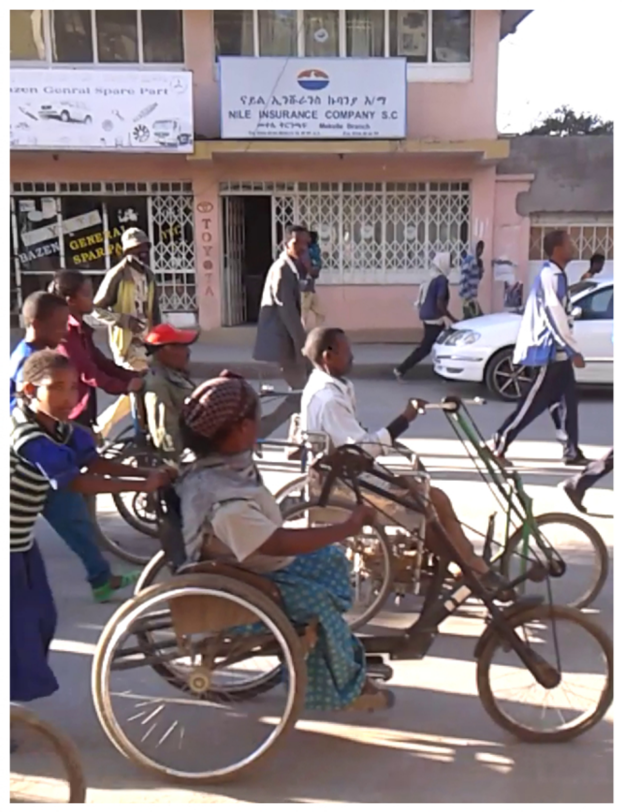
AM

50 / dicembre 2020

RIVISTA DELLA SOCIETÀ ITALIANA DI ANTROPOLOGIA MEDICA
FONDATA DA TULLIO SEPPILLI



Fondazione Angelo Celli per una Cultura della Salute - Perugia

In copertina

Sfilata per le strade di Mekelle (Tigray, Etiopia), in occasione della *Giornata internazionale delle persone con disabilità*. Foto di campo di Virginia De Silva (dicembre 2014).

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

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AM

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Editoriale

AM 50: un nuovo inizio

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Care Lettrici e Cari Lettori,

presentiamo qui il numero 50 di AM, il secondo della nuova veste digitale. La rivista è in corso di verifica e vi saranno ulteriori cambiamenti: la transizione non finisce, ma ci siamo.

Siamo a “un nuovo inizio” e tutto dipende da noi: abbiamo recuperato gli enormi ritardi di AM già con i tre volumi dal 2016 al 2019: 41-42 del 2016, 43-46 del 2017-2018 (firmati da Tullio Seppilli, in quanto egli li aveva già programmati e precedentemente messi in opera) e 47-48 del 2019 (che ricordo essere l’ultimo volume cartaceo).

Nel 2020 abbiamo raggiunto l’obiettivo più ambìto: rendere tutta la collezione di AM dal 1996 a tuttora liberamente disponibile in internet come Archivio, contestualmente all’uscita del numero 49, il primo di AM in edizione digitale.

Come già sapete la nostra rivista prosegue le pubblicazioni *online* con due numeri l’anno *open access* che vedranno un’uscita cadenzata nei mesi di giugno e dicembre con una programmazione triennale.

Grazie a tutte e a tutti per l’accoglienza gioiosa che ci avete riservato per questo traguardo: innanzitutto a coloro che hanno contribuito a realizzarlo, cioè alle colleghe e ai colleghi del Comitato di redazione della versione cartacea di AM, senza le/i quali non avremmo mai potuto ottenere questi risultati; a Cristina Papa e ad Alessandro Lupo, da lungo tempo compagni di lavoro solerti e leali, che hanno accettato di presiedere l’una la Fondazione Angelo Celli per una Cultura della Salute e l’altro la Società italiana di antropologia medica (Siam) con uno spirito di servizio tenace, competente e unitario; a tutte e a tutti i membri del Comitato scientifico, che contribuiscono a illuminare la nostra rivista, organo nazionale della Siam; ai colleghi e alle colleghe del Consiglio direttivo della Siam, che hanno accettato di far parte del nuovo Comitato di redazione dell'edizione digitale e, *last but not least*, a tutti e a tutte voi, lettori e lettrici, che seguendo la rivista e/o contribuendo a essa, siete il principale riferimento di AM.

«Tullio Seppilli sarebbe stato contento». È questa la frase che mi è più di tutte entrata nel cuore allorché abbiamo raggiunto la meta di portare AM su OJS. La nostra rivista ora appare sulla piattaforma dell'Università di Perugia e da qui può raggiungere tutti gli altri Paesi. Anche nella programmazione dobbiamo un po' ripensare il *target*. Abbiamo il compito di rappresentare all'esterno l'identità dell'antropologia medica italiana e grazie all'impegno di tutt* ce la faremo. Pur rimanendo un periodico italiano, guardiamo a un pubblico internazionale, composto dalle colleghe e dai colleghi di tutto il mondo (com'è noto, accettiamo saggi e contributi in diverse lingue: italiano, francese, spagnolo, inglese e portoghese), che sanno guardare all'ampliamento che la disciplina specialistica dell'antropologia medica sta vivendo nel momento contemporaneo a livello planetario.

Con l'uscita del primo numero digitale abbiamo avuto riconoscimenti internazionali importanti, da parte di colleghe e colleghi di prestigio; sono fioccate E-mail di congratulazioni da più parti, dirette a me solo perché in questo frangente sono il direttore di questo periodico, a testimonianza della grandiosa capacità di Tullio Seppilli di costruire reti mondiali nel campo dell'antropologia medica internazionale.

In effetti tutto quello che programmiamo, silenziosamente o loquacemente, lo facciamo nel nome di Seppilli. Certo con autonomia e responsabilità, ma non a caso portiamo avanti una rivista con iniziative nelle quali la sua presenza è molto evidente. E lo mostra questo numero 50, sia nella sezione monografica sia in quella generale.

Ospitiamo nella sezione monografica una selezione dei contributi più pertinenti per l'antropologia medica presentati, selezionati e riscritti per l'occasione da alcuni dei partecipanti alle due giornate di studio su *Antropologia medica & Disabilità* che organizzammo nell'ateneo perugino l'8 e il 9 novembre del 2019. Si trattò dell'esito laboratoriale collettivo, a opera di un gruppo che fondammo proprio raccogliendo la richiesta di coloro che furono i primi tre aderenti: Virginia De Silva, Fabrizio Loce-Mandes e Francesca Pistone, studiosi indipendenti che hanno svolto il loro dottorato di ricerca lavorando etnograficamente sul tema della disabilità e che al contempo hanno preso parte a diverse sessioni del 2° Convegno nazionale della Siam *«Un'antropologia per capire, per agire, per impegnarsi». La lezione di*

Tullio Seppilli, svoltosi all'Università di Perugia, il 14-16 giugno 2018, al quale abbiamo dedicato l'ultimo volume cartaceo di AM (ottobre 2019 / 47-48, con una selezione degli interventi tenuti alla sessione coordinata da Massimiliano Minelli e da me) e il primo numero digitale della rivista (giugno 2020 / 49, con le relazioni plenarie).

Insieme a Massimiliano Minelli, Andrea F. Ravenda e Nicoletta Sciarrino, dopo il convegno del 2018, abbiamo contribuito a configurare un gruppo di lavoro denominandolo AM&D. Una *équipe* che, accanto alla *Call* di quel seminario, ha scritto un documento comune, una sorta di *manifesto*, che qui di seguito riproduciamo per intero, anche perché da esso si evince il debito scientifico e politico che dobbiamo alla lezione di Tullio Seppilli:

> Il gruppo AM&D (Antropologia Medica e Disabilità) nasce dall'incontro di ricercatrici e ricercatori intorno alla tematica della disabilità, a seguito del II Convegno nazionale della Società italiana di antropologia medica (Siam) tenutosi a Perugia nel giugno del 2018 *«Un'antropologia per capire, per agire, per impegnarsi». La lezione di Tullio Seppilli*. Attraverso lo studio e la ricerca, il gruppo intende valorizzare lo spazio di azione della teoria e della pratica antropologica all'interno del campo della disabilità. Le prospettive di antropologia medica che perseguiamo non hanno l'intento di ri-medicalizzare o antropo-medicalizzare la questione della disabilità, ma evocano un'antropologia critico-politica del corpo, dialogica e sperimentale, incentrata sui processi di incorporazione, di ben-essere e, quindi, di salute. La disabilità emerge come un "campo", inteso sia come spazio di riconoscimento reciproco tra gli attori sociali, sia come terreno di contesa regolato da rapporti di forza. Ne risulta evidenziata la natura innaturale e storicamente determinata della disabilità. La pratica etnografica permette di connettere le esperienze più intime di condizioni "disabilitanti" con i discorsi pubblici e istituzionali; di analizzare le ricadute locali di processi globali, come la Convenzione delle Nazioni Unite sui Diritti delle Persone con Disabilità e i documenti delle agenzie internazionali; di mettere in discussione le categorie di "vulnerabilità", "marginalità" e soprattutto "funzionamento" e "abilità". I lavori scientifici del gruppo, nella loro pluralità, sono uniti dal filo rosso di uno sguardo critico e de-essenzializzante, attento alle politiche di dis-abilitazione di alcune categorie di attori sociali e a quelle di riconoscimento, al disvelamento dell'abilismo incorporato, alle retoriche di *empowerment*, di autonomia e di indipendenza coniugate in maniera specifica all'interno dei sistemi neoliberali. Si va dallo studio dei dispositivi dello sviluppo a quello delle pratiche di cittadinanza attiva, dalle esperienze del corpo nella sua continua relazione con il contesto in cui si trova alle infinite possibilità aperte da pratiche insorgenti. Nell'ottica qui delineata il gruppo AM&D si impegna in «attività di ricerca con finalità operative tese a fondare processi di consapevolezza e di liberazione» (Tullio Seppilli). Il gruppo

AM&D è composto da: Virginia De Silva (coordinatrice) / Fabrizio Loce-Mandes / Massimiliano Minelli / Francesca Pistone / Giovanni Pizza / Andrea F. Ravenda / Nicoletta Sciarrino.

Grazie a Virginia De Silva che ha accettato di coordinare il gruppo AM&D e di curare i due volumi che costituiscono in termini di pubblicazioni una selezione di qualità degli esiti di quel seminario di due giornate: la sezione monografica di AM e un numero dedicato a questo tema dalla rivista napoletana di *Disability studies* "Minority Reports". AM e MR si sono uniti in una sfida co-disciplinare: spingere l'antropologia medica e i *disability studies* a un confronto necessario, argomento sviluppato da De Silva nelle introduzioni a entrambi i monografici e più volte ripreso nei saggi successivi da lei presentati.

Inoltre, nella sezione generale, accogliamo scritti eterogenei, che vanno dalle analisi etnografiche sulla riduzione del danno, alla collaborazione transdisciplinare con esponenti della ricerca biomedica fino alla riflessione filosofico-antropologica sulla fondazione da parte di Ernesto de Martino del rapporto fra antropologia e arte.

Anche se in un'ottica del tutto nuova, riprenderemo progressivamente a pubblicare l'insieme delle rubriche che, nella loro ricchezza, caratterizzarono i primi anni della rivista, ispirandoci all'*Osservatorio*, ideato da Seppilli. Cominciamo in questo numero a ripristinare i *Lavori in corso*.

Infine, puntiamo molto sulle recensioni, un genere di scrittura non sempre difeso in Italia. Per noi esse costituiscono una parte indispensabile di AM, perché danno conto di volumi importanti, del presente, soprattutto, ma anche del passato, che a livello mondiale sviluppano la ricerca antropologico-medica orientandola in direzioni plurali.

È al termine di un anno particolarmente complesso che licenziamo questo numero 50 di AM, chiedendovi di continuare a seguirci come già state generosamente facendo.

Siamo ben consapevoli della mole eccezionale di questo particolare fascicolo, che, pure essendo singolo, si avvicina ad alcuni volumi doppi della collezione. Tale ampiezza non si ripeterà in futuro, ma ora essa sta a rappresentare il nostro omaggio alla memoria.

Grazie, auguri e saluti fraterni a tutte e a tutti coloro che in modi diversi sostengono la nostra amata AM.

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Rivista della Società italiana di antropologia medica / 50, dicembre 2020, pp. 481-502

Living with Peritoneal Dialysis in Trentino (North Italy)

Interdisciplinary Research Collaboration between Anthropology and Nephrology

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Abstract

Living with Peritoneal Dialysis in Trentino (north Italy). Interdisciplinary Research Collaboration between Anthropology and Nephrology

We illustrate how peritoneal dialysis (PD) is perceived and managed by people suffering of chronic kidney disease as an alternative to hemodialysis (HD). PD can be performed at home; HD requires hospitalization. PD is underused even if it seems to offer a number of potential benefits, among which increased autonomy and quality of life. Our article sheds light on how PD managment—including logistic, technical, social and emotional aspects—is mostly a patient's responsibility, while HD is carried out by health professionals at the hospital. The article, therefore, critically analyses the autonomy provided by PD and reconsiders its susteinability and costs in light of people everyday experiences of living with this technology.

Keywords: hemodialysis, peritoneal dialysis, ethnography, interdisciplinary research, chronic kidney disease

Introduction

Peritoneal dialysis (PD) is a therapeutic approach for people suffering from a renal failure or in advanced stages of chronic kidney disease (CKD), representing an alternative to hemodialysis (HD). Even if peritoneal dialysis has been available since the 1960s, its use is still limited. In the autonomous Province of Trento (northern Italy), a program to expand the use of the peritoneal method has been implemented since 2008, yielding remarkable results. Indeed, the percentage of PD patients increased from 8% to a maximum of 47% in 2013, decreasing to 29% in 2014. Despite this backdrop, the Trentino's case represents a model of best practice which has been analysed through a quantitative study (Zarantonello *et al.* 2015). The study aimed at understanding the encouraging and limiting factors influencing patients' choice for PD. In particular, the study focused on three main aspects: 1) Family area (family situation, need, and availability of family carers); 2) Personal area (age, physical fitness overall, autonomy in washing and eating, work situation, and distance from hospital); and 3) Cognitive-emotional area (ability to understand, emotional state, attitude to PD). Study's results urged for a qualitative research addressing the real meaning of answers, especially in relation to the "cognitive-emotional area." For instance, the study referred to macro categories such as "quiet," "insecure," "emotional," and "sad," but the actual meaning of these labels was not clear. Based on these premises, the present study aims at integrating the quantitative study performed by Zarantonello *et al.* (2015) with an anthropological perspective able to unravel the complexities of living with PD. Anthropological analysis may help to illustrate the specific aspects, impacting the overall evaluation and sustainability of PD, not captured by the quantitative analysis. Evaluation of these aspects may have value not only for nephrologists, but, more in general, for the design of health interventions introducing new and alternative technologies. Moreover, the study may have significance also for anthropology, since it may represent a proof-of-concept of the importance of integrating an anthropological perspective in health research in order to construct a joint and multidimensional definition of "evidence."

Peritoneal Dialysis vs Hemodialysis

Patients suffering from advanced stages of chronic kidney disease might need dialysis treatment to purify their blood and support their decreased kidney functionality. HD purifies patients' blood by an external machine, equipped with filters, membranes, and pumps. To receive the therapy, patients have to go to the hospital three times a week, each HD section lasting from three to five hours.

Differenly, PD can be done at home on a everyday basis. PD is a simpler renal replacement therapy, since it uses the peritoneum—the membrane covering internal organs—as a purifing element. PD introduces fluids into the patients' body through a permanent tube in the abdomen. The fluid can then be flushed out at night while the patient is asleep (9–10 hours, called automatic peritoneal dialysis) or during the day via regular exchanges (four times every four hours, called continuous ambulatory peritoneal dialysis).

Hemodialysis Examined

HD was first adopted in the 1940s, as a short-term treatment for life-threatening and acute kidney failure. In the 1960s, the approach found application as a long-term treatment for chronic and irreversible loss of kidney functions (Fox, Swazey 2002). HD grounds the imaginary of a body which can be replaced in all its parts through technology but, at the same time, it also reveals the limits and failure of biomedicine in restoring health. HD has been described as a "new life form in which death is increasingly brought into life" (Russ *et al.* 2005: 297), with 20% of dialysis patients withdrawing from therapy each year (Perry in Russ *et al.* 2005) due to either terminal state or deliberate choice. Patients who undergo HD must re-organize their life and their time, because dialysis is "both a time creating and a time-consuming process" (ivi: 304), which entails a progressive colonization of the patient's life by biomedical times and practices. According to Eugeni (2009), who has conducted an ethnography in a dialysis ward of a public hospital in Rome, HD needs disciplined bodies. In the terms of health professionals, "good patients" (Eugeni 2009: 16) are those that show to be responsible, complying with medical prescriptions, while "childish" (*ibid.*) patients are those resisting the increasing medicalization of their life.

Peritoneal Dialysis Examined

No anthropological studies have been published to date about patient's life under PD. A couple of qualitative studies (Petersson, Lennerling 2017; Rygh *et al.* 2012) based on interviews emphasized the increased autonomy and improved quality of life of patients choosing PD. However, these analyses did not contextualize the use of PD within a socio-political setting, neither critically inquiry, for instance, what "autonomy" could mean for a person suffering from end-stage renal failure. A number of studies conducted with a quantitative methodology showed that PD patients had a perceived quality of life comparable or even better than HD patients, which was particularly true for elderly patients (Griva *et al.* 2014; Paraskevi 2011; Brown *et al.* 2010). Not requiring hospitalization, PD should—in theory— allow patients to regain a certain degree of autonomy and agency over their body and health, thus mitigating the radical expropriation of health and body implied by HD. For instance, PD patients can adapt dialysis prescriptions to their daily activities. PD clinic visits are scheduled every 4–12 weeks, thus much less than the three visits per week necessary for HD patients. Furthermore, PD allows patients to perform dialysis while traveling. Another study showed that patients treated with PD enjoyed more autonomy and flexibility, which reflected in higher employment rates with respect to HD patients (François, Bargman 2014). PD may have further clinical advantages, especially when chosen as first dialysis modality. Indeed, it preserves vascular access, does not require anticoagulation, offers better hemodynamic control with lower incidence of hypotension, and preserves residual kidney function resulting in less need for Erythropoietin, better control of electrolytes and water balance (Chaudhary, Khanna 2011). Data used to compare survival between dialysis modalities are mainly derived from large observational studies and registry analyses, given the lack of randomized controlled trials in this field. The available data suggest at least comparable survival between the two modalities (François, Bargman 2014). A recent study in a cohort of CKD patients from the Trento Province showed that the extensive use of PD did not lead to any statistically-significant difference in mortality, and that PD patients were associated with shorter time to transplantation than HD patients (Rigoni *et al.* 2017). Considering the potential risks of PD, a declining risk in PD-related peritonitis over the last decades was reported in the literature (François, Bargman 2014). Finally, in terms of costs, PD is considered cheaper than HD for the medical system, mainly thanks to a decrease of indirect costs, such those related to transports to the hospital and dedicated healthcare professionals (Karopadi *et al.* 2013; Coentrão *et al.* 2013).

Despite these elements, PD is still largely underutilized by patients in Western countries (Khawar *et al.* 2007). In 2008, only 11% of the dialysis population was treated with PD worldwide (François, Bargman 2014), with clear regional differences among countries. While the proportion of dialysis patients on PD reaches 79% in Hong Kong (*ibid.*), PD treatment in the United States has been traditionally low, never exceeding 15–16% of incident or prevalent maintenance dialysis patients (Khawar 2007). In Italy, recent data from the National Registry of Dialysis and Transplantation 2015 Report revealed a prevalence of PD patients around 6%, and an incidence of 16% with an increasing trend in recent years (https://ridt.sinitaly.org/2017/10/09/report-2015/), accessed on 25.5.2019).

The reasons of the reduced use of PD in Italy appear to be related first to organizational and managerial issues (size, public or private nature and policy of the dialysis center) and second to the patient personal choice, which can be conditioned by either family reasons (such as lack of support from family/partners) and type of information delivered on dialysis methods (poor communication and information by health professionals). Several initiatives aimed at encouraging the use of PD have been promoted in Italy, but results are still poor (Alberghini *et al.* 2014).

Methodology

Setting

The Autonomous Province of Trento (PAT) has a population of about 520,000 inhabitants. Within the Province there is a Complex multi-zone of nephrology and dialysis, which is located in the S. Chiara Hospital of Trento where are the Nephrology ward, the service of HD (with medical care continues), the service of PD, the Clinic for chronic kidney disease (CKD) patients and that for kidney transplant recipients. On the periphery, there are six limited-care Dialysis Centers located within Hospitals of the surrounding valleys. In these Centers, it is performed the treatment of HD and of outpatient visits. This type of organization allows a widespread distribution of the presence of the nephrologists in the Province. The PD service is located in the S. Chiara Hospital of Trento, and consists of four dedicated nurses, available 24 hours a day, and a referring physician. The same nephrologists take care of positioning the peritoneal catheters and prepare the vascular access in a surgical room at the start of the treatment period.

Mixed Method Study Design

Since 2008, a questionnaire was introduced to patients who shortly had to start renal replacement therapy. This questionnaire helped nurses to develop an informational exhaustive interview with patient concerning their family and personal status, as well as checking and explaining the cognitive and emotional aspects of living with PD. At the same time, it was the basis of the quantitative study (Zarantonello *et al.* 2015) that analysed 174 questionnaires referred to patients with renal failure at an advanced stage followed by outpatient nephrology. Pending patient informed consent, the questionnaires were collected from nursing staff dedicated to PD, often in the presence of a doctor, from April 2008 to 12 January 2015. 90 questionnaires were related to patients who chose the HD, 84 to patients who chose PD.

In order to better understand some results of the quantitative study, researchers decided to complement the quantitative study with a qualitative one through a mixed method study design (Sandelowski 2000: 248). We have applied a sequential mixed analysis in which one phase (in our case the quantitative study) is conducted first, informing the subsequent (in our case qualitative) round (Creswell 2009: 101). Our study is therefore an example of cross-over mixed analysis, which involves employing results of a quantitative study to analyse qualitative data (but it also may be vice versa) (Onwuegbuzie, Teddlie 2003). We chose to focus only on PD users (excluding HD patients included in the quantitative round) because the focus of the qualitative study was to understand how patients live with PD and not how renal patients decided upon two different kind of dialysis (an aspect dealt with in the quantitative study).

The qualitative study has been conducted by the first Author, starting in March 2015 until November 2015 according to an ethnographic approach. It included participant observation in the Nephrology ward, three in-depth semi-structured interviews with nurses, a focus group with nurses and doctors working in the Ward and 15 interviews with patients. Interviews with patients have been conducted at their homes, so allowing the anthropologist to observe how PD technology has been installed in the domestic environment: which space, logistic and emotional changes has been provoked by the presence of the machine and, in general, how patients and family members related to it. Interviews were in-depth and semi-structured, allowing patients to freely structure their own perspective and concerns on PD, assuring to cover themes such as how PD affected their health condition, daily routine and quality of life. In addition to collecting biographical data (age, occupational and family status, housing, mobility, distance from hospital), the interview explored the medical and personal path which lead patients to choose PD and their assessment of this choice in light of their various life situations.

Patients were accessed through the Nephrology ward and they already had answered the nurses' questionnaire. On the basis of this, researchers selected patients to be included in the sample of the qualitative research, in order to allow maximum variation, considering factors such as gender, age, education, distance from the hospital, emotional profile. This technique is also known as "stratified purposeful sampling" (SANDELOWSKI 2000: 250). Patients' engagement in the anthropological study was assured by the Nephrology staff, who broadly described the project and inquired into patients' willingness to participate in it. Upon acceptance, patients' data were disclosed to the researcher, who contacted patients by phone, describing more fully the aims and objectives of the project. Only after patients' further agreement to be part of the study, a date for the interview was decided. The day of the interview, the researcher described again the study, gaining informed consent. The anthropologist was aware that to be introduced to patients by hospital staff may have had the effect to inhibit free expression of their views on PD and on their relationship with hospital staff. The anthropologist, therefore, made her best to underline that their answers would have been anonymized since the start and in no way their answers would influence the course of their treatment or relationship with

Nephrology staff. She also emphasized that an honest assessment of their experience of living with PD would be crucial to improve it in the present and for future patients. Even if it is not possible to assess with certainty how much these preliminary considerations were taken seriously by patients, nevertheless the anthropologist was reassured by the fact that each patient during the interview felt free to voice a number of critiques, some of them quite intensely. Interviews were conducted in Italian, taped, transcribed (then translated into English for the purpose of this article), and analysed thematically. In the writing of the article, the anthropologist has taken the lead even if the other Authors have contributed to it in specific parts and the argument has been decided collectively.

Living with PD

When a patient is recognized by health professionals as in need of dialysis because her or his kidneys are compromised, she or he has first a quick check with the doctor to assure that the abdomen is suited for PD (lack of pathologies or malformations which may hinder the efficacy of PD). The case being positive, the patient is offered the opportunity to choose either PD or HD. In order to help the patient to choose the best option for her or his medical and personal condition, the Ward offers to each patient a couple of meetings during which nurses deliver information about PD and HD, taking into account the specificities of each case. Patients who decide for PD have a seven days training at the hospital, after which they start the treatment at home. The home is first inspected by the nurses and a dedicated room is identified where the machine will be installed. This space should be kept as clean as possible: carpets, curtains and unnecessary objects (as photo frames, souvenirs etc…) should be removed to prevent the accumulation of dust and domestic animals should be avoided. Every month, a number of bags with fluid are delivered at home which should be stored in another room. Before and after every session, patients have to record on a file their weight and blood pressure. In the following sub-sections, we will illustrate the socio-cultural implications of the main factors which, according to the qualitative study, characterize the experience of living with PD.

Agency

The theme of agency is a key one, highlighted especially by people enjoying a quite good state of general health. Susy is a single woman of 50 years; she was on dialysis since 2014 when a virus deteriorated her diabetes leading toward kidney failure. She chose PD instinctively: "Thanks God, the peritoneal! It has been a very instinctual choice; I've collected information only afterword. For me the peritoneal was immediately alluring because I did not have to stay still for hours… I have a life to enjoy out there!" She was a single child, her sister died many years ago, her father died few years ago and her mother was very old. She had no support but—being a diabetic since she was 14—she was very used to manage the daily routine by herself, that was shaped according to her body needs and idiosyncrasies: "I would have never chosen HD in hospital; I am a long-run diabetic, I am used to manage myself alone." Susy, as many other patients, associated HD with hospitalization and lack of control over one's treatment and one's life. Susy explained how PD allowed her to continue to have a regular life—go out with friends, eat and drink what she wishes, work and devote time to her hobby (she painted and listened music)—with no break given by the commitment to go to the hospital. However, was not just the travel to the hospital that mattered: Susy also did not like the idea to expose her body, and her weaknesses on a regular schedule in the public space of the hospital. She told to enjoy the feeling of autonomy she can maintain thanks to PD. She works part-time in a construction company near to her home. She chose the kind of PD to be performed during the day, to not ruin her night sleep. She performed it when getting up in the morning. After work she had lunch, and then the second session. The other two sessions were performed in the afternoon: after a siesta and in the evening. She told that "it's just a matter of organization. Look [showing the room in which she has all the equipment and explaining the process]. I listen to music while doing that…it's just like being at home and watching TV."

Agency over one's life is a continuous negotiation with the fact of being dependent on PD. Carlo, a man of 74 years retired at the time of the interview after having worked all his life as a chef in a local restaurant. He underwent two strokes and diabetes, which compromised his kidneys forcing him to dialysis. Initially, he wanted to commit suicide "I am not that kind of man just surviving… I need to live fully. […] but then I adapted at the idea and I can still have my own quality of life." Soon after having told this, he showed the anthropologist his fridge full of sausages and, with a sly smile in his face, offered her a sausage and a glass of red wine at 11 am. Being a very active man and wanting to retain his autonomy, he chose PD even if he recounted to have a love/hate relationship "with the machine." He commented on his initial rebellious approach to PD: "I tried to cheat the machine, sometimes I did not do the cycle, but she is a motherfucker… she records the cycles on a card [software] and the doctors discovered my tricks […] sometimes I get pissed off: if I am positioned on a certain way [in the bed] it rings and I tell her "fuck you!" Yes, I tell her bad words sometimes [he laughs]."

A number of other participants told of their failed initial attempts at modifying the therapy, usually reducing the number of days doing dialysis. Carlo's relationship with PD technology was not idyllic, still points to the myriad ways people find to adapt the technology to their habits. This has been proved to be the case also, at a smaller extent, with HD patients: some of them make their best to learn from the medical staff how to handle and manage the dialysis machine and this has been interpreted as a way to impose their agency by claiming "the right to know what it is best for them" (EUGENI 2009: 22).

Riccardo, too, chose PD to retain a certain degree of "normality" in his daily life. He decided for the night modality because he worked full time in a museum. Riccardo was 31 years old at the time of the interview; in 2013, he suddenly discovered to suffer from an autoimmune disease which fatally compromised the functionality of his kidneys. In 2015, he had a kidney transplant, received from his mother. He recalled that, when confronted with the idea of undergoing HD, he was very scared "it's a very hard thing for your body. I do not love to be punctured, blood or not blood. PD is better in this sense because it gives you the impression to partially have a normal life." Moreover, he loved traveling and PD allowed mobility thanks to its portability. HD, instead, strongly constraints one's ability to travel. Still, he recognized PD's disadvantages: "It is an obligation. Every night you have to…first of all it compromises the quality of your sleep: you always have to lay flat on your back, you cannot move, you are always attached to a machine, it might wake you up in the night… but most of all the fact that it's every day and in your private domain."

The presence of PD in one's own environment has been described by patients with mixed feelings: the gains in terms of autonomy warranted by PD also represent its limits. Riccardo's words illustrate how thin is the line between autonomy and dependence and shed light on the dark side of autonomy: he appreciated to not be hospitalized but at the same time he pointed out how this caused the medicalization of his private space and the emotional and practical weight of bearing alone the burden of care. The ideal of autonomy in healthcare has been often questioned (Bureau, Hermann-Mesfen 2014; Fainzang 2016; Raffaetà, Nichter 2015) as it involves a series of complex social, political, and economic issues.

Costs and Responsibilities

The costs and responsibilities implied in the management of PD become apparent when a precarious state of health combines with poor or lack of support. This latter was the case of Maddalena, a housewife of 75 years. She experienced renal failure in April 2013. Doctors suggested PD. Concomitantly, however, her husband was diagnosed with cancer; she had to take care of him and therefore she did not want to also take care of her dialysis by herself. She felt the need to be cared for. Therefore, she decided to delegate all tasks related to hemodialysis to the hospital, performing HD. When her husband died in 2015, Maddalena turned to PD, because her veins were too weak to sustain HD. Maddalena was a widow with two grown-up children who lived about 50 kilometres from where she lived "We do not live far, but not even here, very close, they cannot help in case of need. They come and run away. My son enters into the door and asks me "how are you mum?" What should I answer?! 'I am good darling.' And he walks away."

Maddalena medicated her fistula after every treatment "at the training in the hospital the nurses have taught to my children to medicate me, but they work… what can they do, poor things? What should I do? Make do! How can I do? They [doctors] make things so easy… but it is not." Maddalena also noticed that the gains in autonomy prospected by health professionals in their description of PD are only partially real in her situation. For example, doctors told that with PD she would have been free to travel, going to visit her daughter and her grandchildren for the weekend. Unfortunately, she soon realized that this was simply a mirage, far beyond her mastery. She had no car and to reach her son she should take public transportation, but since she lives in a remote village in the Alps, she should plan multiple transits. Beyond being time-consuming, this would also be very problematic; as she said, with PD "I have to bring with me half a room."

Maddalena's situation brings attention to the micro details of a life with PD, and how these may become big problems for a person like her: "When they [the people delivering the bags containing fluid] phone you, you have to be there. Then, you need to go down, to open the garage… small things but once a person is alone, also those little things are heavy, it's obvious…" She points to the issue of storing the bags:

> They say to store them [the bags containing fluid] at home, but when they bring it, it's so big [opening her arms, indicating the space of the entire room]. I hope it is fine to let the bags in garage, I have to let them down and then I bring some of them at home time by time. When my son come to visit me, or sometimes with the help of the neighbour… poor man, he helps sometimes…but look, I am not that young, I am 75 years, how could I do?

Maddalena has been for her entire life the carer of the family. Now in her voice there is tone of guiltiness with regard to her son (who—right or wrong—she still feels obliged to care for) and her neighbour (who helps her deliberately). Maddalena is, however, also aware that living with PD is a hard task for someone like her: "Bags, there are 6 bags to be thrown away, there is the plastic which cover them, to be thrown in the plastic… If you feel good is nothing, but if you do not feel well, you need to depend on others. And everything requires its things, its attention and all that follow…"

Storing, handling and recycling PD accessories can be considered the maintenance of PD "infrastructure," and it has its own costs which often are neglected in calculus of cost-savings of technology (Puig de la Bellacasa 2014). From delivery to refusal, to engage in PD entails a series of micro actions that, added together, become a very heavy task for those who are vulnerable and frail. Micro, repeated actions might appear trivial for a healthy adult, but indeed are key component of care, this intended as a process which tends toward the continuous tuning of bodies with people, places, objects and technologies (Mol 2008). Maddalena, in a whisper, admitted that, with PD, in the morning she can stay "at home, here at the warm" but soon after she voiced louder her regret and what she lost staying at home:

> Yes, you do not need to go to the hospital, but at the hospital they [health professionals]… it is on them the burden of care. You do not even see the drugs, at the hospital they think at all that, they inject these in the thing [pipe]…Instead here, that box there [indicating a large red box on the wardrobe] is full of drugs, believe me. Of course, there are a lot of medicines to be taken. And there is heparin, to be taken once a week, and there [at the hospital] they put it directly into the hemodialysis. And if something goes wrong there is the doctor…it is completely another situation! Here this box full of drugs, let's hope to keep my mind clear, otherwise I will poison myself!

In the hospital, patients are taken care by nurses, who are key actors of the HD event (Eugeni 2014): they manage the technology, take care of the hygiene and condition of the fistula before and after treatment, they prepare, control and sterilize all the materials employed and they check patients' weight changes during treatment, they clean if something happens and help patients to change positions, to stand up and walk. Eugeni notes how nurses and patients in hemodialytic wards develop deep relationships which engage them emotionally. This is due by this kind of long-term care which penetrates both the patient and nurses' daily routine, and that is not present with this intensity in other hospital wards, more focused on the treatment of acute diseases. Hemodialytic wards are also delimited spaces shared every day for a significant number of hours by the same people. This adds sociality to the medical treatment, described by anthropologists working with non-Western societies as a key factor of healing rites (Taussig 1980).

Emanuele too—a 65 years old who looked older than his age—found HD (done for two months before starting PD) a way to be properly cared for, even if this comes at a certain price for autonomy. He recounted that, in the while he got prepared for PD, he underwent HD for two months: "With HD, the responsibility is fully up to the hospital. Every half an hour they take your blood pressure and if they have to take some blood, they can do it directly from the pipe. At home, instead, is your own responsibility." Emanuele was provincial administrative personnel in the breeding sector, retired for eight years at the time of our encounter. He lived with a wife of same age but they had no children. In 2008, Emanuele injured his foot while working but he continued to work until his foot got deeply infected and he had to be hospitalized. In that occasion, he discovered to be diabetic. The doctor prescribed him some pills against diabetes. According to Emanuele, these pills were the cause of his kidney failure. This conviction caused him with a sour feeling of having been mistreated and deceived. In 2010, the nephrologist put him on a very rigid diet and in 2012 he had to start dialysis. In 2014, he had a kidney transplant. He voiced his complaint that all this journey made him weak and sick, making the organization of PD sessions quite burdensome. At the beginning and end of each PD session, he had to collect a series of information such as his weight, the blood pressure, the duration of each session etc… This duty was very stressful for Emanuele who wanted to perform precisely, so feeling too much responsibility and anxiety. The wife took care of the material management of PD. She was a minute and shy woman, who, at the beginning of our interview stayed silent, letting the stage to her husband. Emanuele made "a lesson" to the interviewer on how the PD works. Even if she already had this knowledge, she let Emanuele speak because it was apparent that his explanatory performance was a way to retain his own sense of control and dignity in face of a situation which heavily impacted on his life. When coming to the practicalities of living with PD, the wife exited her cocoon, shading the curtain of discretion:

> The bags… [she laughs nervously and makes a sign with her hands as to express her disappointment]. Every month we were delivered 70 boxes, 10 kg each. That means 700–800 kg every month of bags, also including a box for the kit with all its plastics, pipes, caps… a massive work. It was a nightmare… it was… [pausing, finding the right words] a mountain of plastic. Once you took them out of their boxes, they made such a volume… a mountain of garbage. A back-breaking work. Then you had to divide everything for the separate refuse collection, go to the refuse collection place, and so on…

Emanuele added:

> We even had to share the weight in different rooms, otherwise it should have been too much load for just one room. Therefore, we needed a room for the PD and two other rooms to store the material. And we always had to check that in the rooms it is not too warm, too cold, no wet, no dust…

When Emanuele exited for a minute the room of the interview, the wife turned to the ethnographer and said softly (to not be heard from the husband) "surely it is something that needs a solid support from the family."

Family Support

The most felicitous examples of co-habitation with PD, indeed, are when patients have a solid family support. Pierino is an ex-carpenter, now a retired man of 79 years, living with his wife of 73. Despite Pierino suffers from physical and mild cognitive impairments, the couple managed quite well their life with PD. The main reason is that their children (50, 47 and 40 years old) lived in the same building, and two of them were even working as health professionals. As Pierino wife explained: "Every evening our son come here and prepare the machine. Every morning before to go to work, he comes and check everything. He switches off the machine, he medicates him [indicating Pierino], he checks the blood pressure and all those things." In addition, when we had the interview—it was around 10 am—one of Pierino's son entered the house checking if he had a good sleep and whether the machine worked well. If the person undergoing PD is moving while sleeping the machine may activate an alarm. On these occasions, Pierino's wife knows that she can call immediately the son who promptly comes and resets the machine. Pierino recalled, in an amused tone, how often his grandchildren (18, 20 and 24 years old) asked him, almost joking: "Grandpa, did the machine ringed tonight?" In Pierino milieu, PD is an affair of the entire and extended family. The technology has been smoothly assimilated within Pierino's life, through family new types of attention, care and even playful interactions. Pierino's wife explained that the PD was suggested by their children; the old couple was, instead, initially sceptical of having to deal with that piece of technology in the house. However, the deep family involvement helped them to integrate "the machine" (how they call it) quite naturally into their daily life: "at the beginning the machine scared us, but it is not true [it is not scary anymore] when you get to know her." Pierino's wife appellation of the machine as "she" (in Italian the word "machine" is feminine) underscores how "she" became a member of the family. Overall, Pierino and his wife assessment of PD was very favourable. Even if they said to be a bit disturbed by the sound of the machine during the night, they appreciated to be free from engagements during the day and Pierino was especially happy to be able to eat what he liked (before he had to follow a strict diet impacting on his life's quality).

A similar story is that of Tarcisio, 75 years, a quite wealthy farmer, retired at the time of the interview, who lived with his wife of 65 years. Living with them, at the upper floor of a nice villa, there was the daughter of 37 years, who gave them two grandchildren. She did not work and had time to help her parents to manage the PD. Given her engagement with PD, she asked to be present during the entire interview. Tarcisio's wife said that at the beginning when the machine ringed in the night it "sounded like the fireman alarm." They were scared, but they could count on the help of the daughter, coming in the night to solve everything and reassure them. Therefore, "finally we understood we should not be scared and now we are able to manage the machine by ourselves even if it rings." Tarcisio's wife told how the PD "entered to be part of our routine." For a certain number of other patients, indeed, the scarce degree of physical and cognitive autonomy was not an important variable affecting the use of PD because the patient could count on a solid and continuous support from the family or carers.

Health Professionals' Support and Trust

The anthropological study indicated that central role of trust and support. The kind and amount of support available to those people already debilitated by age or physical-emotional distress is able to mitigate PD disadvantages. Most of the people interviewed appreciated the fact that they could count on the assistance of the Nephrology ward health professionals in case they would have doubts or problem on how to deal with the technology. The assistance given by phone by health professionals (available h24 and 7 days on 7) was perceived as very accurate and thoughtful: even if distant, the Nephrology ward was somehow perceived as proximate. All patients, irrespectively of age, family situation or health status, said to feel reassured by this careful support. As already mentioned in the "Setting" paragraph, the PD service consists of a referring physician and four dedicated nurses for patients' assistance. This feature creates a close relationship between patient and professionals, increasing a positive feeling of safety and care.

Nephrology Ward

PD patients' need for very close contact with the hospital staff for communication and follow-up has been highlighted also by a qualitative study conducted in Norway (Rygh *et al.* 2012) and one conducted in Sweden (Petersson, Lennerling 2017). Both these studies were conducted in nations with strong welfare regimes. Similarly, PD success rate in Trentino should be contextualized within Italy health system: even if it is quickly changing toward increased privatization (Frisina Doetter, Götze 2011), in 2000 WHO ranked Italy second best in the world (WHO Health system attainment and performance in all Member States, ranked by eight measures, estimates for 1997, https://www.who.int/whr/2000/en/annex01_en.pdf; accessed on 25.5.2019) because it includes free and unlimited access for primary, needed and urgent care, generally considered of good standard. This points to the question whether PD, with its need for continuous support, may fit well enough in other healthcare systems which are either privatized or crumbling. As the ethnography of Sherine F. Hamdy (2008) about end-stage kidney failure patients in Egypt shows, pathological kidneys are just part of the problem: suffering implicates larger social, economic, and political ills, including the possibility to relay emotionally and concretely in state-provided medical services.

Rethinking Agency and Autonomy in Designing Health Research and Technological Interventions

The quantitative study covered three main aspects: 1) Family area (family situation, need and availability of family carers); 2) Personal area (age, physical fitness overall, autonomy in washing and eating, work situation, distance from hospital); and 3) Cognitive-emotional area (ability to understand, emotional state, attitude to PD). Two of these aspects takes the patient as the focus of analysis, taking for granted the western liberal concept of "individual subject." The fact that the study aimed at exploring the varying degrees of autonomy and capability of this subject, confirmed and solidified the existence of this concept as something "objective."

As the case of Maddalena and Emanuele shows, however, for people of a certain age or health status, PD stops to be an individual matter and its entanglement with others, with places and with practices becomes apparent. For example, when the anthropologist contacted the patients at the telephone, more than once, the person willing or able to effectively speak was the carer (e.g. the wife or the son/daughter). Even if the patient is bodily engaged with PD technology, other people may be overall more engaged with PD than the patient her/himself. This pattern repeated during interviews, where the carer(s) felt natural to be present and interact with the anthropologist in addition or in substitution to the patient. Another example is given by the visit to Tarcisio's house. When the anthropologist introduced the topic of the interview, Tarcisio's wife told "I hope to be able to tell you how I find myself with this… [emphasis added]."

The anthropological component of the study brought to light that, as may happen for other diseases, the same identity of people with renal failure may fragment. Health professionals are aware of this; indeed, carers and family members are invited at the informative meetings together with the patient. Nurses fill the questionnaire as if the patient would answer, but the answer chosen by nurses is the result of the patient-family-health professional encounter and negotiations. Nurses, indeed, are aware of the limits expressed by patients taken as autonomous individuals. This makes apparent the unescapable ambiguity between the legal need to get an informed consent from the patient and the reality of the situation. Nurses elaborated with the anthropologist the inherent contradiction of both the collection of information for the questionnaire and the legal procedure of gaining informed consent: during the informative meeting nurses were supposed to speak with the patient, making sure she/he understood the information given, proceeding to an informed decision to. In reality, they often found themselves speaking with the carer because, according to them, some people are not fully able to understand or because they refuse the idea of having to be medicalized so much and look absent, delegating to other their presence. A nurse told that once, during an informative meeting, the patient who had to start dialysis continued to repeat "ok, I am done. Ok, it's the end" and looked absent, lacking any eye contact or bodily feedback with the nurse and what she was telling him. Therefore, the nurse confessed "I stopped speaking with him and devoted my attention to the wife, who was responsive to my words. Sometimes it is just impossible to relate with the patient." Some other times, nurses recounted, a patient may be positive about PD but finally she/he will opt for HD because the carer does not agree to take care of that. This extension of a patient's identity shows the limits of designing healthcare research and interventions on the basis of traditional psychological and socio-demographic variables, as "the individual subject," his/her psychology or other personal features.

The fact that agency may be something different than a capacity linked to an autonomous subject is connected to how technology integrates into patients' lives. It is not only and always a one-to-one relationship (as in the case of Susy and Carlo, for example), but technology is usually part of an extended network. The use of technology, therefore, is not the solution *per se* to hospitalization but it may be a good help if it is embedded in a sustainable socio-technical assemblage.

Costs, therefore, are not eliminated in replacing technology with hospitalization. They are shared between the patient (including her/his network) and public health institutions. To make PD sustainable, some of the budget saved by health institutions should be re-directed to assure support at distance, as the Trentino case has shown. The tension between public and individual costs is apparent to many patients. With health governance obsessed by pressing preoccupations for healthcare costs, a careful consideration of how to share costs and responsibilities among the public (Raffaetà, Nichter 2015) seems appropriate.

Conclusion

Renal failure or chronic kidney disease are serious health problems, which, in absence of either PD or HD, would bring people to certain death. Dialysis is a useful treatment and some of the problems experienced performing it (as disturbed sleep, tiresome management in the case of PD or hospitalization in the case of HD) are the best compromise at hand to make survive sick bodies: "PD is a compromise, same as HD," Emanuele said.

Yet, there are some features that characterize the choice of PD vs HD. PD, in particular, seems to offer enhanced autonomy and agency over one's situation. The article highlights that there are different ways of living with PD. Taking the increase in autonomy and agency as one of the key advantages offered by PD, it shows how these ideas deploy and compound in the lives of different kind of people. In many cases, promises of autonomy and evaluations of reduced costs appear more as a mirage than a reality.

In order to assess the value of a technological intervention it is not enough to focus on the technological object itself or on calculations of costs which are disembodied by the everyday details of how patients manage and live with the technology. PD presents some advantages combined with disadvantages: which of these will prevail in the single case studies is a matter of how carefully and thoughtfully the object is able to participate in the creation of a sustainable and meaningful socio-technical configuration.

Evaluations of PD which solely relay on a biomedical perspective risk overestimate the sustainability of PD, as in the case of Maddalena, who told to not be happy to go for PD "but what should I do… when you are in their hands…" or to jeopardize the trust given to health professionals, as Riccardo highlighted PD "is not all peaches and dandelions. When you meet nurses it all seems wonderful… but they always omit things, probably in good faith, just because they never tried PD personally." This may easily degenerate into rumors: "the Ward makes a certain pressure for PD. They list a lot of advantages: you will be free, you can go wherever you like. In reality is all a different thing; it's a big responsibility! According to me they have provincial guidelines, PD costs the half [of HD]" (Emanuele).

In order to avoid those risks, anthropologists should contribute to health research, which mostly relay on a quantitative approach. The article has shown that often quantitative research is mixed with qualitative insights, even if these are made silent in the analysis (Sutton 1997) and those aspects which are relevant for patients may pass unnoticed by healthcare personnel and quantitative study. In the medical paradigm dominated by the imperative of evidence, it is furthermost needed to question how this "evidence" is constructed (Ecks 2008; Engelke 2008).

PD is not a technology for everyone. However, as emerged by the mixed method design of the study, it is difficult to indicate single factors as determining the choice of PD or its limits because these cannot be taken alone. The analysis should focus on how diverse factors (as age, general health status, support available, dimension and kind of housing) compose in each specific case, adding and relating to other factors. This speaks to the concluding remark: "telling stories" of patients and their life with PD or other medical devices is not a mere narrative entertainment but is a powerful way to assist the design of health governance and implementation of medical technologies.

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Riassunto

Vivere con la dialisi peritoneale in Trentino. Una ricerca interdisciplinare tra antropologia e nefrologia

Questo articolo illustra come la dialisi peritoneale è percepita e gestita dalle persone che soffrono di malattia renale cronica in alternativa all'emodialisi. La dialisi peritoneale può essere gestita a casa mentre l'emodialisi richiede l'ospedalizzazione. La dialisi peritoneale non è ampiamente utilizzata anche questa sembra offrire una serie di vantaggi, tra questi maggiore autonomia del paziente e migliore qualità di vita. La nostra indagine mette in luce come la gestione della dialisi peritoneale (che include aspetti logistici, tecnici, sociali ed emotivi) è principalmente responsabilità del paziente, mentre l'emodialisi è gestita dai sanitari all'ospedale. L'articolo procede quindi a un'analisi critica dell'autonomia offerta dalla dialisi peritoneale e riconsidera la sua sostenibilità e i suoi costi alla luce delle esperienze dei pazienti che vivono tutti i giorni con questa tecnologia.

Parole chiave: emodialisi, dialisi peritoneale, etnografica, ricerca interdisciplinare, malattia cronica renale

Resumen

Viviendo con diálisis peritoneal en Trentino (norte de Italia). Una investigación interdisciplinaria entre antropología y nefrología

En este artículo vamos a ilustrar cómo se percibe y trata la diálisis peritoneal, una alternativa a la hemodiálisis, en personas que padecen enfermedad renal crónica. La diálisis peritoneal se puede practicar en el hogar, mientras que la hemodiálisis requiere hospitalización. La diálisis peritoneal está infrautilizada, aunque parece ofrecer una serie de beneficios potenciales, incluida una mayor autonomía y calidad de vida. Nuestro artículo arroja luz sobre cómo el manejo de la diálisis peritoneal, incluidos los aspectos logísticos, técnicos, sociales y emocionales, es principalmente responsabilidad del paciente, mientras que la hemodiálisis es realizada por profesionales de la salud en el hospital. Por lo tanto, este articulo analiza críticamente la autonomía proporcionada por la diálisis peritoneal y reconsidera su sostenibilidad y costos a la luz de las experiencias diarias de las personas que viven con esta tecnología. Palabra clave: hemodiálisis, diálisis peritoneal, etnografía, investigacion interdisciplinaria, enfermedad renal crónica

Palabras clave: hemodiálisis, diálisis peritoneal, etnografía, investigación interdisciplinaria, enfermedad renal crónica

Résumé

Vivre avec une dialyse péritonéale au Trentin (nord de l'Italie). Une recherche interdisciplinaire entre anthropologie et néphrologie

Nous montrons comment la dialyse péritonéale (DP) est perçue et prise en charge par les personnes souffrant d'insuffisance rénale chronique comme une alternative à l'hémodialyse (HD). La DP peut être effectuée à domicile ; la HD nécessite une hospitalisation. La DP est sous-utilisée même si elle semble offrir un certain nombre d'avantages potentiels, dont une autonomie et une qualité de vie accrues. Notre article explique comment la gestion de la DP - y compris les aspects logistiques, techniques, sociaux et émotionnels - est principalement une responsabilité du patient, tandis que la HD est assurée par des professionnels de la santé à l'hôpital. L'article analyse donc d'un œil critique l'autonomie offerte par la DP et reconsidère sa viabilité et ses coûts à la lumière des expériences quotidiennes des gens qui vivent avec cette technologie.

Mots-clés: hémodialyse, dialyse péritonéale, ethnographie, qualitative, maladie rénale chronique