the "genuine" homeland.

I did my one year-long field work in this emptying area, among people who remained. Their motives were various, some remained because they did not have other alternatives, some had tried work in Southern Finland and had returned. Some wanted to stay. My sample was different from those in the current diaspora studies, where the interest is mainly on (transnational) people who move, are in motion, as refugees, exiles, in search of new identity.

(3) Honkasalo M.-L. - Utriainen T. - Leppo A. eds. 2004, Honkasalo M.-L. - Hinkkanen R. 2002, Honkasalo M.-L. 2003. I studied de Martino's philosophy and anthropology at the University of Rome, La Sapienza, 2002-2003 and become acquainted with the Italian contemporary Demartinian school.

(4) About secularity, see Hervier-Leger D. 2000, Bruce S. (2002).

(5) In this article, I use interviews of elderly villagers, mostly mothers.

(6) The concept of historical agency comes from Italian historicism, notably from Benedetto Croce. As a task for anthropology, historical agency means "historicizing the Other", ie. providing the subaltern classes with the possibility for authorship, and of agency.

(7) de Martino E. 1975 [1958], 3, *il rischio di non esserci*. The other side of *non-esserci* is the state of nothingness, or non-being. The threat of non-being is an essential content of human suffering.

(8) De Martino understands rituals as symbolic practices with the aim to protect people and shelter their *presenza* and agency in the world. Myths are important in this context because with them it is possible to transcend time. For de Martino, religion and magic are the same, *alta e bassa magia*. There are ethnographic grounds for this categorization because Italian rituals in the South are historically layered and contained ingredients from popular religion and Catholisism.

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3.5 *"I never make love without my bra on". Bodily experiences of women with breast cancer*

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Background

Improvements within the field of cancer treatment have meant that the number of women with breast cancer (1) who recover or survive for longer has increased. Some of these women, however, suffer from long-lasting side effects from their treatment, including fatigue, pain and lymphodema, as well as depression, sexual difficulties and emotional distress. Many women feel their breasts are an important part of their body image, and one way in which others can recognise them. A woman may love her breasts or dislike them, but she is rarely neutral (YOUNG I. M. 1990: 189).

Cancer organisations, health care systems and private organisations in Denmark and abroad are involved in cancer rehabilitation programmes. The purpose of these programmes is to re-establish the physical, psychological and socio-cultural competencies (necessary skills and knowledge) of the affected individuals in order to enable them to work and live a normal life again. Cancer rehabilitation covers a wide range of different private and public initiatives, including psycho-social intervention, guidance and supervision, exercises, makeup workshops and a number of recuperative and convalescence schemes. Rehabilitation is a key word in the patient support work undertaken by the Danish Cancer Society. Alongside counselling centres, the Society also established a number of residential rehabilitation courses at different locations in Denmark between 1989 and 2001. Some of these courses focused on women's experiences of their altered bodies and body images (2).

Introduction to the Research

In the present article I draw on empirical findings generated primarily from an ethnographic fieldwork study with participant observation, and from ethnographic interviews at three residential cancer rehabilitation courses (each lasting five or six days) at different locations in Denmark. The first course, entitled “Get along again”, was intended for women with breast cancer. It was held at a Folk High School in the eastern part of Jutland and it was attended by 18 women. The second course was entitled “Spa and Recreation”. This course, for persons with cancer and their relatives, was held at a spa hotel north of Copenhagen. Four out of the seven women who attended this course had breast cancer. The last course was entitled “Body Image”. It was designed for women with cancer and held at a holiday centre in the northern part of Jutland. Fifteen out of the 24 women attending this course had breast cancer. My data also stems from extensive interviews with 25 of the women conducted some two to three months after they attended their respective courses. A small number of the women had had a breast conservation operation, or a so-called a lumpectomy, while the majority had had a radical mastectomy. There were no significant differences between the two groups of women in relation to factors such as age, married status or education.

In terms of structure and content, the rehabilitation interventions offered in connection with the three courses stressed the distinction between the everyday social lives of the women within clearly structured systems of social relations such as family, house, neighbourhood, village, town or city on the one hand, and the rehabilitation interventions seen as ‘not daily life structure’ or ‘anti-structure’ on the other (TURNER V. 1974: 166-167). In terms of structure, the courses took place several miles away from busy cities near a forest, a park or the sea. The women had to leave their families behind and travel for a number of hours by train, bus, ship and/or by car to reach the residential course (many of the women had travelled between five and six hours) (3). Every day the women ate breakfast, lunch and dinner together, and on two of the courses the women shared twin bedrooms. Each course was organised and led by a health professional, be it a social worker, a psychologist or the leader of the patient organisation for women with breast cancer. The course organisers argued that nature (the ocean, trees, flowers, a lake) and special buildings (architecture and history) in themselves have a rehabilitative effect on women who have suffered serious illness, including treatments with long-lasting side effects. In terms of content, the women attended sessions of water gymnastics and floor gymnastics led by a health professional (a physiotherapist or a Mensendick method instructor). Every day and every evening, various seminars were conducted on topics such as the side effects of different treatments, bodily experiences, quality of life, makeup, style and colour, social issues, employment, etc. The content was primarily based on the experiences of the organisers who had all worked with women suffering from cancer for many years as counsellors for the Danish Cancer Society.

Community Spirit and Communitas

Each course began with a presentation round held a few hours after the women had arrived at their destination. The women sat down in a circle in the classroom that they would be using over the course of the next week. The course leaders had moved all the desks out of the way and put tissues within easy reach. They began by introducing themselves and giving some practical information about the course. Each woman then introduced herself, focusing in particular on the story of her illness and her expectations for the course. Many of the women ended their introduction by saying: "I don't think I need to say anything else because you know how I feel. We've all been through the same. We really do understand each other". The other women would look at the speaker, some would nod, others would be tearful, a few would pick up a tissue.

By choosing the same cancer rehabilitation course, by greeting their roommate and having their first meal together with all the other women, they had begun to create a community spirit: "we are all in the same boat" (some women actually used this expression). This community spirit was regenerated many times over every day on the different courses through small gestures including a hand on someone's shoulder, passing someone a tissue or giving someone a hug, and through superfluous utterances such as "we have something in common", "we understand each other". The anthropologist Jean Jackson states in her article that talking between patients with chronic pain often becomes superfluous because the communication had already taken place (JACKSON J. 1994: 218).

According to Turner, we can say that the structure and content of the courses foster the emergence of 'existential or spontaneous communitas': «[...] the direct, immediate, and total confrontation of human identities, which tends to make those experiencing it think of mankind as a homogeneous, unstructured, and free community» (TURNER V. 1974: 169). In the next part of this article, I will show how the existential communitas fostered in this way opened up a social space in which collective stories about bodily experiences and body projects could be produced and reproduced among the women.

Collective Stories about Bodily Experiences and Body Projects

Storytelling had a prominent place on all three courses. During the days and evenings the women produced and reproduced collective stories, often about their own bodily experiences of having had or still having breast cancer, and the different body projects in which they were engaged (such as makeup, clothes and wigs). I call them collective stories to indicate that they are constructed in the communication situations between the women. In the following, I present extracts from two collective stories that were produced between women who had had a mastectomy. I use the term story throughout this section rather than the term narrative, because a 'story' is an experience-near term connected to the women's experiences – everyone can tell stories – while a 'narrative' is an experience-far term associated with academic writings (Wikan U. 2000: 217). To ensure that my empirical findings would be considered relevant for anthropological analysis, I employed the criterion that several of the women spoke about the same subject in similar ways within different contexts.

Conversation 1: Feminine dress for day and night

One evening, during the course entitled "Body Image", I took part in a 'style and colour' event. It was presented by a lady from a 'style and colour' company who had brought along a large number of different coloured scarves. She gave a presentation on dressing in colours that match our hair, eyes and skin colour and in a dress style that matches our body shape. During the presentation, she invited different women to join her on the stage. She put various colourful fancy scarves on the women to determine whether they were a 'summer', 'winter', 'spring' or 'autumn' girl, and she showed them illustrations of different dress styles for different body shapes. During one of the coffee breaks, I listened to three of the women who were having a conversation about colours and styles. They were standing around a small table and had good eye-contact with each other. Below, I quote the last part of their conversation which focused on the way in which a breast amputation had changed the way they dressed and the way they looked at other women:

> «I am more conscious today of wearing nice dresses, skirts instead of jeans for instance, a new blouse with bright colours and so on. I realised tonight that I'm a summer girl, really. I use more makeup than I did before, not only when I go to parties but also when I go shopping. I want to look as normal as possible» says Susan (4) (aged 53). Ann (aged 44) nods her head and continues: «I went to buy a new bra and knickers set just before taking part in this course. I paid more than 125 Euro for a set of 'Mary-Jo' (5) lingerie. When you've lost something you've got to have something else, I think».

Alice (aged 50), who has tears in her eyes, continues: «I understand you both, but I don't do that. I don't feel like putting on a feminine skirt or blouse... or a feminine night dress. I definitely don't want to look at bras, knickers or bikinis, because I think... or rather I know that one day I'll have two breasts again». Alice pauses briefly before continuing, with affection in her voice: «Normally I really do love feminine dresses, especially a nice feminine night dress. I have some in my drawer, but I haven't even touched or looked at them since my operation. Now I just wear a T-shirt to bed and a big sweater during the day» (she is on a waiting list for breast reconstruction by plastic surgery).

Ann responds: «I understand what you mean Alice. But I don't want to go through any more operations. I've had enough of hospitals». She pauses briefly. «But last spring I felt that I couldn't stand to look at other women's breasts any longer. Everywhere I looked, I saw women wearing tight T-shirts and low-cut dresses. You could see their cleavage. They were the lucky ones, while I couldn't get anything to work» she says, pointing to her breast. With a short laugh, she continues: «All those pert, pointy breasts. I didn't realise how much my breasts meant to me before I lost one of them».

Susan ends the short conversation by saying: «Yes, we have to learn to live our lives among women with two perfect breasts».

Conversation 2: Sex wearing a bra, or no sex at all

One evening during the "Get going again" course for women with breast cancer, a female politician and author was invited to talk about: "How to survive with cancer". Her speech touched on the subject of sexuality, and among other things she said: «I never make love without my bra on. It's not up for discussion. It's sex with my bra on or no sex at all». Later that evening, I joined a group of four women who were enjoying a glass of red wine. We sat around a table in a small kitchen. Two of the women had put their wigs on the table. They were making jokes about hot flushes and warm wigs. Suddenly Mary (aged 54) says: «What a woman. She wasn't afraid to share her thoughts and experiences about sexuality with us. I really admire her». She pauses briefly. The others nod, saying «Yes». Mary continues: «I wouldn't dream of keeping my bra on in bed, but I do wear a thin white night dress so my husband can't see anything. The rest is like it was before. I never take my night dress off when we make love, I just lift it up».

Kitty (aged 40) nods and says: «Oh. I do exactly the same. I keep my top on in bed, but not my bra. And I think I wear a top more often now during sex... maybe every time» she says, laughing. «I certainly didn't do that before».

Karen (aged 65) continues: «I have a boyfriend, and we have a sexual relationship. I wear pyjamas, but I never take the top off any more. I definitely wouldn't do that».

Doris (aged 43) reflects: «I kept a T-shirt on in bed at the beginning, you know – while I was having chemo and radiotherapy, but when summer came I took it off. I didn't like... it wasn't because I couldn't deal with my husband seeing me... but, but I felt that emotionally it was very difficult. I felt it was okay from my belly button down» she says, laughing a little, as the other women nod and look intensely at her. «We did have sex… that was important for me... I wanted to be normal... although there was a part of my body that I didn't like. And it was also because my husband wanted to touch other parts of my body» she says, referring to the time when she began to sleep without her T-shirt. «Now we try, but it's so... I cry every time he comes near my scars or the breast I've still got» she says in a trembling voice and with tears in her eyes.

Kitty puts an arm around her and they all sit quietly for a minute or so. Then Karen ends the short conversation on this topic by saying: «I never thought I'd be able to share experiences like these with anybody. It really is a great help to see that we understand each other, that we have similar problems, and most of all that we have to learn how to deal with them» (6).

The existential communitas fostered by, among other things, the various evening events paved the way for the women's conversations on topics of importance to them. In return, the women's use of collective stories and the process of storytelling maintained and strengthened communitas as this utterance from Karen shows: «It really is a great help to see that we understand each other, that we have similar problems… that we have to learn how to deal with them».

When I interviewed some of the women that had attended one of the three courses in their homes a few months later, they often referred to the generated "we understand each other" (communitas), concluding that joining a cancer rehabilitation course had taught them that women with breast cancer have a great deal in common. They repeatedly referred to two things, namely talking and swapping stories, etc. and being together. So communitas opened up a social space where collective stories about bodily experiences and body projects could be produced and reproduced among the women. When I interviewed Alice a few months after her course, she said: «I can't point out a specific moment during the course, or a particular event, and say 'that was the best thing', but being together and talking to all those wonderful women was absolutely fantastic. They showed me that life still has something to offer me. I gained new hope».

Ordering Experiences and Constructing Realities

Stories and the process of storytelling offered a way for the women of ordering experiences and of constructing reality (Bruner J. 1986: 11) and by doing so, the stories and the storytelling in themselves became rehabilitative. The women incorporated bits of the evenings' events, like the speech about not making love without a bra on, into their collective stories. And they used storytelling to organise and explore their new body experiences and their personal experiences, their body projects and their relationships with significant others, first and foremost their husbands or lovers (7). Communitas created a context which enabled the women to lend meaning to and make sense of the extreme difficulties they faced as a result of the total or partial amputation of one or both breasts. I will tentatively suggest that ordering experiences and constructing reality begin with the body: «That is, our understanding of ourselves and the world begins with our reliance on the orderly functioning of our bodies» (Becker G. 1997: 12). In the following section, I will focus on the content of the stories in an effort to understand the collective stories from a 'bodily theoretical perspective'.

The Body as Agent

The women's bodily experiences and body projects became the pivotal point of the collective stories. Take, for instance, the moment when Kitty says: "I keep my top on in bed, but not my bra. And I think I wear a top more often now during sex... maybe every time". I suggest that cultural inscriptions and historical representations quite literally constitute bodies, or body images, and help to produce them as such (Grosz E. 1994: X). In suggesting this, I am concurring with the latest research in the social sciences and humanities, where the body has been transformed from an object to an agent, and where biology is no longer seen as monolithic objectivity (see, for instance, Haraway D. 1991, Csordas T.J. 1994: 3, Grosz E. 1994). The body as agent becomes: «[...] an open materiality, a set of (possibly infinite) tendencies and potentialities which may be developed, yet whose development will necessarily hinder or induce other developments and trajectories» (Grosz E. 1994: 191).

As an open materiality, a woman's body becomes communicative; engaged in ongoing semiotic processes, a signifying and signified body interwoven with and constitutive of systems of meaning and representation (*ibidem*: 18). The women engage in different kinds of body projects such as breast reconstructions, feminine bras, breast prostheses, using more makeup and dressing more colourfully than before their sickness, as part of the rehabilitation process. Bodies act and react, body images are created and recreated, and the body may be said to create culture. The women's utterances within the collective stories can be seen as signs that refer to the way in which they look at their own, and at other women's, bodies. Susan, for instance, ends the first story by indicating that they must learn to live their lives among women with two perfect breasts. The word perfect is interesting, because it refers to a specific cultural understanding of women's breasts.

In Western societies, there is an extreme focus on women's breasts. As far as the woman herself, and others, are concerned her breasts are a daily visible and tangible reminder of her womanhood, a symbol of feminine sexuality and motherhood (Young I. M. 1990: 189). The women's storytelling repeatedly attests to the emotional pain that results from being different, and to the struggle to reduce or eliminate that sense of difference from others (Becker G. 1997: 16). Feminist authors, such as Iris Marion Young, argue that we experience our objectification as a function of the look of the other, and because breasts are seen as the visible sign of a woman's sexuality, the loss of a breast is socially interpreted as a corresponding loss of sexuality (Young I. M. 1990: 189). The women view themselves as being at odds with what others – and they themselves – view as normal and perfect for their gender, age, and circumstances. Plastic surgery also facilitates the realisation of Western societies' phantasmatic breast ideal. The women's preoccupation with their lost breast as something that has to be dealt with, and their decisions to keep their chests hidden etc., make it clear that the sexuality they had recovered was recovered despite their mastectomy rather than through a joint exploration of the new (erotic) possibilities that mastectomy may offer (Weiss G. 1999: 62).

Some women who have undergone a mastectomy suffer a great deal because of these bodily 'inadequacies'. The attainment of 'perfect breasts' through plastic surgery may seem to play into the hands of sexual objectification. But these operations may just as often appear to the women who undergo them as a way of relieving sexual objectification, that is, as a way of drawing attention away from their breasts through their 'normalization' (*ibidem*: 61): «[...] breasts are an inherent bodily attribute subjectively lived and at the same time function as objects, both for men and for women» (Grosz E. 1994: 108).

Bodily Space

From the women's ongoing storytelling, it becomes clear that there is a safety zone outside the body; a bodily space surrounding the subject's body which is crucial for the understanding of bodily experiences and body projects. This bodily safety zone is context-dependent, and it shifts and changes even for individual subjects:

> «[...] it is 'thinner' in some places (for example the extremities, which more readily tolerate body contact than other zones) and 'thicker' in others (which are particularly psychically, socially, and culturally 'privatized'» (GROSZ E. 1994: 79-80).

From the women's utterances it is obvious that their bodily space related not just to the body's surface but also to its surrounding space, which had been incorporated into their bodily experiences. The women considered any intrusion into this bodily space as serious a violation as the penetration of their bodies. The T-shirt, pyjama top or bra were used to denote and protect the border zone, and became the interface between the body surface and the body's surrounding space. This was particularly obvious when Doris described how she felt when her husband touched her body near her scars or the remaining healthy breast. Interestingly, the women in my study only referred to their remaining healthy breast as a potential source of illness, something that may also be affected by cancer.

Summary and Conclusion

In this article I have presented and analysed some of my empirical, ethnographic findings about the bodily experiences and body projects of women with breast cancer who have attended residential cancer rehabilitation courses in Denmark. I have demonstrated how the structure and content of these courses facilitated specific types of social bonds between the women, where communitas was produced and how it opened up a social space in which ongoing collective stories about bodily experiences and body projects could be produced among the women.

The loss of part of their body (one or both breasts, or part of one breast and perhaps a few or many lymph nodes under the arm) had created something like a 'point of no return'. Like Laurence J. Kirmayer, I would suggest that the collective stories I present show that the women's narrative coherence of the self has been shredded, making them more or less unable or unwilling to assimilate unpleasant but crucial facts about their bodies and their selves (Kirmayer L.J. 2000: 155). When Susan says: “I want to look as normal as possible,” or Alice says: “I know that one day I’ll have two breasts again,” they clearly indicate that they long for the time before their breast cancer developed. The social bonds created within the existential communitas helped the women to use collective stories and storytelling to gain new insight into their lives, and gave them new ideas for creating meaning, order and continuity following the unexpected disruption of their lives (the cancer diagnoses, the investigations, the treatments and the side effects).

On the one hand, the women’s bodies were involuntarily marked by the cancer, the investigations, the various types of medical and surgical treatments (incisions, scars, etc.) and the side effects (hair loss, pallor, etc.). On the other hand, their bodies were voluntarily marked by bras, colourful dresses, hairstyles, makeup, prostheses, exercises and habitual patterns of movement. These markings were actively sought out by the women in order to recreate and present their bodies as being appropriate for their cultural requirements (Grosz E. 1994: 142-143). They were not merely ‘technologies of power’ but actively undertaken as ‘technologies of the self ”, meaning that they required the active compliance of the women (Foucault M. 1988: 18).

Through storytelling, the women gave voice to their bodily experiences, their embodied despair and body projects, demonstrating that they strive to be normal; they described the types of body projects that preoccupied them, and their efforts to eliminate ‘the point of no return’. When the women confronted each other during the courses with stories of differences, of how they felt different from others, of how these differences could render social relationships uncomfortable and cumbersome, and of the emotional pain connected with these bodily experiences, they were given an opportunity to stop feeling alone and marginalised which helped them to live with their desire for normalcy and to acknowledge their differences (Becker G. 1997: 16).

Notes

(1) In 1999, 3,776 women in Denmark were diagnosed as having breast cancer.

(2) In 2001 the Danish Cancer Society opened the “Rehabilitation Centre Dallund” on Funen. 20 men and women take part in residential rehabilitation courses every week.

(3) Rehabilitation Centre Dallund is run along the same lines as the courses I have investigated, and the course content is very similar.

(4) Needless to say, all the names of the women in this article are fictional.

(5) 'Mary-Jo' is the name of a company that makes feminine lingerie for women.

(6) My interviews with the women who attended the three residential courses repeatedly return to these issues, especially when talking about 'womanliness' and 'sexuality'.

(7) The small number of women who failed to engage in the community spirit did not contribute to conversations like these, but from my vantage point as an observer they were few and far between.

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4.

On patients and therapists in mental health care
Pacientes y terapeutas en el cuidado de la salud mental
Pazienti e terapeuti nella cura della salute mentale

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4.1 *Writing behind the walls. A walk by the silent side of Italian mental institutions*

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> «[...] noi conosciamo la misura del silenzio. Sappiamo quando è ora di non parlare più. Pochi credono alle nostre parole, quasi nessuno. Pochi sanno che abbiamo un segreto così irrilevante e così vasto che in greco si potrebbe chiamare anima» (MERINI A. 1996: 57)

Introduction

This research is aimed at analysing the experience of commitments to Italian mental hospitals through the inmates' writings, such as diaries, letters, autobiographies and personal documents. They do not only describe the state of things during the period of hospitalization as well as the patients' reactions and answers to this institution, but they also unveil and recall its dynamics. As previously stated in the title, this report is like "a walk on the silent side", on the side of those who, as Basaglia wrote, «are ill mostly because they are outcasts, abandoned by everyone, because they are people with no rights, who are therefore subject to any possible situation» (BASAGLIA F. ed. 1968: 33) (1).

This research being a work in progress, I would like now to present a descriptive analysis of the material I have gathered, by showing some of the multifarious aspects emerging from these records: the way the mental hospitals are described, the dynamics with the medical staff, the relationship between mental institutions and the social and cultural status of writers, the use of drugs and methods of constriction, the way in which subjective real-life experiences of writers are unveiled, the perception of space-time categories within a mental hospital... All materials can be obviously interpreted from a complex and many-sided anthropological point of view, which this research is going to closely examine and analyse. Further reflections will in fact be focused on the following themes: the relationship between writing and strategies of construction of one's self; the relationship between story, personal experience and the mental hospital; the matter, suggested by Byron Good (Good B. 1999 [1994]), on how much and in which way narration can contribute to making sense of events or personal experiences; the question, rased by Arthur Kleinman (Kleinman A. 1988), about the way in which life experiences are organised according to a narrative form. An ethnology of writing shows its value and function within a mental hospital, its role, as underlined by Daniel Fabre, as a space of identity and memory and the methodologies according to which "biographical" aspects are turned into written texts (Fabre D. ed. 1998 [1997]).

Within the field of psychiatry, documents produced by patients were mostly used and studied because of their diagnostic value. These written texts were for long time considered as mere clinical documents and were, as such, of medical interest only. The closing of Italian mental hospitals, the anti-institutional movement, the role played by social sciences – and particularly by anthropology – towards reform movements, its renewed interest in the patient's subjectivity, in his living conditions within the mental hospital and in the dynamics internal to the hospital itself, as well as the growing number of studies about stories of life and about illness narratives, have led to a new sensitivity. This study can be considered as part of this anthropological approach.

The Writings of the Inmates: A General View

This research was focused on the first person written documents of some inmates of Italian mental hospitals, produced during their stay in hospital (text in italics). These were furthermore supported and confirmed by the use of written documents produced after the period of stay within the mental home. The texts written during hospitalization show different features as regards form, origin, place where they were found, preservation and peculiarity to be published (2) and unpublished works (3). The period examined is the 20th century including mostly the beginning of the 1930s in regard to the unpublished works (4) and up to the 1970s for the published ones.

All these materials refer to the framework of mental institutions prior to the reform promoted by the so-called "act 180" (issued on the 13th of May 1978), which ordered the closing of mental hospitals (5) in Italy. According to this old approach, asylums were places of real constriction with «custody-repression tasks based on the most complete limitation of the patients' personal freedom» (Giacanelli F. - Giacanelli Boriosi E. 1982: 17). They were places where the patient was subject to a destructive and dehumanising culture, which could impress the stigma of a deviance due to constitutional weakness and disablement (GOFFMAN E. 1983 [1963]). Franco and Franca Basaglia comment that the approach of a «mental hospital towards an individual who has to become a patient since he is no more tolerated by outside society – due to a break of society rules – is simply that of presuming an sick body and, according to this presumption, seeing it as sick and establishing a relationship without any therapeutic feature, continuing the patient's objectivities, which is in itself a source of regression and illness» (BASAGLIA Franco - BASAGLIA Franca in GOFFMAN E. 1968 [1961]: 12). Basaglia also wrote: «a mental home is a concentration camp, an extermination camp, a prison where the patient does not know either the reason nor the period of his punishment, since he is subject to subjective arbitrary judgements which can vary according to the different psychiatrists, situations and moments. It is an institution where the degree or the phase of one's illness often plays a relative role» (BASAGLIA F. 1963: 12).

The writings of the patients were for a long time thought to be the product of a mental disease and therefore so "counterfeited" by it, as to be unsuitable for any kind of research apart from merely medical-diagnostic research (CAVAZZONI E. 1985). A renewed interest in social sciences as regards the patient's subjectivity not only ruled out the stereotyped conviction that those witnesses could only reflect a world of deviance, but also allowed a different approach to the patients' first person productions, featuring renewed curiosity and awareness.

The writer's disease is certainly reflected in many of these texts, nevertheless all of them, independently from the writer's phase of disease, feature shared feelings, descriptive skills, clearness of presentation, dramatic force and often irony, so as to be turned into an effective evidence of life within a mental hospital, as well as interesting works from a literary point of view.

Due to their formal features, these texts can be divided into real literary genres: autobiographies, diaries, letters, memoirs, and essays (6). Among them, autobiographies are of particular interest; as stated by the historian Augusta Molinari, they are real «autobiographies of the brain», since they represent an attempt to recover one's existence and one's own story through writing (MOLINARI A. 1996). Even if for the most part written under a doctor's inducement – suggesting themes to the patient in order to reconstruct his case history by focusing the story on childhood, diseases, traumas and the family – these texts show a particularly strong introspective element leading the writer to think about his condition and story, by means of a real dialogue with himself. As the narration proceeds all autobiographies show for example an increasingly intimate and sad narrative tone; a detached and "quiet" description of childhood is replaced by a sense of anguish for the appearance of the first symptoms of mental uneasiness and a sense of dismay due to a lack of self control; their inflection becomes now more intimate, feelings are experienced once again through narration and are mediated through personal meditation ratified from a retrospective point of view. These autobiographies become an echo of change and beat the phases of a story, which is most of all "a story of one's brain".

Diaries are probably that kind of literary genre, that which most of all allows us to penetrate the writers' experience of life. Being intimate "writings about one's soul", these texts show a great variety of different features. Some diaries, for example, are only about the period spent within the mental hospital, whereas others are also focused on different phases of life. Their structure varies from a simple succession of events to a more complex organisation, subdividing the text into real themes. They all share a "narration" skill as regards the institution; by taking daily note of any impression, sense of uneasiness, small daily event, but also meditations and memories, these texts do not only reflect the writer's interior life, but also supply lively descriptions of the institution "from the inside", as well as of the relationship with the medical staff and the other patients, the constriction methods, daily life within a mental hospital.

Letters represent, among the written documents produced from the patients, the most frequent kind of writing within the case file preserved in the archives of mental hospitals (7); they are nevertheless not so regular as compared to other documents, since they were linked to a spontaneous need of the patient and not to an institutional procedure. Their presence within the hospital files is justified by the rule of absolute isolation enforced within every mental hospital; the patient's contacts with the external world were severely controlled and the doctors would very often keep back both letters addressed to the patient and those written by him. The texts "selected" by the medical staff were therefore neither sent, nor shown to the patient, but simply registered in medical records. Many of these written documents are calls for help, protest letters, denunciations of ill-treatments suffered or simply thoughts committed to paper, mostly addressed to relatives and friends. There are furthermore letters addressed to the patients' doctor or to the hospital manager. As regards letters as well as autobiographies the patient was mostly led to write under the inducement of his psychiatrist, who was hoping to obtain an interesting document to better understand the symptoms of the disease and to find supporting documentation for the preparation of a case history (CAVAZZONI E. 1985).

Memoirs and essays were also found within these hospital files. The first ones, according to our classification, include narration and stories of particular life experiences, descriptions, memories about small events; essays are on the contrary real treatises on certain themes. In both cases, they seem to take as a model a real literary work, with a title, a layout, an elegant form and the choice of a public as an interlocutor.

The linguistic and stylistic framework of these texts varies from writer to writer, being strongly linked to one's educational level; all these written documents feature a well-considered content, a narrative line, as well as the use of verbs, adjectives and metaphoric images, which are not due to a random choice. Apart from the fact of being more or less familiar with writing, from the variety of tones – which could be solemn or colloquial, ironic or bitter, angry or resigned – and from the different registers, all the patients' works are influenced by the conditioning action of the segregating institution. The writers share their condition as outcasts and isolated people, which is the main incentive to the preparation of these texts. The frequent use of metaphors, similes, and comparisons is an evidence for it; writing becomes a linguistic means to recall feelings made up of other images, as if this was the most appropriate way of representing and telling the story of what one cannot express with simple words.

The guiding thread of all these texts (apart from the essays) consists in the story of one's illness, the estranging experience of being a patient, the uneasiness and the protest against living within a mental hospital; memories, reflections on one's past and present condition, personal history and events unfold on this basis.

Every written document underlines a point of view, a system of values, a kind of narration about life and illness which are instruments to be analysed in order to rejoin the body as biological data to be fed and preserved, with a story and a way of thinking which had once been accurately buried by the psychiatric hospital.

Such an approach towards these documents allows us to examine several aspects of the relationship between patient and institution: the way this is described, the dynamics with the medical staff and other patients, the perception of the self, of space and time within a psychiatric hospital.

Voices from Asylum: The Institution Through the Written Documents

The majority of writings feature a particularly negative image of mental hospitals: they are seen as places where man seems to loose every sense of dignity, and is left in a state of abandonment and indifference. Some diaries read:

> «Who is going to write a novel on the terrible stink of a nurse of a mental hospital?
>
> I am in the street in front of this sad ward and the stink is haunting me: it's the four rooms of tied-up and evil-smelling women. In these bedrooms people scream, cry night and day, and things are being made, which normal fantasy cannot conceive» (ADAMO M. 1991: 26).
>
> «In the dining-hall for breakfast. Nauseating scenes. Impossible to get down, a lump in my throat suffocates me» (NENCIONI I. 1973-1984).
>
> «There are two toilets, but no toilet paper, patients clean themselves with their hands and the flushing system is always clogged, full with excrements. Most of the time the patients' personal hygiene is entrusted with the most efficient ones, who throw pails of cold water on them. The civil department is constantly pervaded by a terrible stink» (MARSIGLI M. L. 1963: 95-96).

Many written documents denounce those processes – described by Goffman – which transform the self within the institution: to trace the story of a patient, to assign numbers, to make a list of a person's possessions to deposit them, to leave one's clothing ... these were in other words all procedures aimed at depriving an individual of his personality in order to let him become an "object" in the hands of the institutional administrative system (GOFFMAN E. 1968 [1961]):

> «In the nursing department, where they bring me, they take everything away from me: clothes, shoes, papers, money and the few jewels I have with me. Even my glasses, without which I cannot read, my wedding ring which I had never parted with all my life, my watch [...] I find myself wrapped up in one of those horrible gowns which should be called sackcloth. Now reduced to the anonymity of the garments of the mental hospital, I will have to search for my self again» (MARSIGLI M. L. 1963: 7).

Evidence deriving from these texts is proven by Franco Basaglia's words: «[within a mental hospital] syndrome has now gained the importance of a judgement of value, of a labelling system which goes beyond the real meaning of the disease itself. A diagnosis has the value of a discriminating judgement» (BASAGLIA F. ed. 1968: 32). One's own identity, story, system of values are by now established by the mental hospital. As Goffman states, the patient's behaviour is accepted and judged only within the boundaries of his disease; in fact, «anything the patient is forced to do, can be considered as part of his treatment or of the health-care goal of a mental hospital; anything the patient could spontaneously do, can be seen as a symptom of his disease and of his state of convalescence» (GOFFMAN E. 1968 [1961]: 228). A brief comment by T.G. – author of one of the autobiographies – «if

I must be mad at all costs, let it be» (T. G. 1901), is an evidence for this, as well as Marsigli's statement:

> «Doctor Aspetti came and sat down in front of me to control me. Did he perhaps believe I wanted to try to deceive him? Hasn't he understood that I am doing my best to look normal, sane? He left me after a few minutes, then he came back to carry out a check, and so he came to understand that I am not ill. When we finished he told me that he is not happy with me and that tomorrow he will do another test. This is the third one I do. What do they want to find if I am sane?» (MARSIGLI M. L. 1963: 40).

Goffman reads furthermore: «If the aim of a hospital is to be able to control the daily situation eliminating complaints and requests on the part of the patient, it will be useful to let the patient understand that the rights he claims and on which he bases his requests, are false, that he is not what he tells to be, and that in fact he is not anything else but a miserable person [...] [the doctors] must be able to prove in detail that their version of the patient's past or character is much more real then his. [...] The patient must "inwardly" convince himself that he has to accept and let people accept the judgement given by the hospital in his regards» (GOFFMAN E. 1968 [1961]: 179-180).

The relationship with the institution and the medical staff varies a lot according to the social and cultural status of patients. People of high social and cultural status have the necessary means to reject and contrast the injustices of the institution, by means of a critical analysis of what they observe. As Basaglia underlines, since they have these instruments they find themselves in a privileged position as compared to the system, because of the fact that they can detach themselves from it and remain critical towards the segregating mechanisms, trying not to be involved and subdued (BASAGLIA F. 1963).

The written documents produced by people of high cultural or social status show their ability to recognize the instruments and symbols of power, to oppose one's own knowledge to that of the psychiatrists, to critically interpret things happening within the institution, keeping a certain self control. The system nevertheless maintains its forcing power, strikes terror, and leads with the passing of time to a progressive submission. Those who do not have adequate economic and social or cultural status are not able to understand and criticize the mechanisms of the institution, or to oppose a system of power, which cannot be modified; one is swallowed by the system, till one becomes submitted to it. An extreme and perhaps more representative example is the relationship with one's doctor: mostly for women patients, his absolute power represents a source of fascination. In a letter to her psychiatrist one of the authors writes as follows:

> «Send me to work as a servant, baby-sitter, cook or dishwasher; because you are for me a God; you can do anything provided that you want to» (CONTI A. 1978: 38).

The coercive measures the patients were forced to submit to, are imposed by means of their social and cultural weaknesses, since the patients had no means to oppose against this systematical destruction:

> «My head is a volcano, notwithstanding my efforts I am not able to find the "reason" of such wickedness» (NENCIONI I. 1973-1984).

Maria Luisa Marsigli, who had a degree and a high social status, is an example: she opposes her knowledge to that of her psychiatrists, she speaks the same language of those who "govern", she selects the instruments and symbols of power, she carries out a critical interpretation of her observations:

> «Sometimes I wonder if the resentment for having failed (since psychiatrists only work on the base of hypotheses) or the fact of being segregated as we are, even if only five hours a day, among monsters, could be the reason leading them to the sadistic desire of punishing their own patients. As a matter of fact their aggressive charge literally seems to force them to punish their non-conformist colleagues also; even prosecutions of the "orthodoxies" against the "heretics" of psychoanalysis are all in all a page of modern inquisitorial history» (MARSIGLI M. L. 1963: 75).

Mental hospitals base their dominion on two antagonistic powers: the patients, on one side, the doctors and nurses on the other. Goffman writes that «the patient is deprived, on one side, of the possibility to know the decision made as regards his destiny [...] this creates a certain distance between the medical staff and the patients, which grants the staff a possibility to control them» (GOFFMAN E. 1968 [1961]: 38-39).

The doctor is the one to prepare a diagnosis, the one having the power to discharge and to put away; his judgement is unpredictable; he is seen like a father and a persecutor at the same time. The attitude of the patients towards their psychiatrist plays on this double aspect: the tone of written documents varies in his regards passing from a reverent and submitted to an aggressive and highly critical approach. All witnesses anyway experience the figure of the doctor as "detached", institutional; many texts observe that the psychiatrist stops within the departments only a few minutes a day. «The presence of a psychiatrist within a mental hospital» as Basaglia writes «has a relative importance. The daily visit to the wards is almost nonexistent: it is reduced to the time necessary to ask the nun or the superintendent a very brief report on the situation; it is enough to sign some forms, symbols of the juridical-bureaucratic personage of the psychiatrist within the hospital, and the visit is over» (BASAGLIA F. 1963: XIV). Still less frequent are the visits of the chief physician, described as real "power displays":

> «It is like when there's an alarm. Nurses and patients try to assume a pose, almost a military one for the first ones and a normal modest one for the second ones. There's that fear which always arises when facing the visit of authorities, which can decide of one's destiny on the base of a word or deed. Here is the Most Illustrious Professor accompanied by his assistant Doctor. A few words can say everything; it is a brief and effective visit, most of all with regards to discipline. Once it is over a perfect silence reigns, souls are pervaded with doubts because of the many orders to be given» (C. P. 1927).
>
> «The chief physician sees us every two or three days (but someone told me he sometimes stopped doing this for an entire month). When he is about to arrive, one has to assume a modest pose and stand on a circle in the living room, just as convicts do.
>
> As soon as the door is opened we have to be silent and look remorseful as if attending church. [...] So it is possible to see sixty mental patients in sixty minutes and the monthly wage is earned» (IOSINI A. 1973-1984).

The real interlocutor, the go-between between the doctor and the mental patient, is the nurse; he watches over the patients, spends the entire day with them, gives them medicines, and he is delegated by the doctor to put into practice all concrete repressive measures. The immediate image of the institution is conveyed through him; he can act as a guardian and accomplice but more often as a warder and executioner. The patients' texts denounce the violence of nurses, expressed through little daily duties: feed the patients, wash them, and give them drugs:

> «*At noon*. I was pushed, drawn, let sit down all of a sudden on a dirty high lavatory-pan, I am subject to the constant trickle of being fed. I regurgitate my wine. A slap. I get up again staggering, [the nurse] gives me a blow with the elbow, the skeleton falls down on the bed. Dirty, stunned, I try to cover myself as best I can. I am cold, I am cold and I am very frightened. I am a mere semblance of a woman, a derelict» (NENCIONI I. 1973-1984).

It is interesting to see how one of the main qualifications required of nurses was that of having a strong constitution to be able to contrast and control the patients by force. The manual Nozioni generali di assistenza ad uso degli infermieri di ospedale psichiatrico states that, among the necessary qualities to be a good nurse, «physical strength and robustness are of particular importance, since they contribute a lot to tranquillity, which is necessary to face certain situations, which one must be able to overcome as best one can» (AMMINISTRAZIONE PROVINCIALE DI AREZZO ed. 1953: 174).

> «The female nurses tied four women to a bed in the nursing department; they now did not have any worry and can do what they like best, knitting or sewing. Many of them are indifferent and insolent, they treat patients as

> beasts. For the most part of them to beat the patients is as easy as to come to agreements with their conscience. I saw one of them, Marina, who crying like a fury (and people say the patients are mad), was dragging Anna by the hair on the floor, then she put her to bed by means of the same system that is by knocking her out for the whole night, and perhaps for the day afterwards. A good case of hospital care» (Marsigli M. L. 1963: 99).

The autobiography of a former patient of the mental hospital of Collegno reads: «When I came back to the ward I remember that the nurse called me to one side and started beating me with a stick and then he sent me to bed and tied me with tapes. I could neither react nor tell it to the Dottoressa, otherwise as soon as she had left it would have been worse. The best thing was to remain silent. While days passed I developed a terror which one cannot imagine [...]» (Autobiografia di un ex ricoverato nel manicomio di Collegno, 1971). Apart from the violent methods – which, instead of being treatment-oriented, became real coercive means aimed at maintaining the system of mental hospitals – the negative effect of drugs, the constriction of the straitjacket and electroshock therapy are to be strongly criticised.

> «Injections have stunned me completely and prostrated me, I cannot even stand on my feet because I am too weak and I feel faint: luckily yesterday evening a good female nurse was moved to pity and listening to my prayers avoided another injection, acting as if she had done it. If she had done it I would not have had the possibility to see Delitala, and Coppola had already gently warned him that it would have been difficult to be able to talk to me, since I was out of my senses. Good systems to make people seem mad, even those who aren't!» (Marsigli M.L. 1963: 46).

> «One cannot be safe from injections and electro-shocks here: if one does something against it, they take you by the neck, legs and arms, twisting you and forcing you to do what you do not want. All for your own good. All because they want to save the dignity of your human person. All because they only know what is good for you, whereas you (they say) are unable to understand and wish» (Iosini A. 1973-1984).

Regarding the electro-shock therapy, Alda Merini writes: «the small room for electro-shocks was very narrow and terrible; the waiting room was much more terrible, there they prepared us for this sad event. They injected us a pre-morphine and then gave us some curare, so as to avoid that our limbs started to be too restless during the electro-shock. Waiting was distressing. Many of us cried. Someone urinated on the floor. I once even caught the ward nurse by the throat, in the name of all my friends. As a result I had to undergo the electro-shock before the others, and without previous anaesthesia, so that I felt everything. I still preserve a dreadful memory of it» (Merini A. 1997: 85-86).

The Perception of the Self: Space, Time, Writing

Written documents convey us the experience of being in-patients, the description "from the inside" of this institution; most of all they are a formidable witness of the subjective life of patients. By writing one establishes an intimate relationship with one's self, one has the possibility to revise what one has interiorised, what one has been; it is a way of restoring a communication which had been interrupted by the institution and paper becomes a privileged confident for feelings, fears, melancholic states of min. A reflection on oneself and on one's own presence within the mental hospital is a frequently recurrent aspect among the examined written texts. The reasons offered for one's hospitalization vary from the statement of one's soundness – accusing others for one's hospitalization – to the full awareness about past irreparable mistakes to be expiated as such. The most frequent attitude is anyway that of seeing oneself as "normal", whereas the descriptions of other patients are often aimed at proving their madness and the sense of horror for the environment in which the writers are forced to live, the image of the self is that of a "sound" person, bound to live with a universe of madness and unjust rules:

> «I am a human being who, as regards me, I cannot understand why a young man like me, feeling me wise and serious, can live in a mental hospital, this surprises me a lot» (B. P. 1920).
>
> «If I was out of here I would be able to defend myself, but now since I am arbitrarily and unjustly closed within this Mental Hospital I cannot do anything» (U. M. 1903).

The change in the perception of time and space within these written documents is particularly interesting. Within a mental hospital moments are suspended and continually repeated without any change. The same daily rhythms and routine procedures beat the passing of time within the institution. Written texts show a progressive loss of the space-time perception; all remains the same as the first day of hospitalization, the same scenes are repeated, the same prayers are asked, days pass among the same frantic voices of the other patients. Time seem simply meaningless.

Ida Nencioni, for example, writes a diary – not only during her stay in hospital – taking detailed note of the date of every day, but during her life as a patient she is no more able to perceive the borderline between one day and another, so that she confines herself to write «first», «second», «third» in order to indicate days, up to a moment when she asks herself whether it is afternoon or evening, and «the evening of which day?' or when she omits any information about time. The perception of this progressive crumbling down of time reveals awareness and acts as a further destructive element of one's own story and life. The concepts of order and duration seem to have become completely meaningless. There is a loss of the chronological process of evolution, because values allowing communication with the world loose their meaning. The temporal structure becomes rigid and the present is isolated from the past-present-future units.

Even the sense of space takes different values, most of all due to the fact that one is deprived of one's own private sphere (GOFFMAN E. 1968 [1961]). One's individuality disappears in favour of community and anonymity; the action of the institution sanctions an infinitely wide space which forces the patient to look for vital borders where to find refuge within the elsewhere and the "outside". One prefers to occupy a mental space, which one can build and create. In many written documents comfort is to be found in memories and in past events, which become spaces for identity and memory. One builds a "hiding place for one's self" where space and time are turned into "categories of elsewhere".

The same act of writing in itself beats a "different" time: the time of writing is in fact that which has been recollected and fixed through it and becomes also a "different" intimate space, where salvation is to be found (8). In a context which destabilises its own system of value by increasing the "risk of existing", writing becomes an attempt to avoid that process which Tullio Altan calls «crisis of the conscious presence» (TULLIO ALTAN C. 1968). The act of writing not only reiterates the thread of a communication between one's own self and the world, which had been interrupted by the institution and by the disease, but also allows a person to regain possession of a seriously menaced self, of one's own story and freedom, of a past in which one can finally newly recognize oneself; as Philippe Lejeune puts it «it is the overwhelming power of desire looking for a way out, willing to find words of expression» (LEJEUNE P. 1986 [1975]: 57).

"To walk on the silent side", to analyse the microscopic transformations of the self within the institution through the writings of the patients could be then an ethnographic contribution to the understanding of profound transformation processes of institutional settings of mental health care. "To walk on the silent side," means therefore to follow a melody, to listen a voice... which is silent no longer.

Notes

(1) My translation. All the text in quotations in the article is translated by me from the edition reported in references.

(2) Among the published works examined during within the framework of this research – see the bibliographic list at the heading “Sources” – this selection has taken into account the following: an autobiography written by Adalgisa Conti, hospitalised in the provincial mental hospital of Arezzo in 1913, when she was twenty-six years old, for sixty-four years. Put away with the diagnosis of “persecution complex with a tendency towards suicide”, she recalled her life in a letter addressed to her doctor which was found within her medical report (CONTI A. 1978) / A diary written by Maria Luisa Marsigli during her two years as a patient within the mental hospital of Santa Maria della Pietà in Rome, from 1968 up to 1970, where she had been hospitalized following to a charge of murder of her husband (MARSIGLI M. L. 1963) / A diary written by Margherita Adamo, hospitalized in the mental hospital of Siena as from 1940 up to 1947 because of drug addiction (ADAMO M. 1991).

(3) The unpublished works were collected at the Archivio Diaristico Nazionale of Pieve Santo Stefano within the province of Arezzo (see the diaries) and in the case files of the provincial mental hospitals of Arezzo, Perugia and Reggio Emilia (including autobiographies, essays, memoirs and most of all correspondence). The authors of the writings found in the case files of mental hospitals are quoted in the article only with initials to protect their privacy.

(4) The Italian privacy act forbids, in fact, the use of any documents produced in the last seventy years.

(5) The complex process which led to the shutting down of Italian mental hospitals was characterized by multifarious procedures within the context of the struggles versus institutions, «which, to get things straight, were not only those based on Franco Basaglia’s ideas, notwithstanding his leading role, and which did not even take place within the framework of psychiatry» (Tullio Seppilli in FLAMINI S. - POLCRI C. eds. 2004: 1). The anti-institutional experience of Perugia turns out to be of special interest as compared to the various ones which influenced the Italian psychiatric panorama, because it proved to have specific features; the Fondazione Angelo Celli per una Cultura della Salute is now working on the *research Project on psychiatric policies in Umbria* promoted by the Province of Perugia and aiming at reconstructing the phases of the complex process of de-institutionalisation of the provincial mental hospital of Perugia.

(6) This classification is sometimes an arbitrary one since the limits between different “genres” can turn out to be very ephemeral; some diaries also show the typical features of memoirs, and in the same way some autobiographies can be included in the epistolary genre. In this case a distinction was made as regards contents and structure of the text: letters addressed to one’s doctor recalling life experiences were listed as part of the autobiographic genre, daily notes were classified as diaries, retrospective narration of single experiences and events are on the contrary seen as memoirs.

(7) The case files of mental hospitals contain many other documents witnessing the clinical, juridical and biographical story of the patient. Even if they vary a lot from one hospital to the other and also within the same institution according to the different historic periods, any file is in general made up of: *case history*, including data on the patient, anamnesis, diagnosis, etiology, symptoms, and very often a “diary” written by the doctor by periodically noting both the patient’s condition and behaviour; *administrative papers*, including the documents issued by the police authorities or the prefecture for the hospitalization of the patient, the correspondence of the manager with public administration or with the patient’s family, and the autograph written documents of the patient; the *reception form* which, once filled in by the family doctor, establishes the patient’s hospitalization.

(8) Seen as a refuge from the and within the institution, writing could be compared to the “secondary adaptations” described by Goffman who explains: «One of these special kinds of secondary adaptation is the so-called “repression activity” or the “Kicks”, activities used by the individual in order to loose oneself into something, temporarily cancelling any perception of the surrounding world where one is forced to live» (GOFFMAN E. 1968 [1961]: 294).

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4.2 *Saints, demons, and footballers: playing (with) power in a psychiatric field*

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Introduction: Gramsci, Foucault, and the Stunt Riders

In a recent discussion of *Subaltern studies* with Neelandri Battacharya, Suvir Kaul, and Ania Loomba, Edward Said (Said E. 2002) recalled the importance of combining different critical methods in analyzing power, and he underlined the crucial role in this regard of authors such as Michel Foucault and Antonio Gramsci. During their discussion Said and his interlocutors pointed out the difficulty of putting together Foucault's notion of the *dispersal of power* with Gramsci's notion of *hegemony*. Joking about the criticism of *Subaltern studies* with respect to this point and the accusation of «*trying to ride two horses at the same time*», they were reminded of the balancing act performed by stunt riders attempting to take advantage of the productive tension between the two authors (Said E. 2002: 9). According to Said, the problem is how to combine a reflection on power with a commitment to social transformation that is supported not only by a theoretical constituency but also by a political constituency. Foucault can be criticized – Said declared – insofar as he regards social reality from the perspective of power and therefore it is difficult to find in his work forms of resistance from below. In other words, in the struggles observed by Foucault we have the impression that we already know how the story is going to end.

In Gramsci, instead, Said continued, evolving political situations have a decisive role because his critique directly involves a political constituency. Even during his imprisonment he reflected on the relationship between the state and civil society, having in mind the social transformations he had experienced first hand in the working class struggles in Turin. For this reason, Gramsci's writings seem to be particularly useful for those interested in reaching historical understanding, in specific circumstances, of transformative actions from below.

> «What I say is basically that Foucault writes always from the point of view of power, there's never any doubt in your mind when you pick up one of his books that power is going to win out in the end. So that the whole idea of resistance is really defeated from the start. [...] Gramsci, unlike Foucault, is working with an evolving political situation in which certain extremely important and radical experiments were taking place in the Turin factories in which he was involved, and from them he generalized periodically, I mean in periodical form. You don't get that sense in Foucault; what you get instead is a sense of teleology where everything is tending toward the same end, and so the attempt to bring the two together involves in a certain sense breaking up the Foucaldian narrative into a series of smaller situations where Gramsci's terminology can become useful and illuminating for analytical purposes» (SAID E. 2002: 9).

Said's considerations and his image of the stunt riders constitute a good starting point for an ethnographic exploration of the relationship between agency and power in the transformation of Italian psychiatry from the mid 1960s to the present. Not only because the works of Foucault and Gramsci have in fact played a significant role in the emergence of democratic psychiatry in Italy, but also because what Franco Basaglia called the "utopia of practice" (BASAGLIA F. - ONGARO BASAGLIA F. 1982 [1974], BASAGLIA F., ONGARO BASAGLIA F. - GIANNICHEDDA M. G. eds. 2000) referred in large part to situations in which the question of power was at the center of local social conflicts.

In this regard – I would suggest – Gramsci's continuing importance consists in his elaboration of an analysis in progress, securely anchored in practice, which does not neglect the complex reading of social processes within which to study the historical formation of a *collective will* (1). Gramsci deals with this question in the Italian context, by concentrating on the relationships between the state and civil society, the formation and function of intellectuals, and the politics of culture, by trying to capture the nerve centers in the social reproduction of the changing and established relationships of domination and subalternity. He is quite aware, in fact, that practical activity cannot be separated from the materiality of power: from the materiality, that is, of relationships and the circumstances in which "the power of a ruling class, exercised through the state, does not merely dominate but ultimately comes to merge with civil society" (FRANKENBERG R. 1988: 328, cf. CREHAN K. 2002: 172-176). It must be recalled that Gramsci is interested in the analysis of concrete historical situations (with an interpretative framework capable of penetrating to the heart of transformations in "smaller situations") in the prospect of social change. In this sense, the subjects to whom he refers are historical subjects, in relationships of inequality, who experience in their own flesh and blood a molecular transformation (2). Gramsci is also well aware that the question of transformation cannot be understood without an in-depth interpretation of those elements that, in a given historical moment, saturate the field of power in the naturalness of daily practices. This is true because power is tied up in a self consciousness and a consciousness of the outside world aimed at defending or transforming the "state of things" by acting through a practical, implicit, and at times inarticulable knowledge. Transforming reality thus requires an interpretation of power relationships and a cultural critique that opens up the concept of "person" and considers historically and progressively the relationship between processes of embodiment and hegemony (3). Such a critique must be developed on the basis of an "organic" idea which, avoiding, on the one hand, what Gramsci calls "economicism," and on the other, what he calls "voluntarism," considers both the question of the formation of a collective will and the historical nature of social consciousness understood as a struggle of political "hegemonies":

> «Critical understanding of self takes place therefore through a struggle of political "hegemonies" and of opposing directions, first in the ethical field and then in that of politics proper, in order to arrive at the working out at a higher level of one's own conception of reality» (GRAMSCI A. 1975 [1929-1935], II: 1385 / English translation: 333).

It must also be recalled that Foucault himself insisted, on several occasions, that his work must be contextualized in a precise historical moment, namely the phase that he called «the insurrection of subjugated knowledge», in which posing questions to power had been the result of a happy meeting between kinds of subjugated knowledge, scattered or diffused throughout society, and historical studies on particular forms of power-knowledge (FOUCAULT M. 1977a [1976], 1977b [1976]). By subjugated or ingenuous knowledge he alluded on the one hand to the emersion, by way of a genealogical study, of historical content that had remained masked for a long time (the case of the *History of Madness* (FOUCAULT M. 1990 [1961]) is emblematic in this regard) and on the other, to the appearance from below of particular, local, or differential kinds of knowledge, which had been part of the "continuous and widespread offensives" in the social conflicts of the closing years of the 1960s. Foucault was referring either to specific social actors or to the kinds of knowledge that viewed them as subjects in the double meaning of agents and objects of analysis (as in the case of "psychiatrized", "patient", "nurse", "delinquent"). Foucault's considerations regard then a crucial point: the historical knowledge of those conflicts was the result of the union between the buried knowledge of erudite scholarship and the denigrated knowledge of the political movements for the liberation of women, of the processes of psychiatric deinstitutionalization, and of the critique of the penal code and prisons (DI VITTORIO P. 1999).

Said is probably right in saying that this opening to struggles that change social reality and to the possibility of reading power relationships in the prospect of transformative action belongs to a specific moment in Foucault's intellectual biography and does not seem to have been developed in his later works on power. Nevertheless, as we have been reminded by Gilles Deleuze, Foucault's works contain many references that indicate a specific interest for social transformations and processes of subjectivization (4), both with regard to the work of formation of knowledge and the treatment of subjects and as a form of struggle for those whom he calls *specific intellectuals*. In this sense, Foucault spoke of power relationships in a genealogical perspective which, in addition to analyzing the logic of social practices and discursive regimes, also provides for a strategic moment that aims at identifying the possible ways of freeing oneself from the grip of power and changing the rules (Deleuze G. 2000 [1990]: 137-158, cf. Deleuze G. 2002 [1986], 2002 [1989]) (5).

In this sense, Italy's public psychiatric care (and in the specific case at issue here, public psychiatry in Umbria) (cf. Giacanelli F. 2002) appears to constitute fertile terrain for an anthropological reflection on the ways in which power is played out. Indeed we could consider psychiatry as one example of a theoretical and practical locus within which was produced a new discourse on power. A discourse arising from specific historical circumstances where political confrontation had to come to terms with a transformative practice that seemed to elude theorization and systematic conceptualization. Probably for these reasons, the central theme of political confrontation and debate in those years was subjectivity; subjectivity understood as a collective politics developed in an intersubjective space, an aspect that Franco Basaglia, in trying to draw up a balance sheet of the results achieved by social movements in Italy, would highlight on various occasions.

> «[...] all these movements and struggles made it evident that, beyond the struggle of the working class that demanded change in living conditions and participation in the administration of power, there was also another fundamental struggle: the desire to affirm oneself not as an object but as a subject. This is an important phase because it is the phase we are living in and it is a challenge to what we are, to the relationship between our private lives and our lives as public and political men. When a patient asks a doctor for an explanation of the treatment and the doctor doesn't know how or doesn't want to respond, or when the doctor insists that the patient remain in bed, the oppressive character of medicine is evident. When, on the other hand, the doctor accepts the objection, accepts being one part of a dialectic, then medicine and psychiatry become instruments of liberation» (Basaglia F., Ongaro Basaglia F. - Giannichedda M.G. eds. 2000: 7).

It seems to me that Gramsci and Foucault, together with the legacy of the experience of psychiatry in Italy, indicate a line of research that consists in recognizing scattered and subjugated forms of knowledge and examining the plurality and dispersion of social practices. Ethnography, therefore, must face a decisive question, consisting in the possibility of bringing to light individual and collective agency in the indeterminacy of social life, with a perspective (perhaps suggested by the stunt rider metaphor) focused on bodies that act and produce intersubjective knowledge (6).

Pursuing these insights, this paper attempts to elaborate on the, in many ways, "disturbing" reappearance of some forms of social action (playing football) in my ethnographic experience, by looking at "play" as a social practice in which processes of embodiment are produced and the position of the agents is exchanged. My point of observation, therefore, is restricted: I am not interested in developing the pairing of play and power in the metaphorical sense. Instead, I do consider important the intersubjective dynamics in which I have been directly involved through the movements and the ludic sensibility of my own body.

What I will try to do then is reconstruct some ways in which power is played out, beginning with ethnographic situations that highlight practices and language centered on social poetics that have as their object the self; a self understood not as a deep identity, but as a negotiated construction of belonging which is developed intersubjectively in a specific "moral and professional world." In going about this I will try to reposition the question of agency in the midst of social action by showing some correlated and ambivalent aspects of the exercise and the subversion of power relationships.

There are correlated and ambivalent aspects of power that can be placed within the problematic relationship between social knowledge and agency through the interpretation of some social practices considered to be marginal in the management of the public mental healthcare system. Playing football or soccer, for example, is something that we would find it hard to recognize as a kind of know-how that is somehow related to psychiatric treatment. In fact, sport is often considered to be one of the elements of psychiatric entertainment (cf. SARACENO B. 1995) rather than as a way of mediating one's relationship with the world and the possibility of interpreting it and transforming it through social action (7). Nevertheless, the game of football offers one of the many possibilities for observing how, in the indeterminacy of social practice, specific meaning attaches to the materiality of relationships and circumstances in which the embodied knowledge and the actions of patients develop and come to be recognized or not by psychiatric caregivers (8); caregivers who have in any case elaborated strategies of political confrontation that require a certain reflexivity on their own practices and on the social context in which they operate.

Football and the Nostalgia of the Ethnographer

In Gubbio, one day a week, two mixed teams of patients and staff of the local mental health center face each other in games of five-on-five football played on a field on the outskirts of the city. I have had the opportunity and the pleasure of participating in these games during a sojourn in the city to conduct my ethnographic study on community mental health through personal observation of the practices of public psychiatry (9). These matches gradually showed themselves to be an occasion for mutual exchange and recognition that had a more familiar tone for me than other experiences in other places of the local psychiatric care network. An opportunity, accompanied by sometimes ambivalent sensations, to rediscover some forms of action that I partially recognized in my embodied memory: those situations in which one is called on personally to participate directly, to show what you can do, to put yourself and your abilities on the line, demonstrating in any event to know the rules of the game and to respect them. By rules I mean, obviously, those strange combinations of spaces and distances, of boundaries and equilibriums, characteristic of matches played in the street or on suburban fields, where there are no referees or line guards, no off-sides rule, where even the goals can be made wider or narrower depending on the circumstances, especially when there is no goal keeper available to guard the home goal.

Maybe for these reasons, the weekly football games in that period of my field work represented a pleasant escape from my ethnographic commitment, occasions for getting outside of my work routine and leave behind the complex flux of positions, tactics, schemes of attack and defense that I had become familiar with in the psychiatric field. In a relatively ingenuous way, perhaps, I had left to football the task of marking off for me a terrain of free action, in which my attention was fluctuating and ludic. At the same time, it seemed at least curious to me that a study of forms and of psychiatric treatment and local mental health care policy, that was attempting, that is, to view psychiatry in a complex way as a field of interactions, meanings, and power relationships, could and should in fact focus its attention on the place and activity that most recalled to my "embodied memory" a practice characterized by parity and competition, that I would place in the disinterested ambit of play. With my research now completed, perhaps it is a kind of nostalgia for those matches that has spurred me again to reflect on the role of game playing in reference to the dynamics of power in the psychiatric field, and specifically, in relation to those processes of effective activation of the rights of patients.

Perhaps for these reasons, I had the impression that those football games and the discussions that accompanied them constituted important moments in the construction of a relationship of sharing and "cultural intimacy" (HERZFELD M. 1997) with the people whom I had met in various places in the psychiatric network with other roles, following other rules, negotiating other relationships. By recalling the expression "cultural intimacy" I mean to focus on those aspects of the definition of self and one's sense of identity that create a feeling of embarrassment with strangers while ensuring internal spaces of shared sociality (HERZFELD M. 1997: 3-4). While in my case the games seemed to guarantee a limited space of play and rediscovered gestures, I was nevertheless aware that football is also a device for producing those images of the self, individual and collective, that pervade the definition of male gender, and for changing (home town, regional, national, ...) identity formation. Football, in fact, is not only an elaborate way of "thinking with one's feet" (*Pensare con i piedi*) as suggested by the title of a story by Osvaldo Soriano (SORIANO O. 1995 [1994]), but also a system of action/reflection that allows us to transform bodily styles into real and true social rhetoric. It is the object of continuing disputes and discussions that reproduce in different ambits the competition acted out on the field. It is a topic of discussion about which everyone may be called to speak and to be observed and judged on the appropriateness of their language and the quality of their knowledge of the game. In this sense, the game of football, played on a small suburban field, cannot be distinguished from discussions about the great challenges of a national and international nature.

In this way, my social experience of football at the Center for psychiatric rehabilitation was to be viewed as something that went beyond the weekly games and that also required a capacity to hold forth on tactical choices, to participate in the "fine" evaluation of the weekly exploits of the heroes of Sunday's professional games. This meant, for example, possessing an awareness that the discussions concerning the progress of the European football championships, the dominant theme in the city's bars in that period, were part of the same ability to understand and act as the weekly game where we faced each other at the Center for psychiatric rehabilitation. These discussions of an international tone were amplified by the multiple ways through which social reality is represented and symbolically transformed by the filter of football discourse. A combination of oppositions and contrapositions at the local and national level just as they are interpreted in the grandstands of the city's stadiums in the lower professional and amateur leagues. On the local level, the provenance of the patients from the Apennine area's two principal towns, Gubbio and Gualdo Tadino, historic rivals, was often translated into memories of football contests that had seen violent clashes between opposing groups of fans. In a larger sense, the agents of polemical exchanges boasted of their belonging to clubs of the upper leagues in disputes in which their adversary was faced with a language of strong sexual connotations (10).

This same elaborate redefinition of local identities, for example, took on a peculiar tone when it was decided publicly and officially in the city to play a football match in honor of the patron saint. That's what happened one evening in September 1999 at the town stadium, when for the purpose of raising funds for the restoration of the 16th century statue of the town's patron saint situated in the main street of Gubbio, Via Garibaldi, a triangular football match was played between representatives of the "*ceraioli*". *Ceraioli* are the men who, each year on 15 May in honor of S. Ubaldo, run first around the town and then up to the chapel at the top of the mountain where the relics of the patron saint are conserved, carrying enormous wood structures, each bearing on the top one of the three protector saints of the cities three medieval guilds (S. Anthony, S. George, and S. Ubaldo). The restoration – officially promoted by the groups responsible for the organization of the annual *festa* and sponsored by the local public administrations – had been announced by a number of posters with the slogan "With S. Ubaldo Toward 2000". On the night of the contest, the local TV announcer, dwelling at length on the reasons behind the initiative, showed a touch of embarrassment in a poorly concealed effort to maintain equal distance and impartiality with respect to the three teams on the field. Indeed, the combination of the football game and the feast of the Three Ceri required a special prudence on the part of the announcer, who, relying on the opposition between "sacred and profane," emphasized how the seriousness of religion would not be even minimally compromised by this noble way of playing in honor of the city's patron saint. The speaker also underlined how important it was that on such a special occasion the two great passions of the men who took the field could come together: football and religious devotion. One could feel, that is, that since the players on the field were the "*ceraioli*" – those very men who are in a certain way the representatives of each of the three saints – the game was not just a match between football teams but a challenge involving the entire system of weights and counterweights in the contest of local identities.

Playing (with) Power in a Psychiatric Field

My participation in the five-on-five football matches coincided with a moment when the rehabilitative activity was being examined in its overall meaning and prospects by the various agents with respect to the possibilities of tracing the outlines of a rehabilitative project defined explicitly in terms of play (11). This means, on the one hand and above all, problematizing the question of athletic competition, the confrontation that presupposes the will and the determination to defeat the opponent, but also, on the other hand, questioning and working through the fear of facing the opponent, which is also the fear of directing toward the opponent that violence which the game at the same time denies and feeds. For staff members this meant rethinking competitive activity in the prospect that this internal contest could be expanded to other situations, matches to be played against other opponents (teams from local parishes, from other rehabilitation centers, etc.).

The game of football, moreover, posed a key problem in psychiatry concerning the relationship with corporeity (12). There are other activities promoted by the Center for psychiatric rehabilitation, such as postural gymnastics, for example, or swimming, which attempt to explore the possibilities for patients to recover deteriorated motor skills. The question of corporeity goes beyond the desire to activate rehabilitative practices to directly impact the possibility of reinforcing patients' abilities and to expand their autonomy. In this interpretive framework, the above-described practices connected to football are also meaningful for understanding how sports can have a place in a web of meanings that allows the various agents to occupy different positions within the same network of social relations – there are, that is, patients who cannot play for physical reasons who are assigned roles as organizers and facilitators – and how the psychiatrists in charge of the center have tried to translate this common legacy into a rehabilitation project. The process of promoting patients' agency can be divided into various phases and focused interventions: correcting posture (those not participating directly should, for example, refrain from smoking and lying down on the wall), gradually putting in the game even those who would rather not play, or opening room for discussion in which, as we will see in the two ethnographic examples that follow, the patient's resistance becomes the fulcrum of processes of social exchange.

In the strategic perspective of redefining interpersonal relationships, staff members have discussed the therapeutic and rehabilitative function of the game of football, highlighting the fact that it is a "game" and not "play." The specific objective of a team sport is thus identified as winning without hurting your opponent, promoting a form of competition that follows several agreed-upon rules. This presupposes a reorganization of the rules of the game, understood on the one hand as rules to be respected in both training and matches, and on the other hand as an instrument for guaranteeing, through the coach, the correct progress of the game and a positive relationship between justice and injustice during the game (13).

In mixed patient-staff games, furthermore, it came out that in order to look after users who remained outside of the playing field, staff would have to attempt to observe everything that was going on and not all play at the same time. For this reason, staff decided, after some time, to keep one of their number on the sidelines, with the task of supervising what goes on during the game (14). This operative decision, agreed upon with the psychiatrist in charge of the project, to resolve the staff's problem through the use of an outside coach, opened up a discussion in which the space for negotiation underwent a drastic redefinition. The paradox noted by staff members in the perceptive experience within their daily activities, as we shall see, do not elude the critical reflection of the patients. A sort of euphemism would have it that everybody was part of a group. But, I would add, a group that must be understood for what it is: an aggregate of subjects in the field of psychiatry.

In fact, the redefinition of the game led to an operation of framing, or perhaps better of *keying* (a true change in the musical key) (cf. *keying* in GOFFMAN E. 1974: 40-82) which, like other kinds of framing, has metacommunicative value (BATESON G. 1976 [1972, 1955]). The interesting aspect in the case at hand is that the metacommunication implicit in the frame changing operation, the unsaid, communicated in the facial expressions of staff, is what was immediately understood by several patients and rejected by one of them, thus highlighting the risk of setting the game in a hierarchical "psychiatric frame."

In this regard, I will now sketch two ethnographic examples concerning how, in psychiatric rehabilitative activities, conflicts and processes of negotiation make it possible to explore the relationships between social action and emerging practices, highlighting the role played by some structural contradictions in the definition of current community mental health policies.

Michele: Getting Out of the Habitus

Psychiatric rehabilitation implies differences and substantially asymmetrical relationships between patients and staff. An example of how these asymmetric relationships can be subverted is the choice of Michele (15), a patient who comes to play, to bring with him some friends from his home town, thus occupying a position not easily definable by the social service staff themselves. Michele does not help to clarify the obscure aspects of his presence at the matches; he comes to play, arrives on time, but he doesn't seem to belong to the Center for psychiatric rehabilitation. He seems instead to constitute an active presence that allows the users of the Center to get some physical exercise, a kind of personal mission to be inserted entirely in the rehabilitation of his friends the patients. Not that Michele fails to recognize his own condition, but he conceives of his presence as a support for the collective project. He presents himself in order to allow the others to lead a healthy life and get themselves into better physical shape.

I first met Michele and his friends during a football match. On the field he is a tenacious defender, with a good game vision and good touch with the ball. Later on he will tell me that he understands football as a game to be played *«savagely... but always with certain values.»* His friends play on various amateur teams in the area and are in good shape; they run more than the rest of us and sometimes we are forced to divide them up evenly between the two teams to ensure that the game is fair. During future games, and in our dialogues at the Center for psychiatric rehabilitation, I constantly hear in Michele's words references to his intimate belonging to the world of nature. He told me about a machine that can draw energy from forms of natural life, of the necessity to slow down or anyway to fight against things that can interrupt the life cycle, death and decay. Something that goes beyond the aging process, which for Michele carry traces of the Angel of Evil. Even in the way he expresses himself, with an enthusiasm that at times seems to cover up a certain preoccupation, he communicates his ambition and a vision of the world in which everything seems to be a process of production and transformation.

> Michele – «Animals, I mean me for example if I could be attached to the earth and bring all of the earth back with me when ... according to the Bible versus, when we go back home. Because death ... there will be the living and the dead, and so in the Christian way the earth is life, everything is life. What you touch, that is life [striking the wall several times]: it's fossils, it's minerals, but it's life. And in the story of plants has had a lot of this too. I didn't believe, I've made some progress, you know, but maybe even I have behaved like Saint Thomas, I don't know».

Michele's relationship to the public psychiatric service has a specific story, based partly on his ambivalent search for autonomy and protection of his possibilities for self-expression and affirmation. It is a story that has also had moments of sharp conflict, like the time he was hospitalized against his will. To Michele, this compulsory psychiatric treatment could not be anything but a brutal struggle, a war, an armed conflict.

> Michele – «I saw it differently, I mean, you understand? Like... it's like they completely block you. Or, nothing that you... for nothing, of nothing ... I mean, no, nobody even knew if they... if they'd locked me up, I thought they wouldn't even... I mean for things to get to that point, I mean... it's not like I'd killed somebody. I mean, a thing... a trauma like it must have been in Bosnia [...] I don't know. Back then, in those days I went from one ... I was starting to see, I was starting to get into a world that I had never seen. The Tso [compulsory psychiatric treatment] is really ... The Tso was really, the way I see it, was a mistake that they didn't realize, or maybe they wanted to do it that way, maybe sedating me two minutes and then... holding me a little. It's clear that I'm the only one who lost out».

Michele's recollection of his hospitalization is now partially influenced by a difficult work situation, a sort of battle against demons and, irony of fate, their symbolic representation in the game of football.

> MM – «So why did you leave your job?»
>
> Michele – «Hey, because my life was at risk».
>
> MM – «On the job?»
>
> Michele – «Those were the years when Milan was winning everything».
>
> MM – «Ah, the devil » [referring to the symbol – the devil – of the Milanese football club].
>
> Michele – «There was a red and black SX [referring to a car] with horns on the front right on the hexagon. You know what a three means on the hexagon? Six, six, six. And it had three doors».
>
> MM – «And how come you had all of those things?»
>
> Michele – «I don't know. When I saw that car I put myself up on my feet and I tried to send that devil away. Because I've gotta fight that car, you know, every year. But I didn't notice that there was a car like that. Later... Because there was the market, the price, the whole bit. Then, black and red, Milan was wining everything. My friend was left paralyzed with that car».

Michele's therapist told me that it was she who decided on the Tso the day she had to go up to the top of the mountain to get him, when Michele had stopped communicating altogether and wouldn't let anyone come near him, completely on his own by then to fight the demons. There followed a long series of re-approaches and separations. When he was released from the Spdc (Psychiatric Diagnostic and Treatment Unit) Michele began a period of nature activities. Together with a group of staff and patients Michele, who is a passionate expert of local flora and fauna, went into the woods, hiking in the mountains, to observe the animals and plants. Afterwards, when there were discussions with the psychiatric staff concerning the possibility of patients moving about the service area on their own, the nature activities of which Michele is a leader became the first rehabilitative project to show possibilities for development.

Staff members often discuss among themselves the caustic remarks that Michele sometimes directs to his fellow participants in group activities, whether in nature outings or football matches; about his references to his companions' being out of shape, or their lack of stamina of agility. Some staff members say that Michele sometimes makes hurtful remarks that should be corrected. "Things that should be returned to the sender." Nevertheless, others say that the problem is not so much Michele's lack of patience as his view of the world and his way of being together with others. In fact, his choice to participate as an "animator" of the football matches is understandable when it is considered that thanks to his emphasis on staying in good shape and his young age he is one of the best players on the field. When Michele and his friends are with us during the matches the linguistic exchanges between the other players are centered on the accounting of strengths and weaknesses, on the "energy" we have left, and on the possibilities of being able to "make it" to the end of the match.

One day, in a group discussion dedicated to the redefinition of the football activity, a nurse began to explain the changes and present the new experts. He referred several times to the need to respect the rules; he gave everyone a photocopy of the rules promulgated by the five-on-five football association, which provides for a direct penalty kick in the case of a feet-first slide even in the absence of physical contact. His references to the rules and to the new coach are central, he said, for a fair and orderly match, and for gradually getting to the point of having everybody play, all together, including those who at the moment are only spectators. One patient smiled and observed that taking the field at age 45 is rather complicated.

It could be seen immediately from the interplay of glances among staff members that the nurse's speech had not hit the target and, on the contrary, the risks of creating confusion had become greater. Indeed, Michele, accompanied by two of his friends – straight from work in the factory where, in that pre-holiday period, they worked ten hours a day, said that these were questions of no interest to him, adding that «We don't need to talk about schemes, we play to have fun, and that's all there is to it.»

The nurse then answered with a long digression, which didn't permit other staff to intervene, on the fact that the experts are experts and that a brief presentation will be enough to understand that and rely on their competence. The expert/coach, embarrassed, said a few words by way of presenting himself, giving a brief curriculum of his athletic activities.

On that occasion Michele concluded that «we don't need experts to play football» and that he was «not going to be anybody's horse». His personal relationship with the Center for psychiatric rehabilitation was certainly not going to be changed by the nurse's strategic proposal (16).

The contrast opened by Michele is tied to his heterodox behavior with respect to local forms of negotiation. He continuously moves outside the role of patient and gets out of the *habitus* (FARNELL B. 2000), acting creatively time after time to redefine the boundaries of the psychiatric field. In this case, Michele proposes a different way of viewing football which corresponds to a different way of viewing the world and its conflicts. Michele's struggle is a struggle with the world which directly involves the classifying logic (17) which places him on the side of the patients even in those rehabilitative activities that, more than others, should transform the distinctions between psychiatric service staff and users. Subjected to Michele's evolutions, the terrain changes the way it does in the imaginary 1942 World Cup championship in Patagonia in 1942, described by Osvaldo Soriano in *Pensare con i piedi*: the goals move, the teams change, the ball disappears (SORIANO O. 1995 [1994]: 198).

Alessandro: Crisis or Contradictions?

It cannot be excluded that the ambivalent situation that staff members found themselves in was also the result of an timely question posed by Alessandro, a 35 years old service user, and the center forward of our football team, who asked explicitly if "the experts were experts for everybody, even Michele's friends, or only for us patients". Alessandro's sensitivity for the internal divisions in the social network of psychiatry and his capacity to highlight the embodied character of the conflicts give us the opportunity to explore another meaningful aspect of the game of power in outpatient psychiatry. A game, as we shall see, constituted by the relationship between agency, intersubjectivity, and processes of subjectivization.

Alessandro came into contact with the psychiatric service in 1987, after experiencing his first problems during military service. He had some long periods of hospitalization in the Diagnostic and Treatment Center before entering a therapeutic community where he was until 1996, the year he came to live in Gubbio in a "group apartment" of the mental health center. With Alessandro, as we have already seen with Michele, daily life experiences and collective history is expressed with the same language of struggle and armed conflict. The tiredness he frequently complains of is tied to an everyday struggle against difficult situations that present themselves in brief daily encounters: mothers distracted toward their own children, people that have no concern for others.

> Alessandro – «Yes, life is a constant struggle, Massi. But... it's not like I'm giving in, but I do have a bit of difficulty getting myself settled... settled into daily life. I feel like a kid who has fought in a war, far away, I mean».
>
> MM – «You feel tired».
>
> Alessandro – «Oh yeah [...] Because I've always had to struggle, Massi. There is no rest in my life».
>
> MM – «What do you need to struggle against?»
>
> Alessandro – «Hey, I fight against everything, Massi. I fight for the animals, I fight for... to stay at home, to get people to go back home when they take the car, when I work in my parent's store I always say "hello Miss, your mother loves you, try to love her back"... Because her mother cares about her a little. It keeps me really busy».

His is a rigorous personal commitment, there are no social ties, given that societies, made up of states and super-powers, are necessarily carriers of values contrary to human solidarity.

> Alessandro – «But mostly people today, Massi, are looking to expand their territory. They want to be bigger, bigger, bigger... States, for example, the continents, no, Massi, there's a little bit of nasty guerrilla war, but the third war, I don't think the third world war will ever come. No, Massi?»
>
> MM – «And this expansion, at the expense of others, does it regard only states or relationships between people too?»
>
> Alessandro – «Between people too, even between people in the neighborhood».

Sometimes Alessandro senses that something isn't going right; he alternates moments of hyperactivity with moments of gloomy silence. At home, his housemates see him go off on his own and avoid conversation. He sits in the kitchen keeping a tight hold on the little statue of the Madonna that usually sits on top of the television. Or else he goes out for a walk, to think, in the public gardens, in the church near the square, or sitting on a bench under the monument to Saint Francis. Alessandro's dialogue with Holy Mary and Saints, observed with interest and participation by social workers and his friends, can be seen as a modulation of relationships that leads him to negotiate his "presence" in an intersubjective environment. This modulation of relationships, characterized by a religious idiom, is the key that leads Alessandro today to actuate a strategy of hospitalization/withdrawal in the local General Hospital; when he feels bad he goes by the Psychiatric service and asks his therapist to arrange for him to be hospitalized in the Internal medicine department.

On one occasion, there was an incident at the Psychiatric Center. One afternoon, while we were waiting at the Center for Psychiatric Rehabilitation for our weekly match (and realizing that there weren't enough players) the air became rather tense and we saw a nurse going off several times to make phone calls. The situation was one in which people talk without talking (18). Somebody asked "How is...?" without mentioning any specific names. The nurse answered that he was doing well now, that he had gone to bed. The one who showed the most disquiet was a social service staff member who invited a patient to not go near the door of the room while the nurse was on the phone. Outside the people continued playing at football, kicking the ball around... a few calling back and forth in loud voices, some laughing. A staff member went out to see what's happening and assured us: "Everything's okay".

The next morning I had a previously scheduled meeting at the psychiatric service with a psychiatrist who attempted to reflect on the previous afternoon's episode in which Alessandro was involved. Yesterday morning a staff member had forgotten to give Alessandro his usual medicine. In the afternoon somebody at the Center for Psychiatric Rehabilitation probably made an inopportune reference to a difficult situation experienced by another patient at the Center for Diagnosis and Treatment in Perugia and Alessandro became really angry. Usually he directs his anger at the Germans and sometimes at the Americans but on that occasion his accusations were addressed at those who were on duty and particularly at his own psychiatrist. At that point, the psychiatrist had to make a decision and refused hospitalization, trying to resolve the crisis without it. He told me that it had been necessary to talk for a long time, but above all to take time to reflect.

This incident was an opportunity for me to explore ethnographically the presence of contesting hegemonies in the psychiatric worker's daily practice. On that occasion, the psychiatrist and nurse interrogated themselves as to why there are some (particularly the professional nurses) who, remaining strictly within their own area of competence, forget what must be understood and dealt with in a team dimension. In this regard, it is interesting to note how the reconstruction of the episode in the words of the psychiatrist impacts directly the critical current condition of local psychiatry.

> Psychiatrist – «There is now, and has been historically, a problem with the staff meeting... only a few participate in the meeting... [...] A public service, in my view, only works well when there is continuous exchange, a continuous confrontation of roles... and when everyone continually knows what the other "does" [...] Because if Alessandro comes up, he comes up and somebody makes sure to give him his medicine only because he is the patient of Doctor X and nurse Y; it means that we expect something like that [referring to the crisis] today, tomorrow, or the next day. And then we think that Alessandro is sick... I'm not sure if I'm making this clear. I am convinced that the local psychiatric service can only function like a tribe. A tribe without totems. [...] Yesterday, for example, the nurse and I got together to recount, no, to reformulate, why it was that Alessandro became angry. That is of a quality, that work... It seems like a dumb thing, but it goes back to the nurse, goes back to me, that in reality I'm reading something. I'm looking for a story, I'm not looking for some device for Alessandro's symptoms. Because really it's the story that explains him to me, it's the story that makes it so that yesterday I decided not to hospitalize him. No hospitalization yesterday, maybe today he's already worse, but it means that...».

In fact, whoever failed to give Alessandro his medicine felt that that it wasn't part of their duties and that the administration of medicine had to be handled by the nurse and the psychiatrist, thus precluding any collective management of the crisis. But the psychiatrist recognizes in this a deep contradiction of the current redefinition of public psychiatry: the fact, that is, that a local community approach cannot be undertaken by a "specialized" psychiatry in a health system made up of professionals. A crisis is never a crisis of the individual, but a crisis of the service. The challenge, as Franco Basaglia well understood, is to let oneself become involved directly in the social contradictions opened by an individual crisis, looking at social transformation in a broad sense and not in a merely institutional sense (BASAGLIA F., ONGARO BASAGLIA F. - GIANNICHEDDA M. G. eds. 2000: 13).

With regard to the above-described episode one should observe the shadow projected by recent institutional transformations. The incident, as we have seen, called into question the use of drugs as a regulator of social relationships. What is the place of the handling of the drug in this tangle of meanings and power relationships?

The reading of the failed administration of the medicine can be seen, in fact, by some as the effective "cause" of Alessandro's crisis; but some staff members perceive a subtle and problematic aspect of the event when they consider the interruption of the medicine to be a "reason" for Alessandro's anger, who perceived the missing act of care as a form of negligence and incompetence, connected to a failure to take responsibility with regard to his condition. Alessandro's perception, which evidently must have been indirect, was progressively fueled over time in relation to the questioning glances of the staff members called into talk about the responsibility for the omission. In both cases, the drug must be placed in a intersubjective and generative network of practices, knowledge, and institutional relationships, in which it plays a role of a symbolic and social shift.

Concluding Remarks

By taking advantage of the inspiration that comes from the teachings of Gramsci, and using one of the escape routes that Deleuze suggests in Foucault, I have attempted to show with two ethnographic examples how power is no longer merely reproduced and manipulated but ironically explored by agents as molecular forms of transformation of the embodied self.

The first example brings out the relationship between practice and embodiment. In a sense, psychiatric caregivers play various games, but they fail to notice the crucial places in which one game turns into another. In this regard, caregivers try to expand their control through a series of procedures that lead to a breakdown and re-articulation of what is the embodied knowledge of the patients. Therefore the intention of promoting the empowerment of patients conflicts in this case with the failure to recognize the patients' embodied knowledge.

In their direct relationships with patients, psychiatric staff members are involved in forms of decodification of the other's behavior that require a certain kind of reciprocal trust. When they move, however, to the operation of psychological framing they fail to notice that they are not only changing frames but the entire linguistic game. And since every linguistic game can be understood only by exploring its grammar against the background of a form of life, sometimes the caregivers fail to notice that the interrelationship of agency and structural power takes place within a conflictual and dynamic relationship between emerging bodily practices and strategies of governmentality (FOUCAULT M. 1992 [1988]: 14).

This kind of contradiction emerges particularly in situations in which the inarticulable part of social activities takes on a crucial role. Failure to deal with the consequences also means not being able to recognize resources that are present in the community. The ironic effect in this case is given by the dissonance between the process of acquiring corporeal ability, actively promoted by staff members (to which as we have seen corresponds a vision outside of the game on the part of social service staff) and a kind of "panoptic drive" among social workers. Those social workers go into crisis when a patient thinks of sport as the reinforcement and development of the life force at the expense of the regimentation imposed by the new "idea of the team." One way of exploring this kind of contradiction may be to concentrate on the intersubjective dimension in which practices are acquired in a context and on the situated experience of participation or non-participation in such practices.

In the second ethnographic example, marked by uncertainty in the management of risk and crises, the intersubjective dimension is particularly evident. Alessandro's incident is a catalyst that allows us to highlight the interweaving of relationships of power and resistance in the psychiatric field. Regarding the Italian experience, we must remember that, historically, intersubjective spaces have been formed in a period in which mental health care was considered as a social problem to be handled within the framework of the society's structural contradictions. Today, instead, staff members are becoming aware that public finance tends to distinguish between questions of health and social problems, entrapping psychiatric care in a medicalized and pharmacological framework. This situation gives rise to an aspect that Bourdieu brought to light in his *La misère du monde* (BOURDIEU P. ed. 1993: 337-350): psychiatric caregivers represent, in this case, those members of the street-level bureaucracy who experience directly, personally, the contradictions of a State in which the right hand of public finance prohibits itself from knowing what the left hand of social service agencies is doing. In this way, an incident which develops starting from the patient's elevated process of subjectivization can brings to light some structural contradictions of the current situation of public psychiatric health service.

The progressive transformation of local health departments into autonomous agencies is the result of a new administrative policy that has had a heavy impact on the public health care system. This amounts to a structural change in the public health system in which a business model and the language of economic rationality have begun to take the place of past struggles for expanded patients' rights. It is a phenomenon that is part of the larger panorama of welfare policies in Europe and that has affected regional governments in Italy, making budget cuts a priority even with respect to mental health. In some cases this change has met for caregivers involved in community mental health, one of the most advanced sectors of social experimentation, a step backwards into the medical management of social contradictions. Today many caregivers and social workers are asking themselves what might happen in the face of the current attack by the parliamentary majority on the Psychiatry reform law (*Legge 180*), if in fact dynamics of de-socialization of disorder and of repression of social conflicts have already widely penetrated the classificatory logic of the management of social services.

If the separation of responsibilities and actions of caregivers were to find economic recognition only in the hospital model of medical care, all support would be removed from the objective articulated years ago by Franco Basaglia: to bring the contradictions of psychiatry into medicine.

> «One of the important things about the new Italian law is not so much and not only the question of the closing of the asylums, as it is the insertion of psychiatry within the health assistance program, because the true asylum is not psychiatry but medicine. And it is on this new asylum that we've got to act. At the moment that psychiatry as a social fact enters into medicine there develops an enormous contradiction, and it is from this point of view that I consider very important what will happen in the future, not because medicine might be able to resolve the contradictions of psychiatry but because all of the contradictions of psychiatry will also become part of medicine» (BASAGLIA F., ONGARO BASAGLIA F. - GIANNICHEDDA M. G. eds. 2000: 181-182).

As we have seen, in the local context, patients use a religious language to communicate those conflicts that staff members recognize in the administrative policies of the psychiatric service, but which they have trouble noticing in patients' embodied knowledge. In such circumstances, recognizing subjugated or marginalized kinds of knowledge is not only a step toward socializing the experiences of patients, but also a step toward understanding power relationships, points of resistance and emerging practices (19). In this regard, failure to deal with the embodied knowledge of patients and psychiatric workers means not being able to recognize new forms of subjectivity and community resources for the social formation of a new "collective will".

This political issue seems to me rather interesting also for ethnographic practice. Indeed, the staff proposal to redefine the practices by effecting an analytical separation between play and game recalls the complex relationship between habit, acquired ability, and ludic sensibility. In particular, the staff members' attempt to elaborate the violence implicit in athletic competition recalls, in fact, a problem relative to imagination that becomes an instantaneous embodied act. One way of exploring these contradictory processes may be to consider in our "embodied ethnography" (TURNER A. 2000) the intersubjective dimension in which practices are acquired, and the situated experience of participation or non-participation in such practices. In this research on agency and molecular transformation of the agents (including the ethnographer), it might be ethnographically fruitful to examine the different games played by the same agent and how those games have meaningful relationships to the mimetic formation of habits.

Such problem was well rendered by Walter Benjamin in two essays on play. In the first, having to do more with play as the acquisition of childhood habits, Benjamin emphasizes how repetition contains in a veiled form the element of invention and discovery tied to the initial acquisition of a practice.

> «Habit is born as play, and in habit, even in its most rigid form, a small residue of play survives right up to the end. Petrified and no longer recognizable forms of our early happiness, of our first horror – that's what habits are» (Benjamin W. 1993a [1974-1989, 1928]: 91).

In the second essay, on gambling, and specifically on roulette, Benjamin focuses on those instants in which the gambler does not let himself be carried away by risk and uses his body to choose the number to bet on. He writes:

> «The authentic player effects his most important bets, which are usually also his luckiest ones, at the very last minute. One might think that he is inspired by the characteristic sound the ball makes in the instant before it falls into a slot. But it could also be sustained that only at the last second, when the tension is at its peak, only in the critical moment of danger (when there is a risk of letting the opportunity slip away) there becomes activated in him the capacity to orient himself on the gaming table, to read astutely the numbered cloth, if 'read' were not once again derived from the field of optics» (Benjamin W. 1993b [1974-1989, 1928]: 602).

Benjamin does not oppose the experience of risk, the wager, the game of gambling, against his intuitions concerning the bonds between play and the acquisition of practices/habits. He is interested in seeing the deep bonds in the opposite direction of that which leads from play to habit. To the fact, that is, that it is not only possible to explore the path that goes from play to habit, but that it is also possible to see in the inverse direction the passage from acquired technique to the movement of the embodied subject in the instant of danger: the instant in which thought and decision are *motor innervation* (20). The gambler's "sensitivity" thus resides in his capacity to let himself be receptive to the impulses of the "lightest innervation." Play thus represents the "acceleration in the central point" in the moment of danger (Benjamin W. 1993b [1974-1989, 1928]: 603).

We can now consider in this regard two interesting aspects of "ethnographic practice". In the first place, it is not only inopportune to attempt to separate the agonistic from the aleatory (in the terms of Caillois R. 1995 [1967] the *agon* from *alea*), but it is ethnographically fruitful to examine the different games played by the same agent and how those games have meaningful relationships to the mimetic formation of habits. Habit understood as body technique and sensuous knowledge tied to a two layered notion of mimesis: «a coping or imitation, and a palpable, sensuous connection between the very body of the perceiver and the perceived» (Taussig M. 1993: 21).

Secondly, such elements are central to an understanding the agency of agents constantly involved in intersubjective spaces, even when they seem to be subject to material and symbolic isolation. The dynamics of the game itself and the criss-crossing of different social fields allow us to place action in an intersubjective space, which produce particular forms of knowledge about the persons involved. In the specific case considered here, my nostalgia, mentioned at the beginning, that seemed to be imposing itself in my re-evocation of football, might thus have a corresponding side embodied in the practical experience of the game. And therefore the disturbing effect of the juxtaposition of football and power relationships could have activated, in Benjamin's terms, a sort of dialectic between "habit" and innervation in the ludic sensibility of my own body (Benjamin W. 1993a [1974-1989, 1928], 1993b [1974-1989, 1928]).

Along this line of research it might be propitious to conclude evoking a "dialectical image" (cf. Benjamin W. 1997 [1974-1989, 1942]) invented by Antonio Gramsci in one of his youthful writings. In that text, Gramsci compares the image of football with that of a card game ("*lo scopone*"), to observe how in the card game the «perverse plotting of the brain» becomes bodily movement and the reciprocal diffidence is played out in a «strategy of the legs and the tips of the toes [*una strategia delle gambe e della punta dei piedi*]» (Gramsci A. 1960 [1918]: 433).

Notes

(1) With the expression "collective will", which is directly related to political will, Gramsci wishes to focus attention on a particular form of human action: «will as operative awareness of historical necessity, as protagonist of a real and effective historical drama» (Gramsci A., Gerratana V. ed. 1975 [1929-1935]: III, 1559 / English translation: 130). A will that, in his view, supports precisely «Those historico-political actions which are immediate and imminent, characterised by the necessity for lightning speed, can be incarnated mythically by a concrete individual. Such speed can only be made necessary by a great and imminent danger, a great danger which precisely fans passion and fanaticism suddenly to a white heat, and annihilates the critical sense and the corrosive irony which are able to destroy the "charismatic" character of the *condottiere* (as happened in the Boulanger adventure)». (Gramsci A. 1975 [1929-1935]: III, 1558 / English translation: 129). In this passage Gramsci seems to have in mind also what happened with the emergence of the European dictatorships at the beginning of the 20th century. And perhaps this is why his analysis seems to be analogous to what Walter Benjamin would write some years later with regard to the "state of exception" in his *Thesis on the Concept of History* (Benjamin W. 1997 [1974-1989, 1942]). In this specific instance, however, Gramsci is interested in understanding those molecular transformations that will go on to form a "collective will."

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(2) On “molecular processes” and “body politics” in Antonio Gramsci see Pizza in this volume. In this regard, as Ronald Frankenberg has remarked, following the approach of Gramsci on Marx, it may be opportune to explore the experience of the practical and practicing human subject, considering the body and embodiment as “the action zone” (Frankenberg R. 1990: 188-189). Tullio Seppilli (Seppilli T. 2002) has recently suggested paying careful attention – via Gramsci – to a well-known passage of Marx’s *The German Ideology*: «The production of ideas, of conceptions, of consciousness, is at first directly interwoven with the material activity and the material intercourse of men, the language of real life. Conceiving, thinking, the mental intercourse of men, appears at this stage as the direct efflux of their material behaviour. The same applies to mental production as expressed in the language of politics, laws, morality, religion, metaphysics, etc. of a people. Men are the producers of their conceptions, ideas, etc. – real, active men, as they are conditioned by a definite development of their productive forces and of the intercourse corresponding to these, up to its furthest forms. Consciousness can never be anything else than conscious existence, and the existence of men is their actual life-process» (Marx K. - Engels F., Arthur C.J. ed. 1998 [1846]: 68).

(3) When we consider the processes of hegemony examined in the works of Ernesto de Martino it becomes apparent that his analysis of the crisis of presence unfortunately develops only a part of Gramsci’s reflections on the internal dialectic of subjectivity and the molecular transformations of the “persona” (Pizza G. 2001-2002, 2003). It might be fruitful, on the one hand, to extend those reflections in the direction of the relationship between “individual presences” and “collective presences” (cf. Signorelli A. 1997 on this theme with respect to the subordinate classes in the South) and on the other, to explore the formation of the “collective will” in de Martino’s work (uncompleted) on psychopathological apocalypses (de Martino E., Gallini C. ed. 1977).

(4) In particular where Deleuze argues that for an adequate interpretation of the processes of subjectivisation we need to consider the historical transformation of disciplinary devices. In Foucault devices are a peculiar combination of regimes of visibility and regimes of discourse (Deleuze G. 2002 [1989]: 65). The reference to *subjectivity* in Foucault is a rather complex and controversial question, while what he calls the *process of subjectivization* seems to be more concrete. The term subjectivization refers to those social processes in which an individual is transformed into a subject in accordance with specific power relationships. I believe it is important to clarify that such subjectivization processes are not exclusively tied to disciplinary or restrictive actions, but belong to those practices of self consciousness that permit introspection and narration, the construction of one’s own actions as a “responsible person” and “citizen”. In Foucault, the term subject has essentially two meanings: «subject to someone else through control and dependence, and subject tied to one’s own identity by consciousness or by self-consciousness» (Foucault M. 1989 [1982]: 241). On biopolitics and the interaction between processes of objectivation and subjectivation in the social and historical production of health see Fassin D. 2000.

(5) On this aspect and on the relationship between Foucault’s thought and Basaglia’s work see Di Vittorio P. 1999. A critical anthropology of the psychiatric practice could grasp, in lively social action, two questions that permeated the intellectual and political field of those years: I’m referring to the rather contradictory conjunction between “dynamics of subjectivization” and “the crisis of the subject” in contemporary philosophy (see Passerini L. 2003: 46-69).

(6) On relationships between intersubjectivity, intercorporeality and agency see Crossley N. 1995. Aaron Turner used the concept of “socially constituting configuration” referring to «the configuration of subjects who are present, and are therefore actively involved in negotiating cultural practices and the meanings drawn from them. Since the anthropologist will generally be examining processes among configurations in which they themselves are present, this socially constituting configuration should be seen as a socially constituting ‘we’ or ‘us’ rather than socially constituting ‘them’. At any one time and place this collective constitutes the embodied subjects doing culture» (Turner A. 2000: 56-57).

(7) In Italy, there are interesting experiences of implementation of social networks and mental health policies based on sport activities of psychiatric users. Cfr. Cardamone G. - Missio G. - Zorzetto S. 1998, Cardamone G. - Zorzetto S. 2000.

[8] On the relationships and conflicts between the expert models used by therapists and their patients' immediate experience and knowledge, see van Dongen E. 2002.

[9] The research was carried out between November 1998 and June 2000, in a Mental Health Centre in the territory of Gubbio (province of Perugia, Umbria).

[10] On the social construction of male gender in football practices and discourses see Hughson J. 2000. On football as national narrative in processes of (individual and collective) identity formation see Pardue D. 2002.

[11] Football must be viewed as part of a lager sphere of rehabilitative activities promoted by the Mental health center. Unlike other such centers operating in the region, the staff of the outpatient psychiatric service in Gubbio has opted against the constitution of a semi-residential center to be visited by all patients seven days a week. It has been decided instead to diversify the activities, on the basis of the interests and requests of users, and not to organize schedules and procedures on the basis of the available resources and abilities of the staff. This means that each patient can attend one or more activities of his choice on some days of the week, and that the Center for psychiatric rehabilitation does not require the continued presence of the patients throughout the entire day (it does not, for example, provide for lunch inside the center). Thanks to this flexibility, a rather high number of users, about 60 people, habitually attend one or more activities of various kinds: theatre, reading and writing, music, cooking, painting and images, audiovisual production, *bricolage* (construction of small objects, mostly toys, in wood), photography, study and organization of nature outings, postural gymnastics, swimming, five-on-five football. Each patient follows a plan which includes the activities of the Center for psychiatric rehabilitation as well as job placement, pharmacological therapies, consultation with family etc. Each rehabilitative activity provides, therefore, for each patient a double focused project – individual rehabilitation/therapy and group activities –, agreed upon with the psychiatrist and followed by a social service staff member. At the end of each day, the social service staff involved in the various activities fill out a register with the attendance and a specific "activity diary". The Center also hosts weekly and bi-weekly group meetings. The situations of individual patients are also discussed in other meetings, formal and informal, between staff and therapists during the daily activities of the center.

[12] A relationship that is particularly complex in the case of a diagnosis of schizophrenia, which has tended to be filtered through interpretive models of a medico-psychiatric nature.

[13] See the metaphor for the "administration of justice on earth" represented in a football game suggested by Bromberger (Bromberger C., Casalino L. ed. 1999 [1995]: 84-85).

[14] To understand social workers' attention directed to "observation" of the game it must be recalled that five-on-five football is the activity in which social service staff have greater autonomy with respect to other psychiatric service staff. There is a greater delegation on the part of the psychiatrists and this means, in certain ways, an additional burden of responsibility for social workers: if something seems not to be working they are more on their own in making decisions.

[15] All names used in the text are fictitious.

[16] On the relationship between strategies and tactics see de Certeau M. 1990: XLV-XLVI.

[17] Intervention in the denomination and classification of a behaviour, a disturbance, or personality trait, as is well known, is decisive in psychiatric contexts. These are precisely the cases in which "classification" is the essential terrain of political contest. A contest that can be reconstructed by referring to the circumstantial combinations of action and embodied knowledge made by agents involved in negotiations for their own recognition (Bourdieu P. 1988 [1982]: 121-131).

[18] This is one of those moments in which the boundaries and the division of roles are most marked. Here the differentiated access to knowledge between staff and patients was most clearly determined, and I was much close to the latter. In such circumstances I had to work on glances and, therefore, to think over the limits imposed on me by my "positioning" in the interactions. I'm referring to the redefinition of boundaries around the cognitive and emotional sphere of the patient which is involved in psychiatric daily work: tone of voice; restricted communication in groups of two or three people; the closing of doors through which one can only see those on the other side staff-members entering and exiting; their doing things with attention that in other

moments are merely part of the slow and constant flux of ordinary routine actions. In fact these are the moments in which I most experienced the changing game of nearness and distance in which my presence involved the staff.

(19) On the interaction between social practices and "emergent forms" see WILLIAMS R. 1980: 31-49.

(20) The idea of *innervation* was developed by Benjamin both in writing concerning theatre and childhood and in studies on the poetics of Surrealism. The discovering of new practices in the playful acquisition of habits is microscopically explored in BENJAMIN W. 2001 [1997, 1938].

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4.3 *The loneliness of fetishes. Some reflections about the policies of ethnopsychiatry arising from a recent French debate* (1)

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In this contribution I would like to present some reflections about the policies of ethnopsychiatry. It is a very large issue, that concern many aspects of the work that some anthropologists as well some psychiatrists are carrying out in different countries, in Europe and elsewhere.

In the last two decades European ethnopsychiatry has experienced a very important turn, shifting from a previous traditions where the studies were focused mainly on the different categorization and healing practices of what in Western tradition we call mental illnesses to a new field of research. I mean the study of the mental problems involving the migrants that come in European countries coming from the former colonies. The spreading of migratory phenomenon in our countries runs with the spreading of those studies.

The idea is that those who are now coping with this migrants are often facing different therapeutic traditions. Culture has become an important issue in researches in this field as well as in the clinical work. A conspicuous number of psychiatrist cope now with culture and claim the relevance of the different cultures and therapeutic traditions in their clinical work. Our journals publish regularly articles and case-studies devoted to these issues.

As I told, my main concern is with what I call the policies of ethnopsychiatry, that is to say how the theories and practices play a political role in the arenas of our countries. I claim in that there is nothing new. Since the '40, when J. C. Carothers at Mathari mental hospital in Kenya coined the term "ethnopsychiatry", it has played (with his theories and practices) a very important political role contributing to define – together with other theoretical and practical tools – the reasons which has justified and mystified the power relations between colonizers and colonizeds.

I would like to discuss this issue focusing at the beginning on the recent debate about the aim and nature of ethnopsychiatric work, and then to turn back to the first ethnopsychiatrists in order to try to analyse it in a genealogical perspective.

1.

In these years a very violent polemic about the policies of ethnopsychiatry has taken place in France. Also in Italy some researchers have written articles about it (Coppo P. 2000; Beneduce R. 2001). The focus, or it would be better to say the main character, of polemics is the theories and clinical work of a very prominent French ethnopsychiatrist: Tobie Nathan. His main opponent is a well-known French anthropologist who is also a medical doctor and who has been working for many years in Africa: Didier Fassin.

Tobie Nathan is surely one of the most known ethnopsychiatrists, and his work has fascinated a large portion of the French intellectual landscape. For instance the science-philosopher Isabelle Stengers has working with him and also written a book with him (Nathan T. - Stengers I. 1995). Besides a famous intellectual as Bruno Latour has written a booklet about the his work (Latour B. 1996), and has written also articles in magazines and newspapers.

Many magazines and newspaper have published articles or reviews about Tobie Nathan and about his books, sometimes have also published very critic, or even polemic, articles against his work: it is, for instance, the case of "Le Monde" and "Le Nouvel Observateur".

Tobie Nathan is a very controversial figure, but he surely is one of the most known French, or maybe European, ethnopsychiatrist. In the last years various research and clinical centers devoted to ethnopsychiatry, in France as well as elsewhere, have started to work following his theories and methods. Articles dealing with his work and his theories have been published in different international journal, among which: "Transcultural Psychiatry" (Corin E. 1997; Freeman P. 1997; Streit U. 1997).

Tobie Nathan is a George Devereux pupil, then he comes from the most prominent and influential European school of ethnopsychiatry. Nathan's relation with his master is in different ways very controversial. In different occasions, in writings as well as in interviews, he has deeply thinks over this relationship. Anyway he never has refused his filiation from George Devereux.

Tobie Nathan was born in Egypt, in a family belong the Cairo's Jewish minority. After the Suez question in 1956, he escaped with his family from Egypt and, after passing a period in Italy, settled in France. It is there that he became a psychologist and met George Devereux becoming a pupil of him.

I do not want here to illustrate exhaustively Nathan's theories and practices. I am not a Nathan biographer, and I did not carry out any study on his *opera omnia*. I prefer to refer to the current polemics just to propose a reflection on the policies of ethnopsychiatry. Or, as it would be better to say, about the possibility that the ethnopsychiatry itself could be considered, both as discipline and clinical practice, a political tool. Obviously, it is necessary understand which kind of tool and for which policy.

To do that it is necessarily to briefly outline the Tobie Nathan's work and then to summing up the main terms of the current polemic.

I would like to start describing the clinical encounter between Nathan and the migrant patient. First of all, against a well rooted Western tradition, it is not a "face to face" encounter, it is rather a plural one. This is true in different senses. The therapist is not alone: he is surrounded by other therapists, which have studied with him. Most of them came from not Western countries and are invited, during the clinical session, to interpret the patient trouble not only with looking at them from a Western psychology perspective, but also using his own home traditional knowledge. Then from the side of therapists there are different people; they share a common knowledge – that is to say the psychological one –, but at the same time every one carry in the therapeutic setting a knowledge which came down from his\her homeland traditions. Moreover everyone bring on the therapeutic scene his\her own mother language. As we shall see later, the language is a very important topic in Nathan's construction of individual, and ethnical, identity. The patient also does not came alone. He can choose to came accompanied by relatives, or a ethnic community leader, or even a social worker. This present a very close analogy with what usually happen in African traditional therapeutic setting, where the patient goes to the healer with relatives or prominent community leaders. Then the patient side is, as well as the therapist's one, plural. In this side everyone can talk about the trouble and even give his/her own interpretation of the problem.

The latter is a point stressed by Tobie Nathan. In answering to Didier Fassin he insisted on the plural character of his therapy. What does it mean?

According to Tobie Nathan, his own therapeutic setting is not only plural, but first of all *horizontal*. His setting, according to him, makes void the hierarchy present in classical Western clinical setting. There is not a therapist who hold the knowledge and a patient who must accept his knowledge and his prescription. Everyone contributes to the creation of diagnosis and healing process.

Tobie Nathan in describing his method writes:

> «About twenty chairs are disposed in a circle in a large room. When the patient enters (very often accompanied by some relatives, or social and health workers he trusts) the co-therapists are already seated to their chairs. The co-therapists are "living mediations", because they are of different origins and able to manage with traditional languages and interpretation systems. But they have also achieved a degree in French universities (psychiatrists, psychologists, teachers, sometime – but rarely – anthropologists; all of them have experienced a psychoanalytic work). All are seated in a round, no place is different from the others and then the whole make possible to think at the setting as a collective work» (NATHAN T. 1996 [1993]: 55).

During the sessions everybody talks. Once the patient has told his story, and explained his troubles, the long thread of interpretations start to be unraveled. Everyone proposes his own view of the problem; it can be rejected or, more often enriched through the discussion or the disclosure of new details. There is not a theoretical framework which has a prominent place in the interpretative work.

«By passing incessantly from a cultural area to another, this practice alternates a multiplicity of theoretical universes. It is "multi-theoretical" by nature. It does not rest on any wide theoretical concept, therefore invites to detailed analysis of processes» (NATHAN T. 1996 [1993]: 56)

According to Nathan, his method avoiding to give a hierarchy of interpretations can be seen as democratic.

Nathan, in his clinical work, has never used traditional healers. Though he trusts their methods and often does fieldwork in Africa in order to improve his knowledge of traditional systems of thought and therapy. Anyway the traditional way of thinking about mental troubles are very important in his work. This is why he hold a precise idea of culture. An idea that remind those of fifties and sixties anthropologists. In fact Nathan, in the last years, has often attacked the anthropologists, accused by him to have a very "weak" concept of culture.

According to Nathan there is an equivalence between language and culture, they are interwinned. A language is a distinctive mark of a group and it is the main vehicle for the culture. To define a language it is necessary that it can not be understood by people which do not belonging to the group. «In other terms the language is not a generalised system of exchange – that is to say that it can be understood by everyone eves if he or she does not any tie with the speaker – it is restricted to the closed group which practices it. In other words, it needs that the Bambara, to be defined as language, become "dull" for Soninké, Peul or Wolof languages» (NATHAN T. 1994: 83).

Ursula Streit describes, maybe in a too uncritical way, the Nathan's ideas about the relationship between language and culture:

> «Nathan tries to define the function of the cultural system in the construction and homoeostasis of the psychic apparatus. He suggests that "culture is the system which not only gives coherence to the social sphere, it is also the internal system of individuals which ensures the closure of their psychic space" (NATHAN T. 1994: 176-177). The core of a cultural system includes: language; theories concerning the nature of the person and, more specifically, the nature of infant; theories on the nature of the afflicted and of disorders (which ore interrelated and often redundant). He sees this basic core as substantially closed to outside influence and compare it with the system of language "which only can be a system of generalized exchange, and not a private code, if it is coherent, almost closed and hermetic towards other languages (NATHAN 1994: 178)» (STREIT U. 1997: 335-336).

From this theory of language and culture becomes a very important consequence. The concept of a "uniqueness" of therapy. The Western clinic, at least on the "psy" ground, fail in healing the migrant because they belong to other cultural universes. A man is building by his ancestors, his gods and the myths of his groups. One cannot escape that. To heal a Bambara we need to find a *bamanan* – a Bambara traditional healer – because «he is the only one who hold the knowledge to heal a Bambara (INGLESE S.F. 1996: 130). In other words, within the Nathan's framework a Senegalese migrant is forced to be for ever a Bambara. In this way Nathan creates a strange hybrid that, from a hand, seem to work with the alternance of paradigms (from the psychologist's one to the patient's one), to the other seem to rest on the specificity of the patient cultural universes. The consequence is the idea that the "cultural worlds" can dialogue between them only in a very difficult and specific way. On the other hand, the Nathan hybrid reaffirm strongly the idea of a cultural specificity, and even more of the great relevance of cultural roots and origins.

2.

It is against those ideas that Didier Fassin mainly focused his polemic with Tobie Nathan.

It is not the first time that Nathan is involved in polemics. Often they have been very heavy and violent. In the last years for example, he has been involved in discussion regarding the quality of his work of collecting ethnographic data, and – in another occasion – regarding the results of his clinical work. He was accused to not give any data about follow-up, then it is not possible to understand if his patients have really improved through his therapeutic work. In both occasions the polemics were very violent, and Tobie Nathan has answered energically to the accuses moved to him.

I think that the current polemic with Didier Fassin is very different from the others. It is not a problem of intensity, or hardness. What is different now it is properly the kind of object in question. The Fassin argumentations against Nathan challenge the theoretical frame of Nathan's ethnopsychiatry and put the question of its political role.

In 1999 Didier Fassin publish on the French review "Genèses. Sciences sociales et histoire" an article with a very explicit title: *L'ethnopsychiatrie et ses réseaux. L'influence qui grandit* (FASSIN D. 1999). The arguments he raised against Tobie Nathan are very hard. At that point, in any case, they not challenge the whole frame of his ethnopsychiatry. In fact the article was focused mainly on the French intellectual network which during the last ten years has worked with, or on, Tobie Nathan; and on what they have written about him and his clinical centre. Fassin used the concept of network to try to explain the reasons of the Nathan's fame among the public institution devoted to the migrants care and among a larger part of public opinion. He suggested the hypothesis that the fame achieved by Tobie Nathan rest not only, or it would be better to say not mainly, on the efficacy of his method, rather rest on the relationship he has created with these prominent intellectuals. The title of the article is, to this regard, explicit. *L'influence qui grandit* is a word-game based on a well-known book written by Nathan and titled *L'influence qui guerit*. The *influence* is not of use to heal, rather it is very useful to increase his social position. As one con see, it is a very violent attack. It is, in any case, limited to the Nathan's skill to form an alliance with some prominent intellectual figures.

Fassin wrote another article about Nathan and ethnopsychiatry. The article was published by the most prestigious French anthropological journal: *L'Homme* (FASSIN D. 2000). In this case Fassin made an attack to the whole theoretical framework of Natahn's ethnopsychiatry, and probably to the political functions that the ethnopsychiatry, as discipline and practice, has assumed from its origins.

The article has a precise rhetorical construction. It is played on the comparison between the Nathan and Carothers practices. J.C. Carothers, a medical doctor, was in charge as director at the Mathary mental hospital in Kenya during the forties and fifties. Taking advantage of his position he carried out many researches about the mental illness in Africa. More in general he was concerned with the "African mind" in health and disease, to quote the title of the most known book of him. He was surely a prominent and influential figure among African psychologists and psychiatrists. His researches and writings were favourably received by the psychiatrical and also anthropological communities. His fame was so wide that the WHO asked him to write a book on African psychology and psychopathology (CAROTHERS J.C. 1953). Besides he was probably the first to use the term ethnopsychiatry. Which kind of ethnopsychiatry was he carrying on? It was a form of psychiatry that today with a polite term we call "differentialist", but if we want to be clearer we have to call it simply "racist".

In his article Fassin refers to a booklet of Carothers devoted to the analysis of Mau Mau rebellion in Kenya colony: *The psychology of Mau Mau* (CAROTHERS J.C. 1954). It was a report commissioned to him by the English government, when he was already retired from his charge at Mathary hospital. The English government asked him to carry out a research to explain the real and deep reasons of the Mau Mau rebellion in order to became able to prevent other rebellions.

It is important to stress that now it is well acknowledged among historians and anthropologists that Mau Mau rebellion was an anti-colonial and nationalistic movement which arose, mainly among the Kikuyu, from the claiming the rights to the land expropriated by English colonizers. In short it was a political and class movement.

Carothers in his booklet is not concerned with this kind of reasons, nor analyses the political motivation of the rebellion leaders. He assumed that the real and deep reason of the rebellion was to be find in Kikuyu mentality and psychology. According to him the Kikuyu (but he said the same things for all the Africans) were individualistic, cunnings, litigious and with a great tendency to secrecy and violence. Frustrated in their desire to became like the British they would have developed against them resentment and grudge. As Fassin stresses (FASSIN D. 2000: 235), a socio-political phenomenon is reduced by Carothers to a psychopathological one, utilising traits of Kikuyu culture (or it would be better to say of a cultural stereotype) and features of their supposed personality. Besides he utilised also the idea of the psychical upsets provoked by the collision with Western civilization and society. I would like just to stress that the Carothers analysis is not the only case where the psychology is used to explain the anticolonial rebellions. The same has done by Mannoni examining the Malagasy rebellion (MANNONI O. 1950; BLOCH M. 1997). The attitude to explain the local rebellion through a psychological framework or, more precisely, using the theoretical framework of the clash of civilizations and the cultural stress due to the exposition to the urban and westernised lifestyle was almost spread in that period (cf. MOORE S. F. 1994). We can say that it was a very common way to cope with the arising anticolonial movements, even though in the case of Carothers and Mannoni it was supported, and reinforced, by a specific psychopathological framework.

According to Carothers the Kikuyu personality, the urban life, so far from their traditional way of living, and the stress provoked by that were the real causes of the rebellion. For him, with great satisfaction of English government and English farmers in Kenya, the land rights were not important at all. The solution he pointed out was very simple. It needed to drive the Kikuyu, and the other natives as well, away from the towns and to gather them in villages in order to allow them to find again their ancestral way of living that could fit their needs better than the modern Western life.

An Australian historian, Jock McCullock has written regarding the Carothers booklet:

> «With Carothers's monograph the science of ethnopsychiatry formally entered the domain of political action. *The psychology of Mau Mau* showed how well suited ethnopsychiatry was to the shaping and rationalization of conventional settler beliefs about Africans. It was the only science that was capable of providing a strictly hierarchical definition of human nature, and in that sense it was the one science whose shibboleths corresponded perfectly with the structures of colonial societies» (MCCULLOCK J. 1995: 71-72).

According to Fassin the original sin of ethnopsychiatry rest in the attempt to "culturalize" the "other people" psychic troubles without paying attention to the social causes. In the current work of most ethnopsychiatrists, he said, it is still possible to find the same "original sin".

In fact Fassin accuses Nathan to hold the same inclination. Nathan's theories and practices propose, according to Fassin, the same culturalist paradigm.

The Nathan ethnopsychiatry insists, as I have showed before, on the traditional therapies. First of all he strongly claims everybody can be really healed only using the therapeutic operators of his own home culture; that it is to say healers, gods and fetishes. In this way Nathan, according to Fassin, push the migrants back to their original cultural horizons, and denies the possibility they can open towards different cultural horizons.

Summing up, once again, as in Carothers time, the ethnopsychiatry insisting on the relevance of the cultural of origin, that seems to be for the migrants something like a fatal embrace, risk to become – or maybe effectively is – a good allied for xenophobic and racist policies, giving them a sort of scientific sanction.

From this point of view, and this is very important to my opinion, the Didier Fassin violent attack involve not only the Nathan's version of ethnopsychiatry, but the ethnopsychiatry as discipline and practice or at least the "culturalist side" of it.

Nathan answers vigorously to this attack. In a long article (NATHAN T. 2000) he reaffirm the efficacy of his method and insist on his democratic character. He said his clinical work, as I have described it above, tend to erase the distance between therapist and patient. It allows to have both the same dignity in the clinical setting. In his clinical work the psychological knowledge belonging to Western tradition has to face openly the traditional therapeutic knowledge of his patients home countries. It is from the confront between these two forms of knowledge that arise the solution of the problem which affect the patient.

Nathan refuses the Fassin accusations about his culturalist inclination. He also refuses, with more energy and open disdain, the accusation to be, consciously or more probably not, on the same side with whom want to establish xenophobic and racist policies and practices. He affirms that behind Fassin's argumentations and accusations is hidden a neo-stalinist practice which want to criminalize the adversary.

Anyway Nathan lacks to give a convincing and clear answer to the most important and serious of Fassin accusations: to conceal the social dimension in favour of the cultural one. In other words, to deny that power relations, social inequality and marginality count as, or more, the one's own culture in developing pathology and in what is played within the therapeutic setting.

3.

These are the main polemic features. It is not my intention to take the part of one or another. I think it would be a useless exercise. Surely the Nathan practice, as well as his theories, are in some ways very interesting. They open new space of reflection and research, into the relation between pathology and culture and about the place of culture in therapeutic process.

At the same time it is necessary to stress, as Fassin did, how some position of Nathan are very perilous. His very old-fashioned idea of culture, as a whole which can be handed down through generation, as well as the idea of a strictly equivalence between language and culture are to my eyes not convincing at all. First of all, what is very riskily in his theory, and in that a agree with Fassin, it is the idea that every culture can be seen as separated by the others, and that any individual can find his way to cure himself and, of course, to heal only within his own culture. If we transpose it in a political level, we risk seriously very dangerous consequences.

Why do I choose to discuss about this polemic in a conference devoted to the anthropology at home? Because I think that it challenges a very important issue for our disciplines which is the political role they play or can play in our arena. To answer this question the ethnopsychiatry have a central place. Is it really so culturalist to conceal very important social question? And more, if it is true, does that attitude come straight from the beginning of the discipline.

Nathan comes from a very different tradition from the Carothers one. He is a pupil of Devereux, then his theoretical landscape is completely and radically different. Anyway it is true that something permits to compare Nathan and Carothers. Both of them, even if they are divided by forty years, deal with mental illness, but do not discuss only about that. Their theories rest on a more general theory about the specificity of the African cultures (according to Nathan) or about a more general idea about the so-called "African mind".

In his book McCulloch said a very important thing. Carothers did not deal simply with illness. The books he wrote, and mainly the most important one: *the African mind in health and disease*, are to be seen as an attempt to elaborate a more general theory on colonial citizenship. That it is to say that for Carothers the most important question was to understand if, and under which conditions, was possible for the Africans to became loyal imperial subjects and citizens. In other words, was it possible to imagine the Africans became more English? I would like just to remind that a similar question – with very different answers of course – was posed also by Frantz Fanon.

I think that behind the issue today we discuss there still is the problem of the theory of citizenship.

We discuss about integration, about deculturation or, as Nathan claims, some of us try to become the defenders of the traditional cultures threatened by the globalization processes.

I think the main problem which rises from the French debate, even if underlied, is not so far from the one pointed out by Carothers, that is to say the question of citizenship.

When – within the contest of the problems risen from the migratory dynamics – one discusses about integration or, on the contrary, when one emphasizes the irreducibility of the therapeutical systems, or even more when one claims for the uniqueness of any culture, the core of the problem is always the same: what is the place in the social arena for the new citizens.

Is it possible to discuss this issues, and the underlaid question of citizenship, without reflecting about the place we have to assign in our analysis to the social, economic and political questions?

These questions which resound the ones put by Fassin cannot be eluded.

To do that, in my opinion, it is necessary to proceed reflecting on colonial psychiatry; it cannot be considered as a settled history, on the contrary we have to deal with his (often concealed) legacies. On the other hand it is evident that it is not possible to discuss about the migratory dynamics without facing the social inequalities and the class relations.

I think we can agree with Ania Loomba when she stressed that the most important Fanon legacy to the current debate in ethnopsychiatry, and maybe in a wider range of our studies: how do we to interrelate the question of psychic oppression and trauma to the material, economic aspect of colonialism?

Ania Loomba writes:

> «While theories of language and the psyche have given us sophisticated vocabularies of subjectivity, we also need to think about how subjectivities are shaped by questions of class, gender and context. We need to peg the psychic splits engendered by colonial rule to specific histories and locations» (LOOMBA A. 1998: 179).

Notes

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□ Nel caso di più lavori di uno stesso autore o curatore pubblicati in anni diversi, i riferimenti vanno organizzati per ordine cronologico. Nel caso di più lavori di uno stesso autore o curatore pubblicati nel medesimo anno, i riferimenti vanno organizzati per ordine alfabetico (in base al titolo) e le date vanno contrassegnate con lettere minuscole progressive: esempio: (1990a) e (1990b).

□ Nel caso di un lavoro prodotto da più autori o curatori, i riferimenti vanno collocati *dopo* quelli in cui il primo autore compare da solo. Nel caso in cui il primo autore compaia in differenti lavori con differenti co-autori, la collocazione alfabetica terrà in conto ciascun insieme di co-autori (esempio: *prima* BIANCHI M. - ROSSI C., *poi* BIANCHI M. - ROSSI C. - NERI F. *e poi* BIANCHI M. - VERDI G.).

□ Nel caso in cui un autore risulti *anche* curatore di altro o altri lavori, questi ultimi vanno ordinati *dopo* quelli in cui egli è autore.

Altre norme bibliografiche

■ Laddove i lavori indicati in una vera e propria *Bibliografia* – laddove cioè non costituiscano oggetto di rinvio dal testo o da una nota e non siano dunque *riferimenti bibliografici* – la indicazione relativa alla data di pubblicazione può essere data anche in questo caso entro parentesi, dopo la indicazione dell’autore, o essere invece data dopo il luogo di edizione. Lo stesso vale nel caso di singole indicazioni bibliografiche isolate.

■ Per i contributi destinati a rubriche come *Repertori* o *Osservatorio* – curati redazionalmente o direttamente commissionati a singoli collaboratori – possono volta a volta valere nella costituzione delle schede bibliografiche criteri integrativi finalizzati a fornire un maggior numero di informazioni relative alle pubblicazioni (ad esempio le pagine complessive del volume o la sua eventuale collocazione in una collana editoriale) ovvero altri criteri concernenti invece materiali diversi quali tesi di laurea o di dottorato oppure documenti filmici o videomagnetici. Tali criteri saranno comunicati per tempo ai singoli collaboratori cui il contributo viene richiesto.

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