L'ALTRO DIRITTO
RIVISTA

Carcere, devianza, marginalità e governo delle migrazioni

2018, N. 2

L'ALTRO DIRITTO
RIVISTA
CARCERE, DEVIANZA, MARGINALITÀ E GOVERNO DELLE MIGRAZIONI

FONDATA NEL 1997 DA DANILO ZOLO E EMILIO SANTORO

EDITORE PACINI GIURIDICA, PISA

Pacini Giuridica

L'ALTRO DIRITTO
RIVISTA

CARCERE, DEVIANZA, MARGINALITÀ E GOVERNO DELLE MIGRAZIONI

2018

ISSN 1827-0565

Il presente numero monografico della rivista “L’altro diritto” contiene una selezione di saggi raccolti nell’ambito di una *call for papers* internazionale promossa dal *Research Unit on Everyday Bioethics and Ethics of Science* (RUEBES), che ha invitato gli autori a confrontarsi sul tema *Freedom and Healthcare: Exploring Mutual Interconnections in Contemporary Societies*. La selezione e revisione dei contributi ricevuti in risposta alla *call* è stata curata dal coordinamento interno del RUEBES tramite un processo di referaggio tra pari.

L’obiettivo principale di questa iniziativa era quello di approfondire la conoscenza relativa alle connessioni e ai condizionamenti reciproci tra la sfera della libertà e quella della salute, muovendo dall’approccio della “bioetica del quotidiano” formulato da Giovanni Belinguer, e già punto di riferimento per la creazione del RUEBES, avvenuta nel 2016 presso “L’Altro Diritto - Centro di Ricerca Interuniversitario su Carcere, Devianza, Marginalità e Governo delle Migrazioni”.

Gli otto saggi selezionati per la pubblicazione su questo numero monografico sono il frutto di altrettante esperienze di ricerca, e raccontano di molteplici contesti, ordinamenti giuridici, sistemi sanitari, e pratiche professionali. Tali esperienze sono state realizzate utilizzando metodologie sia qualitative, sia quantitative, ma privilegiando sempre una prospettiva spiccatamente interdisciplinare, in conformità allo spirito di quest’iniziativa e alla stessa *mission statement* del RUEBES. Il risultato è un’opera che nel suo complesso mette in risalto il valore specifico delle connessioni che presiedono al rapporto tra libertà e salute, connessioni che, sotto il peso della materialità del sociale, si traducono in autentiche relazioni nelle quali si ritrovano immersi norme, corpi, soggettività, oggetti, pratiche, valori, cultura e culture differenti.

Una prima macro-area d’indagine percorsa da quest’opera è quella della salute mentale, crocevia per eccellenza di ogni credibile ricerca su libertà e salute. Fra i pregi degli articoli selezionati in quest’ambito, può essere forse annoverato il fatto di andare al di là dell’analisi tradizionale sulle dinamiche di funzionamento delle istituzioni di custodia – per quanto la stessa rimanga comunque di imprescindibile valore e fonte primaria di conoscenza, sia per il settore delle scienze sociali in generale, sia per quanto concerne l’approccio particolare della bioetica del quotidiano. Invero, l’area della salute mentale viene qui in rilievo, da una parte, in quanto terreno scivoloso per il ricercatore alle prese con le metodologie di ricerca qualitativa, quelle in cui il contributo dei pazienti diviene essenziale per il buon esito della ricerca stessa. Come mostrato dalla riflessione che apre il numero monografico, le implicazioni correlate al coinvolgimento dei pazienti psichiatrici nella ricerca qualitativa sono tali e di tale portata da metterne in crisi la stessa cornice etica, aprendo interrogativi rilevanti in un *continuum* epistemologico che muove dalla neutralità (presunta) e sfocia nella validità (formale e informale) della conoscenza empirica generata in questo settore. Dall'altra parte, la salute mentale è indagata anche a partire dalle connessioni (relazioni) che la patologia e il suo protrarsi nel tempo instaurano nei confronti della cerchia dei prossimi, ovvero, coloro che sono chiamati a stare accanto al paziente, sia per amministrarne gli interessi su un piano giuridico-formale, sia per prendersene cura e garantire la necessaria assistenza nella quotidianità.

Una seconda area d'indagine su cui gli autori di questo numero sono stati chiamati a fornire il proprio apporto è quella che concerne l'accessibilità alle prerogative di cui si compone il diritto alla salute da parte di una popolazione vulnerabile quale quella rappresentata da immigrati, migranti, richiedenti asilo e rifugiati – categorie del diritto troppo spesso sovrautilizzate a detrimento di un fenomeno più ampio e complesso che andrebbe più opportunamente narrato a partire dal concetto di "migrazione forzata". L'interesse per la ricerca in quest'area deriva, in particolare, dall'incidenza degli ostacoli formali e informali che gli appartenenti a queste categorie sovente riscontrano nel tentativo di accedere ai servizi sanitari nelle società di accoglienza. A tali ostacoli, si aggiunge una vasta serie di discriminazioni e prevaricazioni, sovente tollerate, e talvolta persino legittimate da quelle stesse istituzioni che sarebbero invece deputate al loro contrasto.

Un'ulteriore area di indagine toccata da quest'opera è quella della commistione fra genere, violenza e salute, la quale, come facilmente intuibile, assume una rilevanza fondamentale in una prospettiva di ricerca volta a promuovere l'approccio della bioetica del quotidiano. Le esperienze riportate in quest'ambito, da una parte, mostrano il peso che la cultura locale assume rispetto alle scelte terapeutiche a disposizione delle coppie alle prese con problemi d'infertilità, in uno con le peregrinazioni fisiche e psicologiche a cui le stesse sono di conseguenza costrette. Dall'altra parte, invece, richiamano l'attenzione sul ruolo che la violenza di genere può assumere sulla tutela della salute di coloro i quali la subiscono.

In chiusura, si presentano i risultati di una ricerca che offre un importante spunto di riflessione sull'uso – *rectius*, l'abuso – delle piattaforme di *social network* da parte dei professionisti sanitari per la condivisione di immagini tratte da ambienti di cura. Questa riflessione rende evidente come le violazioni della *privacy* individuale e dei connessi obblighi di confidenzialità si accompagnano a un più ampio tradimento dei caratteri di fiducia e di senso che dovrebbero presiedere alla relazione tra professionisti sanitari e pazienti. Ciò si traduce in un'ulteriore conferma rispetto alle difficoltà incontrate dal diritto nel regolare l'utilizzo delle nuove tecnologie, il ché rimanda, a sua volta, all'urgenza di un'etica pensata *ad hoc*, che fornisca una chiave di lettura adattabile alla molteplicità dei contesti in cui i professionisti sanitari si trovano ad operare, e all'eterogeneità degli interessi alla cui protezione devono contribuire.

Il lavoro è arricchito dall'avvincente prefazione di Graça Carapinheiro, studiosa riconosciuta e apprezzata a livello internazionale per l'apporto fondamentale che la sua attività di ricerca ha arrecato nell'ambito della sociologia della salute, e in particolare per il suo contributo allo studio delle relazioni di potere-sapere che si generano e si riproducono nella pratica quotidiana delle istituzioni ospedaliere.

Freedom and Healthcare

Exploring mutual interconnections in contemporary societies

Edited by Carlo Botrugno & Joana R. Zózimo

Research Unit on Everyday Bioethics and Ethics of Science
L'Altro Diritto Interuniversity Research Centre on Detention, Deviance, Marginality and Migration's Management - Department of Legal Sciences, University of Florence
35, via delle Pandette 50127 - Florence (Italy)
Web: http://www.adir.unifi.it/ruebes

Freedom and Healthcare
Exploring mutual interconnections in contemporary societies

An open access digital publication by L'altro diritto Journal, 2018 – ISSN 1827-0565
Issued on November 2018

Freedom and Healthcare: Exploring mutual interconnections in contemporary societies

Preface

Graça CARAPINHEIRO
ISCTE - Lisbon University Institute

Presented in the form of essays, this special issue brings together eight research studies carried out by scholars connected with various subject areas of the social and human sciences and with a wide range of research contexts and models. These scholars are involved in various ways of considering, imagining and recreating the observation of the real and its contexts, on the basis of innovative, reflexive, penetrating and searching approaches. The topics covered by the special issue focus on people who not only experience health and disease issues but also situations of ethical and bioethical vulnerability, associated with subjective and objective conditions of everyday existence that militate against a number of ways in which freedom is exercised, and respect for civic, social and human rights is assured. The authors intend to shed light on grey and shady areas, rewrite the part of these experiences that has been officially erased, and scrutinize the most personal and intimate meanings and feelings, ranging from those of people who are considered powerless to those who are thought to have no history or memory, or even, at the limits of these representations, those who are thought to lack consciousness or cognition, dispossessed of the perceptions, representations and identity considered valid in human terms.

The research studies presented here aim to retrieve the ideas underpinning the ‘ontology of the victim’ from the vision that unites and unifies them around isolation, loneliness, neglect and domination, as factors inherent in the cultural, moral and religious manoeuvres that are orchestrated on guilt, fatality and destiny – which, in most cases, the victim is unable to understand, resist or control. These dominant ideas contain the main filters that edit the stereotyped faces of the victims. So what these texts aim to achieve, as an alternative, is to circumscribe the complexity of the circumstances of their oppression and encourage a rediscovery of the social, political, cultural, ethical and bioethical substance that underlies their structural constitution.

Accordingly, with regard to the different situations studied, other forms of knowledge and reflexivity are suggested and mobilized. They aim not to go along with ‘old’ orthodox epistemological and methodological ideas, which produce many more invisible than visible aspects, and omit the constant interference of ethical and bioethical implications in the before, during and after of research processes, by practising the principles of an empathic, sensitive and critical epistemology and by adopting methodologies that do not avoid dipping into experiences lived through. This, in turn, is done and redone in strict accordance with what sensitivity and intuition indicate as the best paths towards a rediscovery of the countless forms of expressivity in the dimensions of the human.

It is not a question of portraying what is human, since the rigid frame of a portrait is incompatible with the plasticity of the experiences and forms of expression gradually acquired by human realities, as they become known in greater depth, rapidly expanding beyond the contours of the frame. Nor can a researcher be equivalent to a photographer, who is limited to registering images, scenes and scenarios, on the basis of a ground plane positioning that creates the best viewing angle. The creation of a portrait is almost always equivalent to extreme separation of the subject and object, to amplification of the tendency to exclude the viewpoints of those being portrayed, to enhancement of the clearest forms in the foreground of the photograph, and to the blurring or even suppression of the near middle ground, middle ground, and far middle ground. In fact, all the zones further away from the camera lens – precisely at the point where different social worlds abound, with all their cultures, world views and forms of cognition. These worlds can only be mapped, to allow an insight into the dynamics of the movements driving the interconnections that cross their latitudes and longitudes and their points of convergence and contact and of dispersion and flight. It will never be possible to simply create a portrait of these dynamics.

The articles of this special issue will acquaint the reader with the singularities and complexities that involve the human experiences of fragile and vulnerable people; the tough dimensions of what is lived negatively; the identities shattered and reconstituted at the expense of manifold forms of pain and suffering, though also of resilience, resistance and the ability to prevail; the relational element established at the (very porous) boundaries that separate humanity and inhumanity; the emotional element felt directly in the skin and bone, in the flesh and the mind.

The authors provide us with access to interesting epistemological and methodological incursions that can sensitize readers to new ideas and renewed opportunities that integrate social utility into the science yet to be carried out, in the light of new ethical and bioethical commitments, negotiations, alliances and contracts, and new moral and emotional ways of reciprocally involving the researchers and researched in the research. Thus, the scientific work is more and more committed and tied up with existential frameworks that are ruled by the fear, risks, stress and woes of being forgotten, hidden, humiliated and offended: there are no longer two sides, but just one, which encompasses all the subjects who accepted being involved in the extensive context of its production. This means a new emotional and subjective order in the definition of research strategies and the acceptance without complication of a new order of values anchored in new forms of joint participation, thus allowing the spread of multiple forms of social utility.

The topics dealt with here, asserting their well-founded inclusion in the issue of “Freedom and Healthcare”, significantly extend the boundaries of the subject areas of health and disease usually researched and expand their perspectives and approaches on a theoretical level. They do so, on the one hand, by calling on concepts and subconcepts that have held a steady position within the sociology of health, disease and medicine, e.g. the dichotomies ‘autonomy and dependence’, ‘self and identity’, ‘domination and subordination’, ‘normal and pathological’, ‘normal and abnormal’, ‘nature and nurture’ and ‘body and mind’, among so many others; on the other hand, by inventing ideas and concepts that allow proximity with new phenomenologies that interweave, in people’s daily lives, new forms of social constraint, institutional containment, resolution of ethical dilemmas, and limitation of individual freedoms.

The analysis thus encounters the complex relations established between independence and Alzheimer’s disease. In this case, the state of consciousness of oneself and the world, of a self entirely affected by the disease or only in part, demands a personal, psychological, biological, anthropological and biographical identity analysis, and the separation of this from ontological identity: between being something and somebody, remaining someone who is not any more, trapped between the then self and the now self in memorial personhood. How are all these transformations to be envisaged, in light of the concepts of identity, independence and freedom? How are the possibilities of what is human to be evaluated?

Another interesting conceptual challenge is related to the health risks of international migrations and the dimensions of human dignity that arise here, in accordance with the careful thought to be given to the distinction between, on the one hand, bioethical issues related to the dilemmas regularly posed by advanced technologies in health care (which encompass controversial and contentious choices and decisions regarding, for example, the subjection of patients to intensive care and end-of-life processes) and, on the other, the necessary transference of these questions to the territory of health care access and of social inequality in treatment resources available and empowerment for citizenship in health. Concepts such as frontier bioethics, between wishing to be treated or not, or between extending life and shortening death at any cost, and everyday bioethics, which are the oxygen of basic health rights, contain incalculable analytical potentialities for assessing the problems of social justice.

Other conceptual innovations have been included in this publication: around the human narratives on the flight from terror; on piloting through the treatments involved in reproductive strategies, using various forms of therapeutic pluralism; on the informal care of people with mental disorders and the management of emotions and the self under the pressure of the associated stigma; along with new concerns about protection of the right to privacy when the experience of illness travels freely on the social networks. In all of these, the survival of what is human is called for, in the values, the rights and the possibilities of being able to be free.

Lisbon, 17th July 2018

Introduction

Freedom and healthcare: Turning interconnections into relations

Carlo BOTRUGNO & Joana R. ZÓZIMO

The L'Altro Diritto Research Unit on Everyday Bioethics and Ethics of Science (RUEBES) has invited scholars to submit original contributions with the aim to explore mutual pressures, bonds and interconnections between Freedom and Healthcare. Too often, indeed, these two spheres are conceived as separated, which entails overlooking the conditionings – both in a positive and negative fashion – one might exercise on the other.

Although contemporary health systems are metaphorically conceived as places in which health is protected and individuals' rights are guaranteed, a consolidated tradition within sociology of health and medical anthropology has successfully highlighted how often freedom of choice and freedom of expression are overcome by consolidated paths of (in)formal powers, professional relationships, and social roles. Hence, the effect of these may be unpredictable and not straightforward, either intimidating patients and inducing subjection or fostering autonomy and flexibility in healthcare institutions. Moving from these various acknowledgements is a premise to critically seek for a wider understanding on the boundaries and dichotomies that too often inhabit Freedom and Healthcare – such as the normal and the pathologic, the free and the compelled, the healthy and the unhealthy –, as well as to the complex interconnections that mediate between them.

When looking at the results of our exploration, it is remarking how Freedom and Healthcare are not only strictly intertwined – as easily foreseeable – but also generate multiple and diverse relations among patients, professionals, caregivers, services, social practices and culture(s), locally and internationally. In most part of the cases scrutinised in this special issue, both the relations and their intrinsic value remain on a hidden ground, non-formalised, making them an invisible space where material objects, knowledge and emotions meld. Therefore, gathering our input, the authors of this special issue have successfully contributed to shed light on the value of these relations, be it for improving our understanding on the difficulties in accessing healthcare services, be it for highlighting the challenges for individuals to see their fundamental rights effectively guaranteed in the meanderings of contemporary healthcare systems, or to help us reflect on the limits and appropriations of the research work we do.

On this opening issue, a first area of concern is mental health and illness, which undeniably is a paradigmatic case when looking at the interplay of Freedom and Healthcare, namely ‘Freedom within Healthcare’. In the last decades, it has been widely acknowledged that people who experience mental disorders should not be ‘confined’ or ‘segregated’, but rather ‘(re)integrated’ into society, which has led to wondrous changes in psychiatric care systems around the globe, opening them to a variety of care approaches. Yet, still nowadays mental healthcare maintains, to a significant extent, its historical valences of physical custody and normalisation. In addition, psychiatric intervention is often part of standardised diagnostic and therapeutic paths, which seldom contemplate and tolerate diversity, non-conformity or disagreement, thus leaving little room not only to freedom of healthcare, but more widely, to individual ‘freedom of being’. In this context, scholars from the most diverse fields have argued that psychiatric intervention might be an institutionalised and formalised way of reducing said diversity. However, from another standpoint, for some individuals, being admitted to a mental healthcare facility might represent an opportunity to access specialised care services and better their individual perspectives. As surprising or even distressing as this fact can be, acknowledging it and exploring its roots and contextual aids may lead to a wider understanding beyond standard assumptions on ‘freedom within health care’. Being open to the miscellaneous contours that (mental) wellbeing can assume is therefore a helpful attitude to guide us in the many exploratory paths these intricate dimensions may lead us to.

Moving from this ongoing debate, in her article on the ‘social usefulness’ of science, Joana R. Zózimo provides us with a very profitable opportunity to reflect on both the ethical and epistemological implications of doing research with users of a psychiatric department. Accordingly, people with mental illness experiences are given back its ‘epistemological dignity’, which means they are included into an iterative, self-reflective process allowing the researcher to challenge the most consolidated visions about science production and scientificity.

Focussing on a specific population of people with mental-related conditions, those affected by Alzheimer's disease (AD), the article by Stefano Fuselli and Letizia Mingardo also points out at a very polemic issue, which is the contraposition between patients' autonomy and the relational needs that are implicit in experiencing these disorders. Problematising the notion of empowerment, whose influence in contemporary debates has led psychiatric patients to be often depicted as self-reliant and autonomous, the authors make a bridge between the underlying arguments for this depiction and how AD patients are commonly envisioned and allowed little independence and self-determination. Their work proposes a 'relational self', which calls on to a perspective in which patients' autonomy and identity are defined in relation with their own context, their life-world.

To complete a first section of articles devoted to mental health is the article by Anna Prokop-Dorner, who, in line with the approach of Everyday Bioethics, sheds light on a fundamental issue, too often disregarded, as the role of caregivers of psychiatric patients. Among the strengths of this theoretical reflection, is extending the stigmatisation process traced by Ervin Goffman to caregivers themselves. This allows us to discover notable insights on the social processes that convert the relation between patients and caregivers into a cultural taboo.

A further section of this special issue focuses on another main dimension within Freedom and Healthcare, which is health protection and healthcare access in 'absence of freedom'. Even though one can expect this situation as exclusively relevant to individuals who have been formally deprived of their freedom – such as detainees and inmates –, in our contemporary era we are witnessing a dramatic, terrifying attack to health, freedom and life of million migrants and asylum-seekers worldwide, which can be easily included in this dimension. This, not only bring us back to an atmosphere of persecution of otherness that was thought as definitely overcome only few decades ago, but also, as highlighted in the article by Carlo Botrugno, makes it clearer how the distinction between migrants and asylum-seekers, despite maintaining some relevance, is being politically used to legitimise attempts of introducing 'zero tolerance' policies in what concerns the management of forced people movements. Considering the tremendous impact this has produced on both migrants' health and their access to healthcare services, it is suggested that bioethics' scholars should engage further with this area of inquiry, as in the premise of the Everyday Bioethics' approach, which inspired the establishment of the RUEBES itself.

In this regard, an empirical look is offered in the qualitative study conducted by Inês Vieira between Italy and Portugal, which aimed at gathering some of the complex meanings and challenges related to access to healthcare services for refugees. This study contributes to unfolding the material gaps, contradictions and distortions lying between the formal definitions of international protection to the benefit of refugees, and the practical 'steps and paths' they have to cover in an attempt to bypass the material obstacles that separate them from an effective access to healthcare.

From a different standpoint, another qualitative study, presented by Inês Faria, gives us another example of constricted healthcare choices experienced by Mozambican couples looking for alternative ways to accomplish their parenthood projects. The structural organisation of resources they are presented with induce infertile couples to engage in alternative strategies – defined as 'therapeutic navigations' – to pursue their own reproductive intentions. The interplay of these forces allows them to challenge most consolidated paths in their healthcare system and social context, therefore materialising more autonomous versions of the possibilities these could have given them.

A further relation, relevant to Freedom and Healthcare, is the one between gender-based violence and victims' health, as characterised within Lia Lombardi's article, which presents the results of a research-action study conducted in four Italian municipalities. This work highlights indeed how gender violence cannot be satisfactorily analysed without going back to the roots of culture and society, and involving a large series of actors (e.g. health professionals, social workers, teachers) and facilities (e.g. healthcare services, social services, education institutions), which can take an active role in contrasting or legitimising such a phenomenon.

Closing this special issue, is the quanti-qualitative study conducted by Leonardo S. de Morais, Vinicius A. Dargél, Marcia S. Fernandes and José R. Goldim, focussed on the ethical and legal implications of sharing images taken in healthcare settings and/or during medical procedures, on social media platforms, in particular on Instagram. The findings obtained in this study are clear insofar as they connect healthcare professionals' behaviours to their insufficient awareness of the duties of privacy protection coessential to their role. Thus, recalling the Debordian premonition that advised on the growing importance of ‘being seen’ in contemporary societies, this article provide us with a stimulating insight over the need to reinforce the moral and ethical background of healthcare professionals, which would help them being compliant to available provisions, but also ‘ethically proactive’, which means being able to foresee the impact of their actions before someone would ban their behaviours.

Finally, we would like to remark that this Special Issue represents the result of a year-long working process between many actors in different and sometimes very precarious places, which are enough reasons for any well-intended person to not even think of starting it. However, it is also a good – we hope – testimony of how a fruitful, ongoing, transparent and perseverant dialogue may lead us to the extraordinary place that lies beyond our boundaries and expectations.

We thank all the authors, for all the good work they generously shared with us, and Graça Carapinheiro for her preface, granting us such a good kick-off for this issue. We also want to sincerely thank Emilio Santoro, director of the L’Altro Diritto Interuniversity Research Centre on Penitentiary, Deviance, Marginality and Migration’s Management, whose sensibility and intuition has allowed the idea of the RUEBES to be converted into reality.

Florence and Lisbon, July 2018

Science is neither neutral nor immediately useful: Ideas on research ethics and social usefulness

Joana R. ZÓZIMO*
L'Altro Diritto RUEBES - University of Florence
CSG/ISEG - University of Lisbon
CES/FE - University of Coimbra
LIGMH - New University of Lisbon

ABSTRACT: As social researchers, we are more and more used to justify the limits and ethical consequences of our research projects to external entities like bioethics committees. Yet, less common have been formal training and explicit debate on the ethical implications of our work. By this, I mean that its ethical importance, utility and legitimacy are not as formalised as other scientific and methodological precepts, considered essential to scientific work. This matter, I argue in this paper, has epistemological and heuristic repercussions in the short, medium and long term, in what interferes in the scientific process and the kind of knowledge produced. Therefore, my proposal is to take on this practice seriously, by considering the ethical meanings and values of what we are doing before, during and after the research activities we undertake. By means of the ethnographical information I have gathered for my doctorate work on what is good care for severe mental illness, I present some examples of ethical problems I have faced, transitory solutions for them, and some ways of turning this ethical turn into practice. Finally, in the conclusions, I build up on the implications of ethical reflexivity for the researcher and in science.

1. Introduction

As social researchers, we are used to justifying the limits and ethical consequences of our research projects to external entities like bioethics committees. Less common are formal training and explicit debate on the ethical implications of our work, which have been pointed out in the last years as important steps to further develop our ethical capacities as scientists.

---

* Corresponding author: Joana R. ZÓZIMO | joana.zozimo@gmail.com

Yet, this does not mean that these concerns are ignored altogether in the academic praxis. It means their importance, utility and legitimacy are not as formalised as other scientific and methodological precepts, considered essential or intrinsic to scientific work. Hence, this ethical turn should be done as an internal move, with implications on how work is done and seen from the outside, other than a simple response to external demands (Becker, 1988).

This matter, I argue, has epistemological and heuristic repercussions in the short, medium and long term, in what interferes in the scientific process and the kind of knowledge produced. Therefore, my proposal, in this text, is to take on this practice seriously, by considering the ethical meanings and values of what we are doing before, during and after the research activities we undertake.

The context for this discussion is my doctorate[1] work on what is ‘good care‘ for severe mental illness[2], a delicate field in its organizational and symbolic complexity, aggravated by its relative invisibility and difficult legitimisation as an issue that needs to be recognised and worked upon (when compared to other public health problems, as for example cardiovascular problems). I find it a particularly pressing theme from which to reflect on the necessity of evaluating sociological research from an ethical standpoint. Social scientists should ponder and act on ethical concerns, according to a position in which these concerns are not mere accessories, be it theoretically, methodologically and epistemologically (Pegado *et al*., 2016).

The need for formalizing the ethical training of researchers, even though still not a mainstream one, has been noted in a more or less disperse way in civil society – for example in the questioning posed by ever more reflexive and informed citizens (Eizagirre, 2017), in bigger demands for substantiating research studies to ethics committees (Raposo, 2016), in evaluating the ethical and political dimensions of sociological work according to different methodological approaches (Nunes, 2011; Raposo, 2016). Also, the EU framework supporting research and innovation declares, in its last program’s (Horizon 2020) orientation

---

[1] Under the supervision of Professors Fátima Alves and Sílvia Portugal, and financed by a PhD Grant from the Portuguese Foundation for Science and Technology (*Fundação para a Ciência e Tecnologia*), ref. SFRH/BD/85712/2012.

[2] Empirically based on an ethnographic study, which included 6-month daily participant observation conducted from April to October 2016 in two ambulatory units of a Psychiatry Department in a Portuguese general hospital, and interviews with users of these units. During this time, I participated in all the activities that these units provided in terms of care, social rehabilitation, or social events, as well as team/department meetings. All the people with whom I worked there were aware of my role as researcher and the project I was developing there.

guide, that it is a strategic interest to reflect and research on "Responsible Research and Innovation"[3]. This interest is rooted in a contemporary debate that has led to the new General Data Protection Regulation (Reg. EU nr. 2016/679), which stresses an accountability-based approach when it comes to using other people data; and the recent revision of the European Code of Conduct for Research Integrity (ALLEA, 2017). Even though it is still a recent and ongoing process, Eizagirre (2017) draws an extremely interesting and updated analysis on this subject of responsible research.

A recent effort to present sessions about ethics in the last National and European Congresses of Sociology, the organization of seminars dedicated to the theme by the Portuguese Sociological Association, or the volume recently published by the Law School of University of Minho (Oliveira & Mac Crorie, 2016) compiling the colloquia held there between 2014 and 2015 on ethics and human rights, are some examples of an emerging movement of debating, publicising and looking for solutions beyond said external pressures, among social scientists in Portugal.

I would like to stress in advance that, although aware of the importance of questioning our own work, I do not ignore the systemic constraints to scientific liberty and legitimacy, felt by many of us nowadays. Professional instability and organizational pressures, to align with research streams that have greater possibilities of success (i.e. getting financed and published), justify survival-oriented attitudes from researchers, research centres and faculties (Nunes, 2011; Raposo, 2016; Eizagirre, 2017). I am also aware of the recent attempts to devalue scientific work, challenge it and dismiss it as bogus and illegitimate[4].

However, this awareness also motivates healthy critique and discussion of the values guiding social research and how can one zeal for their abidance, that is "(…) a debate on the type of science and technology that we find socially fair, adequate and desirable." (Eizagirre, 2017: 101, original in Spanish). Let me be clear that I do not mean to discredit scientific work in this paper, but to discuss ways of enhancing its internal coherence, quality, and

---

[3] For more information on the subject, see https://ec.europa.eu/programmes/horizon2020/en/h2020section/responsible-research-innovation; and http://www.rri-tools.eu/.

[4] As I will not be able to develop it further here, see, for example, the case studies compiled by the Union of Concerned Scientists (https://www.ucsusa.org/), information on the several marches for science held across the world on the 22nd April 2017 (https://www.marchforscience.com/), or publications from the Heterodox Academy (https://heterodoxacademy.org/).

consequently – I hope – strengthen science's external legitimacy, as we show to have thought these problems through and adopted solutions to deal with them.

Hence, in this path, I have been asking myself some pressing questions related to (i) making scientific research usefulness as compatible as possible with ethical principles – i.e. how to balance academic importance and its social relevance with ethical demands; (ii) not reproducing stereotypes on mental illness or care while researching them – i.e. how to avoid normative visions when considering ethical questions; (iii) developing ethical competencies and reflections, by sharing explicitly the ethical concerns and corresponding solutions found in given research project (as researchers often do when they publish their methodological considerations).

As I found it difficult to answer to these questions satisfactorily, I will base this paper on them, hoping to contribute to the discussion. These are intimately linked to the kind and amount of information we decide to give to participants while doing research and how we give back the images built – in short, how we imagine the production of scientific knowledge and incorporate that vision in a particular posture as researchers.

I have found that an ethically-conscious position in science not only implies respect for anonymity and confidentiality of those who generously give us information about their lives; serious and rigorous treatment of these data and an honest formulation of conclusions, as stated in the Deontological Code of the Portuguese Sociological Association (APS, 2008), but also a cordial, empathic and respectful treatment of those surrounding us in the empirical field. It demands, as in any other human interaction (but even more here because our responsibility as researchers is greater), not only a rational and logical dimension, but also an emotional dimension repeatedly omitted from methodological manuals. In these manuals, the research process (although there might be some warnings about its non-absolute-linearity) is presented in consecutive phases, rationally organised so to distance ourselves from the reality we study, in order to look at it 'objectively' – that is not entangling us in internal or external illusions and preferences. Yet, there is usually one missing phase in the research process concerning ethics, namely on the type of relationship we expect to have with the interlocutors in the field, and how will they look, after we disseminate results.

Therefore, ethics becomes important in our relationship with interlocutors in the field, beyond the choice of what information to make public, a concern many times limited to maintaining their names anonym, but that surpasses said immediate relationship and endures in time and spaces. A research relation concerned with its ethical implications calls for training our emotional capacities and not individuating them from what we usually call rational capacities – an argument I will not develop here, since I have already done it elsewhere (Zózimo, 2018), but that I will summarize in three points: (i) an amount of *empathy* is necessary to build a trusting relation with someone we interview or participate in activities with; (ii) it is an 'ethical' issue to respect and treat our interlocutors as subjects and not objects (while at the same time keeping some analytical distance); and finally (iii) we need at least some 'intuition' to take responsible decisions in the middle of fieldwork experiences happening very quickly.

Morally, the pretension of 'not objectifying' presumes a greater involvement allowing us to leave a mark of respect and responsibility in the field, to stay in it, and come back to it (whether it is us or other researchers returning to that 'place' to do research). Scientifically speaking, these ethical pretensions also contribute for producing better and more useful knowledge, once the relation we establish with people in the field allow us to first capture and then talk, more closely, about their experiences.

The goal of this paper is to discuss the place of ethics in scientific practice, not only as a set of abstract principles but as a processual and consequent dimension, that is in its relation with methodological decisions and to the limits of what is known through scientific practice. Obviously, this reflection is not meant to close the argument, but as an approach to the theme aimed at eliciting ethical practice and stimulating further debate. I will move from the assumption that science is not neutral (cf. Feyerabend, 1977; Latour & Woolgar, 1986; Ewick & Silbey, 1995; Bourdieu, 1999; Law, 2004; Nunes, 2013) and its actions are not justifiable in themselves in the name of scientific quality or criteria.

My argument articulates ethical concerns with an idea of social usefulness that can be closer to that of the scientific usefulness of knowledge and science. This reflection expands onto the methodological and epistemological components of this knowledge, i.e. that ethical considerations are to be included as an indispensable part of research's design, with consequences on how we decide to apply research techniques. It is a matter of establishing a closer relation between ethics, theory and methodology, assuming that a scientific stance deemed to be 'ethically responsible' can sustain and provide (i) more accurate knowledge, closer to what is experienced by the researcher and its interlocutors; (ii) more respectful interactions with the field and those about and with which we produce knowledge; (iii) a scientific production that contemplates on its usefulness not only academically, but also socially. Hence, unfinished as this discussion may appear, it departs from the premise that every work is done in layers and that ethical habits should be deepened in this discussion and from the contributions of other colleagues.

> In time, we may be prepared to construct an analytic and prescriptive framework for guiding professionals in the paths of ethical practice; but for now, we may have to be satisfied if we can challenge the complacency engendered by an excessive faith in objectivity and the rights of image makers. (Gross *et al.*, 1988: 7)

I divided this paper's outline in four: starting with two theoretical parts, in which I lay the basis for my argument on the need to establish a mature ethical stage in the research process and include it in social researcher's training, by clarifying what do I mean by ethics (point 2) and why do I argue that science is not neutral nor immediately useful (point 3). I will then move to an empirical part (point 4), in which I explore some of the main ethical concerns I had to deal with while gathering information on the field of mental illness, as to illustrate, share examples and allow debate on the solutions found. Finally, I will draft conclusions (point 5), giving special attention to the consequences of this arguments for science and for researchers.

2. What do I mean by applying ethics in the field?

Evident as this may sound, social research is a human activity that interferes in other people's lives, even more as it gains social visibility and legitimacy. So, to think in ethical terms has a situated and contextual relevance, which means that a case by case approach is more adequate than defining fixed and absolute ethical boundaries. In this particular context, ethics frames and aggregates orientations for action, delimiting our decisions and behaviours, it is a practical tool other than an overall theoretical exercise. Hence, even if ethics is undeniably rooted in moral values (i.e. what we consider unethical is related to what is culturally found to be right or wrong), these values are inevitably negotiated in professional praxis. Thus, if it is my aim to formalise ethics as a tool, a phase and a transversal concern in science then I need to make as clear as possible what do I mean by it, and that is the scope of this section.

In the health field, the relevant ethical framework is usually provided by bioethics, officially defined by UNESCO as "the systematic, pluralistic and interdisciplinary study involving the theoretical and practical moral issues raised by the life sciences and humanity's relationship with the biosphere" (ten Have & Jean, 2009: 32-33). The value of this definition, as others discuss (Nunes, 2011; Raposo 2016) is that it encapsulates an idea of applied ethics and a systematic movement towards interdisciplinary interpretation, defying simplistic visions of absolute protocols for research work. This protocolling, besides ignoring the complexity of an ethically responsible fieldwork, endangers forms of research – as the one I developed for my PhD – in which uncertainty is assumed as a fundamental part of the discovery process, by dismissing them as unreliable. Indeed, the UNESCO declaration defends social, cultural, national diversity and states the complexity of the field, not restricting it to medical research but applying it to science in a broader term. However, as Raposo (2016) problematizes, a good amount of ethics committees sees bioethics almost strictly in a biomedical way, which creates great obstacles to disciplines outside this spectrum. The main obstacle posed by this narrower view on bioethical challenges and prescriptions is that the frame of reference used by the main advisory and consultant bodies for health research (i.e. bioethics committees) is very different from the frame of reference that guides other forms of research, like the one social sciences do. So, if in other fields of social study these demands may go unnoticed, when one works on other people's health, one is frequently – and rightfully – obliged to answer before ethics committees, which evaluate the ethical limits and consequences of health research projects. The problems arise from these committees' deficiencies (cf. Coelho *et al*., 2008; Nunes, 2011), as the insufficient plurality of disciplines represented that may hinder research projects developed in different configurations:

> The same author [Vassy, 2010] refers to this committee with an example of how these type of institutions, due to its simplified understanding of

> sociological research and its processes, may become obstacles to the very possibility of doing certain types of research, especially those that use ethnographical approaches (*ibidem*, 251-52). (Nunes, 2011: 170, original in Portuguese).

Additionally, if we consider that there is not one ethics, but several types of ethics that may not always be in articulation with each other, but in confrontation, this can lead to scholars from disciplines outside bioethics, or biomedical area, being asked to fulfil almost impossible parameters. We need, therefore, to clarify how are these ethical evaluations done and decisions taken, and aim for developing more diverse procedures of ethical evaluation.

I understand ethics as a set of orientations concerning problems of behaviour, close to the Wittgensteinian distinction between moral and ethics, of which Cristina Beckert reminds us:

> moral relates to *norms* and ethics to *problems* (…) *ethics* exists in the order of personal experience, the way how each of us conceives his/her own existence and acts in accordance when faced with others. On the contrary, *moral* exists in the order of social convention, in the way relations are regulated within society, by rules and norms of behaviour. (Beckert, 2002: 16, original in Portuguese)

Ethics cannot, from this perspective, be the application *per se* of moral norms previously established, but a constant problematizing of choosing 'what is the best to do' at a given moment. As there are many concerns influencing our decision and preceding it, the fundamental ethical drama is the impossibility of having an *a priori* solution (Beckert, 2002: 16), then. Most of all, I am interested in talking about ethics not only as a bureaucratic requirement in a methodological path, but as a transversal, ethical-methodological process needed throughout our work – demanding constant reflection and adaptation as with any other methodological or theoretical tool. That is, ethical considerations are not resolved by an ethics committee's approval of our research protocol, or when an interviewee signs an informed consent – those are only some steps of the way. The 'applied ethics' I am thinking of is applied every step of the way – it means considering the questions I ask when I am interviewing someone; my physical posture when I am talking to someone during lunch; the information I share and how I share it when I am writing. When it comes to doing research involving people, and especially when they are ill, my argument is that ethical concerns must mean much more than they usually do.

In this perspective, if ethical principles are important for the ethical evaluation of a researcher's behaviour, researchers should not overlook the role that empathy can also play in it. This means that, when deciding if an action is ethical, our own self can be used as the basis for two basic empathic exercises. First, I should weight my behaviour as if 'I' would be in my interlocutor's shoes: for example, if I was the one being interviewed what do 'I' think it would be okay to be asked or how would I feel better approached. Second, I should weight my behaviour referring to who my interlocutor is, and how would it be if I was him/her: for example, if I would be him/her in his/her place, what do I think it will be best for him/her when in contact with a researcher.

However, 'ethical bases' are far more complex for many reasons: to begin with the researcher, s/he is not only representing him or herself as an individual, but also as a professional and scientist. Secondly, our interlocutor is not only an 'individual' for us, once scientific analysis will aggregate his/her story with similar ones and design an image of a group with somewhat similar experiences, to which s/he has connections. Hence, when drawing an ethical decision our referential is not only an individual (e.g. the person in front of us at that moment), but a collective (the group of people with similar experiences, or the groups of fellow researchers). So, one premise to be considered when deciding what to do, is 'for whom' is a decision good. For the researcher, for science or for the people with/on which is one doing research? This premise adds, to ethical problematizing a question of 'with whom' do we make the decision, i.e. if we limit ourselves to our own considerations, to the ones of our peers and our professional *métier*, or do we integrate considerations of people outside that core – and if so, 'which' among these do we choose to integrate (i.e. only patients, only professionals, family members, or all of them?).

Recalling the difficulty of defining solutions in advance, and the need for adapting to the person or the situation, it is nonetheless possible to establish some ethical directions for a responsible research: (i) ethical decisions cannot only be related to the existential order of the researcher; (ii) it shall prevail that scientific usefulness cannot surpass individual interest, free-will and well-being of the interlocutors and its environment (UNESCO, 2005, article 3.2); (iii) since it is difficult to know what is the interlocutors' interest and will, it is crucial to integrate them in various steps of research process, whenever possible; (iv) since it is not common to include our informants in the production of scientific knowledge, it is necessary to think on the methodological consequences of this precept; (v) obviously, informants can refuse to take part in it. If ethics is a never-ending exercise and one that we cannot do in a void, I shall repeat that these precepts and the arguments put forward in this paper are thought of in the context of studying mental health and illness, particularly referring to the experiences I had during fieldwork – even though one may expect (and hope) them to suit other areas of research.

This type of questioning puts us closer to Agger's 'public sociology' (2007), Frankfurt's school of 'critical philosophy', the public involvement suggested by Mills (2000), or Walker's (2013) proposal of an 'empathic sociology'. Following these contributions, sociology's function and responsibilities, like other sciences', is not limited to describing and analysing the social world, but also includes assuming the importance of scientific discourse and proposing ways for solving the problems it studies (which means proposing and defending determined models of society):

> Such a task could not be carried out in a detached manner, something that these thinkers understood. It instead required an active engagement with those individuals and groups that the sociologist sought to understand, a dialogical presence in their lives as equals attempting to understand and to find solutions to common human problems. (Walker, 2013: 6)

Including the perspective of the 'public' in our work is an ethical need when one claims to work for individual autonomy and self-determination, as many researchers claim, especially when studying presumable vulnerable and often unheard populations, and it also plays with the very need and utility of social sciences. Accordingly, competition between sciences for the production of knowledge is not only decided according to the accuracy of the knowledge that is produced, but also to the perceived/shown usefulness and legitimacy it has conquered (Roy, 1985; MacLean, Anderson & Martin, 1998; Goldfarb, 2008; Grimpe, 2012).

Considering 'to whom 'our work is useful is an ethical and existential decision for science, also because it justifies its legitimacy and subsistence. Notwithstanding the fact that much scientific knowledge would not be useful within these parameters – or at least not immediately or evidently – and that ‘useless’ research is still needed, the idea that knowledge is worth it and legitimized by itself is less and less bearable in many contexts. Even if knowing that one may have to wait many years until some scientific finding is perceived as useful, and that much of our work is made of wondering and wandering until we make sense of it, this does not exclude the need of an assumed concern and determination for knowing ‘also’ because that knowledge is useful to the general world and not only to the academics.

Ethical decisions depend therefore on an idea of ‘people’, their rights and capacities to enforce those rights (Becker, 1988: xii) and on an idea of ‘goodness‘ attached to our actions that, in a research context, is also linked to an idea of usefulness. This discussion, as philosophical as political, is theoretically resolved in our cultural context in the 2nd part of the 20th century, with the Nuremberg’s Code, and stabilized to a great extent with the 1978’s Belmont Report containing the 3 fundamental principles for the involvement of human subjects in research – autonomy, beneficence/non-maleficence, and justice – that will represent the basis of the four-principles approach developed by Beauchamp and Childress (2009) as one of the most influential bioethics theory ever. At the same time, the approach has been criticized for several reasons, among which for overestimating a person’s autonomy, as a patient, for what concerns its capacity to have an active voice in healthcare settings and assume a leading role in fundamental decisions concerning his/her life (Harris, 2003; Dawson & Garrard, 2006).

This autonomistic vision of the individual goes hand in hand with power differences in healthcare, whose discussion – at the same time moral and philosophical – could be coupled with a notable body of methodological theories and practices that tend to see individuals involved in research more as objects than as subjects. This tradition raises obstacles to ethical reflection in sociological research, and it may even partially justify why ethical concerns do not have a more important role in it, i.e. once people have been converted into ‘objects’, we no longer need to consider our behaviour towards them. Namely, when we equip ourselves with strategies preventing those people’s particularities and contexts from interfering in the way we apply our techniques, and to uniform the data we collect. The question of ‘power ’is exemplified by Beckert (2002) when she refers to the different rights people have, and the unequal knowledge they have on these. It also makes us wonder on the alliances between people when, for example, they have similar professions, so empathy may be facilitated by installed habits and hence should be evaluated critically.

Thus, what I mean by applying 'ethics' in social sciences[5] is that within the methodological evaluations we traditionally do in the course of research, there must be a mandatory ethical evaluation about the way we relate to the subjects of research (or informants). This reflection must then have consequences on the decisions we make in our work, limiting it and potentiating it. This ethical-methodological stage would comply with the objective of working:

> against erasing bioethics' primary vocation of problematizing and questioning, against all methodological and conceptual stabilization in crystallized doctrinal solutions, a stabilization that is paralysing, cynically uncertain, and, ultimately, total, totalizing and totalitarian. (Cascais, 2002: 48, original in Portuguese)

As I have argued in the beginning of this paper, thinking about the ethical consequences of our work must not only be evoked as an answer to external demands. Only by showing a systematic concern and elaboration on these questions, internal to sociology as well as to other social sciences – for example, formalized in internal ethics committees (that should still be multidisciplinary, nonetheless); in frequently updated deontological codes; in mandatory ethical training in every step of sociological training/work, etc. – can social science hold its legitimacy in any area of research, not only in health and illness. However, as we may see in the next section, this may be not only a problem of social sciences or sociology, but of scientific epistemology in general.

3. Science is not neutral and is not immediately useful

Many times, the research work I was involved in required asking people about their intimate stories (for an example, cf. Lopes *et al.*, 2016). These experiences led me to

---

[5] Even though extending these arguments to science in general would make this a never-ending paper, from what I know about other science's research *praxis*, much of this could be applied to disciplines outside the social spectrum.

conclude that an ‘ethically responsible’ fieldwork demands, on one hand, enough time and being available to listen to the person (one of the limitations of using a questionnaire that usually is expected to be quick, for example) and, on the other, some emotional involvement with the person that is sharing his/her experience.

Typically, science and scientific work rely on a set of requirements, without which its products are not considered scientific. These requirements correspond to other sets of values and quality indicators that distinguish common knowledge from scientific knowledge. And although much has changed since the 19th century, the type of science that is still more valued is the one where emotional involvement, subjectivism, and more time-consuming approaches(like ethnography) are seen with suspicion and expect to be closely watched (Guerra, 2006). Science traditionally requires scientific knowledge to be empirical, methodologically valid and reliable, the process of its making should be retraceable, reproduceable, and hence the final product – knowledge – to be objective. Of course, many prominent authors (John Law, Bruno Latour, Boaventura Sousa Santos, Jeanette Pols, Annemarie Mol, just to name very few) and important academic institutions (e.g. University of Amsterdam’s Anthropology Department; the Chicago school(s), the Centre for Social Studies in University of Coimbra) have pursued other ways of doing science, successfully established the scientific importance of qualitative methodologies, and the contributions of more engaged scientists. Yet, the quantitative-objectivist hegemony is not only a lived experience of any scientist – especially if you are a social scientist and you are doing qualitative work – but also a fact in scientific production, measured in financed projects[6] and indexed publications (van Dijk *et al.*, 2014). I will not centre my paper on those different requirements, but would rather move to discuss something that is usually rather implied – i.e. why and what for does one do science? What is the use of investing billions of Euros in scientific activities rather than in infrastructures, for instance? In few words, what is science useful[7] for?

---

[6] Most recent data, from the Portuguese FCT, on the amount of PhD grants and Research Projects by scientific domain available at: https://www.fct.pt/images/stat/B82.gif; and at: https://www.fct.pt/images/stat/P3.gif. Most recent data on scientific production, from the Portuguese Directorate-General of Statistics on Education and Science are available at: http://www.dgeec.mec.pt/np4/210/%7B$clientServletPath%7D/?newsId=116&fileName= IB2015_Destaques.pdf.

[7] I do not disregard the debates on ‘utility’ and ‘utilitarianism’, on which I will enter in the near future. In this article, I rather build on the notion of ‘social usefulness’.

Some purists would argue that knowledge is worth it in itself, and philosophically I would agree, but as a social scientist and a researcher in a country where science financing is one of the lowest in the OECD countries (OECD, 2018), I am used to having to justify my work a little further. Again, these justifications should not only be an external requirement but, I argue, an ethical and internal one. If we are convincing people to work with us in our research work – not only other scientists but especially outsiders – we should be able to tell them why their time is well spent. Why is science usefulness also an ethical question? Exactly because of the people I mentioned. Our ethical concerns should not only relate to anonymity or informed consent, we should be able to tell those people what it means to participate in our research – be it useful or useless for them, and even for academia in the foreseeable future. What I find unethical and even un-scientific is to assume that our work is inherently useful and important 'just because it is scientific'.

These reflections talk back to a notion of narrative legitimacy and also to the importance of methodological decisions: for example, if one says it is important to understand our interlocutors' perspective on their own experience, then one should ask herself, first, how ethical it is eliciting answers and then pressuring the respondent to answer according to our timetable. Secondly, the question is not only ethical but also methodological: is this pressure scientifically rigorous, as it increases the researcher's influence in the answer? This is only one example of how an ethically weighted decision may have consequences in the methods we use to collect and produce data. It is not enough to say we have the respondent's best interest in mind and we are much interested in his/her narrative – we need to make space and time for it, which has many implications in the time, economic resources, or effort we put in collecting data.

Hence, many parameters on which research is based are not defensible either ethically nor methodologically, and need further and more frequent debate. Law recovers Appelbaum's warning that "the danger of method is that it gives over to mechanical replacement" (Law, 2004: 11) not leaving space to investigate the less visible parts of reality. This is particularly important for ethical discussion, because we risk reproducing hegemonic discourses – and many times oppressive ones – with the questions we make and the methods we use (cf. Ewick & Silbey, 1995; Bourdieu, 1999). This risk is even bigger if we ignore it, since:

> [t]he subtlest and most pervasive of all influences are those which create and maintain the repertory of stereotypes. We are told about the world before we see it. We imagine most things before we experience them. And those perceptions, unless education has made us acutely aware, govern deeply the whole process of perception (Lippmann, 1922 apud Gross *et al*., 1988: 30)

From a constructivist and comprehensive perspective on reality, we know that we inevitably produce images of that same reality. These may be, literally, photographs or videos (cf. Harper, 2004; Denzin, 2004) or, symbolically, metaphors or representational comparisons – and so the power to represent the other is also the power of constructing, in some way, the other. This justifies the requirement of being aware of these images' power, as part of an ethically aware position in social sciences' work. Since the image we produce, as objective as we could claim it, is never neutral (i.e. it is not indifferent whether it exists or not), one cannot elude his/her responsibilities. This does not mean we shall do science in fear, my proposal is that we shall consider its implications while doing it.

If the image's metaphor is good to illustrate our work of producing and interpreting data, it also speaks about the modifications we introduce, with greater or lesser success, on the way people and situations are seen by those who listen to our work. Accordingly, in the case of people that experienced a mental illness diagnosis – and also because sociological research in Portugal is still rather rare on this theme –, the importance of the images I might produce has been a constant concern of mine throughout my research.

This also resonates with an explicit or implicit idea – frequent in scientific discourse – that one of the goals of social sciences' research is to altruistically give visibility to populations that are made invisible, people historically less powerful in defining the truths that are produced about them. This is a very noble objective: but how do we do it? What and who are we making visible? To whom? For what? Why is that visibility useful? Notwithstanding the different valid answers one can give to these questions, these are answers we must look for in scientific, social and cultural expectations.

Even notions of 'social disadvantage' or 'minority', which are politically important and stressed by concerns with social justice, crystalize images of vulnerability with which the groups portrayed may not recognize, or may be unreal and stereotyped (Nunes, 2011; Pegado *et al*., 2016; Raposo, 2016). These reflections suggest, in my opinion, but also in that of

Becker (1988) or other authors in the same collection organized by Gross *et al.* (1988), that research's usefulness should not only be scientifically measured – i.e. only taking academic/scientific processes into account. Defending this demands a thorough ethical auscultation, one that balances even temporarily the interests of the researchers and those of people in the context we are studying. As noble as research goals may be, the 'power of representing' must not only be orientated by those that have more power to influence the ways of representing themselves and others, as scientists do.

Even methodologically, an-only-scientific usefulness may be a hindrance, as many of the interlocutors I met in the field made very clear. One of the people I 'have not interviewed'[8] explicitly told me his/her hesitations towards the interview and it being recorded were related to the image s/he was giving of him/herself, especially in professional terms. In this case, as in many others who rejected being interviewed[9], these interlocutors of mine made clear (i) they did not want to be seen (for more on this see for example, Hostetler & Kraybill, 1988); or (ii) maybe they did not find an obvious use of that interview for them, even if they might say they recognised an abstract usefulness in science[10].

This poses an important challenge to sociology, or at least it did to me as a sociologist: the obligation, especially as social research gains more visibility, of reflecting and justifying the social usefulness of our work. This concern is both ethical and methodological because confronting the usefulness of our work with the usefulness given to it by those that are most affected by it, or whose experience I am portraying, pushes us to recognising them the importance and visibility we so nobly defend(ed).

---

[8] A category I will develop in a future paper, as well as the notion of 'disperse participant observation'. So, firstly, 'non-interviews' are conversations we have with people who, despite refusing to do the interview, talk with us lengthily (not only but) exactly about what we wanted to ask them in the first place. Secondly, I call 'disperse participant observation' to a present an active attitude of observation and analysis of the many interactions and experiences we have in our lives, also outside our professional context, which resonate with our study, even stronger than the narratives we collect in the context of research. These ways of 'not doing research', that is of not doing it in an institutional and expected way, had intrigued me lately and, of course, raised many ethical questions about whether to use them or not.

[9] Even though they would always say they thought my work was very praiseworthy, that they valued science and that when they agree on doing these kind of 'stuff' is because of the importance of knowledge.

[10] Of course, other reasons can be put forward: the lesser legitimacy of social sciences, the fact that I am a young female researcher, being in a hurry, lack of confidence, etc. But since some of the people I asked for an interview had known me for some months, meeting me on a daily basis, and these other reasons seem to be more covered in the literature, I would like to focus in this idea of 'not wanting to be visible'. This does not only have to do with shame or stigma, but also with the right to privacy, of course.

By social usefulness I mean a particular kind of usefulness – not only the uses of science for various dimensions of society, but also its usefulness for 'those impacted' or for those in the group being portrayed – which is not limited to an abstract recognition of my job's importance. This means that while doing scientific work, scientists should also equate serving these people goals and what they find as suitable priorities. By this, I do not mean that scientific work must be replaced by these concerns, but that these should be more clearly added/considered when doing science. And if one recognises, as I do, that invisibility may be a form of oppression and violence, then we should find ways of doing research that accommodate and also make visible the needs of who and what we intend to make known.

How is this different from scientific usefulness? To start, a scientific product should prove to some extent that it is scientifically robust. Secondly, it is measured in its academic worth. So, you do not only need to do 'good science' – one that produces or analyses empirical data, that describes its methodological path and clearly states its limitations and what was done to control them, where the analysis and data have been validated and considered reliable by more than one researcher, etc. – all of which allows scientists to be more certain that the knowledge they produce is closer to the lived experience of what happens in the share of reality they study. You also need to publish it in high impact journals – preferably international, be quoted as much as possible, giving way to better chances in financing and a university career[11].

Complying with these standards determines whether science is useful in its own terms, but it is a stretch to assume it is socially useful or even scientifically useful to those within the field we are studying. This does not mean I only defend research projects that are 'socially useful' in the terms above described. It means that there should be a concern in (i) specifying the presumable outcomes of the research we do; (ii) weighting those outcomes against their

---

[11] Very recently, while finishing this paper's revisions, the Portuguese National Council of Ethics for Life Sciences published a recommendation on "Integrity in scientific research" (CNECV, 2018). In it, is stated the importance of discussing (i) the difficult balance between what they define as science's intrinsic quest for 'truth' and the metrics used to evaluate researchers and research institutions; (ii) the need for implementing an entity, in any Higher Education or Research Institution, to supervise scientific misconduct; (iii) the need for a national and public debate that could reach a consensus around a National Code of Scientific Conduct; (iv) and the creation of a National Committee for Scientific Integrity, to advise on the cases of most serious misconduct, nationally. I will not be able to further elaborate on this document, but I invite the Portuguese-speaking readers (the only version available is written in Portuguese) to read it as it is one of the few statements issued in Portugal, by a national-level Institution with responsibilities on this particular issue, it is well grounded in literature, and updated in terms of the everyday challenges of doing research.

ethical and methodological implications in the work; (iii) reflecting on the usefulness of those outcomes beyond science and academy. I argue for the importance of these concerns because science might even be socially useless, but is never neutral and this should make us think on its moral dimensions and lead to ethically pondered decisions.

Summarizing: is it ethically defensible to acknowledge my work may not be useful for people in the field of mental health? Yes. Is it ethically defensible to overlook this issue and assume my work is useful for them? No. After these reflections, I will now move on to describing the main ethical dilemmas I was faced with while collecting information on mental illness care experiences.

4. Some examples of ethical problems and transitory solutions in studying mental illness

In the fieldwork I did for my PhD, it was difficult to ask how was my work useful to those portrayed in it, since only two of them gave me an interview and the interactions in the field were not controlled by me, so very seldom I was able to ask them direct questions in a context where they could feel comfortable of saying no. However luckily, I could get some spontaneous comments on my work, for example, that they thought I had collected already a lot of information on them and that it should be sufficient to portray the reality there; that they enjoyed the period of time I spent there; that they knew I respected them and I was not as other researchers that disregarded their feelings or the things they wanted to talk about. Also, others said they considered it was very important that someone went there and saw how things were and could tell others about it. Of course, it would be best to have been able to collect more lengthily their thoughts on how this work could be useful for them, but still I hope that my effort to write, in my thesis, on what were the main subjects of discussion that arose in the field, rather than on the subjects I thought would be more academically interesting might further reflect the main interests of the people in those units.

As for the ethical dilemmas I had to deal with, due to the characteristics of the fieldwork I have done, I will mainly focus on produced by (i) belonging/alliances, (ii) information, (iii) proximity, and (iv) eliciting dialogue. I found them also to be more adequate for a first text on the subject.

4.1 Belonging/alliances

Concerning the dilemmas of belonging, entering and leaving different groups[12], my main focus was on the influence of these mutual participations in the relation I established with the people in the field. The solution I have adopted was to compartmentalize the several contexts, making my best not to share ‘any’ information (even what seemed harmless) I had obtained within the other groups. This demanded a constant work of self-policing not only on what I said, but also over my bodily expressions, especially facial ones. Moreover, my concern with my bodily *hexis* was constant since the beginning of my observation, in line with Bourdieu’s warnings (1999) on the information we disclose through our physical posture. I am referring to the self-scrutiny of how I would dress, how I would seat (especially in therapy groups), my reactions to what I listened to and saw, whether I should look people in the eye or not, how to greet different interlocutors, among other things. These concerns had not only a methodological basis – since these influence the relationship with the interlocutors – but also ethical – in what is transmitted physically also demonstrates a higher or lesser attention and respect for those around us, according to the cultural codes in which we move.

Having spent a large amount of time together with people receiving treatment for mental suffering, there were moments in which I observed a lot of things without any professional being present – for example, manifestations of that suffering. The dilemmas I was faced with reminded me of the principle of beneficence previously mentioned. I have asked myself several times then if I should speak to the professionals about it, i.e. if it would be better for the ‘patient’ if they would know that s/he has been unwell. Also, as I have been introduced to the team by a technician, a doctor, there was an overall assumption that I was part of the professionals’ team, which involved certain expectations attached to ‘belonging’, that I frequently had to dismiss – be it within me or with others.

---

[12] During the time spent in the hospital, I had to go from a unit to another, and in all of them I had to navigate among groups with professionals, people with an experience of mental illness, their families, but also among groups of colleagues with whom I would share my observations.

In any of these cases, I have always decided on behalf of the patients' autonomy and free-will, and even though that would be uncomfortable in the beginning, fortunately I was not presented with a life-threatening situation, and eventually felt at ease with this decision as time went by. It also helped realising that there was a space of communication between the professionals and the patients to which I normally did not have access (i.e. individual consultations), and in which they would share more than they did when I was present.

4.2 Information

Being conscious that I had more 'information' – or 'different information' – on some of the patients and the staff than what they have disclosed to me or in front of me, posed me a moral conundrum. Not sharing this (or parts of) information involved, at least apparently, not to 'say all' or to 'be untrue'. As *naïve* as this thought might be, it still troubled me, so it might trouble other researchers as well. Even after concluding that no one has all the information at all times and that some things are simply not of my concern, it still took some emotional auscultation and empathy to not disclose my uneasiness or showing that I already knew what 'a' or 'b' were telling me, and thus affecting the relationship (with me and other interlocutors).

One concrete example of this happened when I learned that one of the patients, which I knew quite well as I have been there when s/he entered the group and was still there when s/he eventually left, had been committed to the hospital after being extremely violent towards his/her parents, which has been considered an acute psychotic episode. This left profound marks in her/him and hers/his family, and also resonated and impressed me personally and professionally. Managing my behaviour, in a way that could be true to my ethical concerns towards my interlocutors, meant a careful observation of what I would show when s/he was present, (i) not letting on that I already knew what happened, or that would lead me to judging her/him negatively; (ii) not pretending to know what happened, since I only knew one side to the story. This concern was augmented by the fact that I knew that it was very important to her/him 'not to lose face', i.e. to keep the appearance that everything was good and nothing very serious had happened before entering the hospital.

Problems posed by information came also allied to being concern with autonomy and free will of the people I dealt with in fieldwork (patients, family, and professionals), exceeding by much the mandatory protocol of informed consent. That meant, for example, giving as many information as possible, as often as needed, about my work, whether I was asked or not – e.g. in the moments I had to introduce myself, which were frequent since people would often leave and enter the therapeutic groups I was in; always saying that any of them were free to tell me if they did not agree with my presence, and ask if any of them wanted me to leave in some particularly delicate moments[13].

Even though I had this in consideration, obviously, when one is doing participant observation, it is impossible to always ask everyone that enters common spaces, for example, if they agree with my presence there. Contextually, I think it is enough to make sure that the people that are clearly being analyzed/represented are as informed as they can be about why are we there.

In addition to my verbal explanations, I distributed information sheets with a description of the research project, my contact and my supervisors', to the people with whom I did interviews, to those I asked to do interviews with, and the people with whom I was during the participant observation time and that asked for written information. Although imperfect it could have been, this was one of the ways I used to distribute as equally as possible the information on my motivations and objectives.

Another way of dealing with this dilemma is involving the people in data analysis and/ or the evaluation of the final text, a sometimes-difficult solution as it asks for a much greater effort and involvement from interlocutors and researchers, and depends as much on the real and symbolic possibilities of developing a relation that would allow this fruitful work. However, as in any other methodological/technical decision, a researcher should not hide him/herself behind the argument of difficulty. To pursue this strategy, is not necessary that all the interlocutors participate with the same intensity in producing knowledge and data, and this does not mean giving up on trying some of them do. In that moment, empathy and intuition are quintessential, because they allow us to understand if a 'yes' is a 'yes' or a 'no'. If we understand that a 'yes' is a 'no', and we have exhausted our attempts to include them,

---

[13] These triggered comments from some professionals, more than once, which would tell me that if they thought I could be there, then my presence was completely justified for the 'patients'. I answered that I felt more comfortable nonetheless and continued doing so. No user ever told me to leave during the time I was present.

then we should not insist with that/those person(s). A good test to our intuition and ethical empathy, and check whether we have got it wrong, is, for example, suggesting that the interview could be done in another time, when s/he would feel more at ease, or leave our contact so that they could contact us back.

Asking for a bigger involvement of participants in producing knowledge eases the assumption and assimilation of a more balanced relation between researcher and interlocutor, more balanced roles in pursuing scientific objectives, and the possibility of adjusting our research's usefulness. It may, however, and naturally, result in a less pacific negotiation of the final texts that account for that work. These texts are, ultimately, a responsibility of the researcher, yet a solution for the conflicts that may arise should avoid breaking the relation researcher-interlocutor. One solution might be presenting the two or more interpretations of the facts and the dialogical process originating it.

4.3 Proximity

Regarding proximity, a series of factors like a prolonged period of observation, my professional and personal posture, the receptivity of the people intervening in the groups, my participation in many moments of the life of those units, all led inevitably to a 'close relationship' with said intervenient (patients or professionals). What are the consequences of being there and later leaving the groups? How to deal with the intensity of closeness, the alliances forged and associated expectations? Clarifying my position within a certain methodological and theoretical standpoint, one that does not immediately pursues the objectivity of science (Zózimo, 2018) and that defends, as already mentioned, the ethical need for more involvement with research interlocutors (for instance, because it signals them we are not treating them as objects), led me to deal with this dilemma by practising being as most available as possible to every demand (intensity/lightness of relations, etc.) in those interactions and from those intervenient. An availability and interest that have been stressed and voluntarily appreciated by many of the people I met, from the various groups I participated in.

Additionally, practicing several moments, every day, of decompression and reflexion about what had happened in the hospital – alone or with colleagues[14], made me understand that as in other contexts and with other people – and maybe even more in the hospital where people were always coming and going in the units, people were used to dealing with significant people leaving. Hence, I should not be worried the proximity developed in that context would harm in any way my interlocutors.

This example also shows that some of our concerns about our own conduct are exacerbated by the 'researcher role' and the 'research setting' we assume, which put us and our interlocutors under a different light than (i) they put themselves, or (ii) one would put oneself in a similar situation. One shall not forget those places are not a research setting, they are still parts of a hospital, perfectly recognizable for someone who enters those rooms. As I see it, this light is necessary and useful exactly because it fosters a position of vigilance towards the way one behaves, but it also can be counter-productive when not balanced with some proximity towards the contexts one is studying and those that intervene there. Hence, a mixture of both may help us putting our presence in perspective.

This is just one more way of problematizing the idea of 'deepening the relation', historically rejected in the scientific context by many traditions and that, among others, for example Tiago Correia proficiently discusses (2013). Deepening the relationship must be seen as a way to promote trust between researcher and interlocutor, instead of a problem in sociological research. This trust (i) will be reflected in data that more closely express the thoughts of the interlocutors than those of the researcher, which is one of the main reasons why we do fieldwork; (ii) may allow for a higher level of participation from the interlocutors in producing knowledge about their experience.

This trust entails more responsibility for the researchers and interlocutors, which are not seen as objects anymore but as subjects in an interaction aiming to produce knowledge. This assumption may be an ethical problem in itself, as we can ask ourselves about the legitimacy of a researcher asking that from an interlocutor in the field. One way of addressing this is enforcing the 'others' capacity of refusing to participate, which happened very often during my experience in the field. This ability and possibility of refusing can and must be ensured

---

[14] Among the various friends and colleagues with whom I have the privilege of counting on, I owe a special thank you to Daniela Craveiro, companion to many and long reflections.

with a particular research conduct, namely when choosing the contexts and the paths to approach people. For example, when foreseeing the refusal to hold an interview of the people I contacted, I looked for ways of contacting them when no professional was around, so that they would feel at ease to refuse[15].

Concluding my remarks on proximity, it seems to me that my ethical concerns about it are also dismissed by the importance it may have in understanding what is useful to talk about when describing the work we do. For example, the fact that I was present in so many situations in the field, and that I worked on having a close relation with the people there – also because I shared information about myself – helped not only collecting data but also choosing the dimensions I would write about when analysing the data. As mentioned before, in the beginning of this section, instead of just keeping to classical categories of analysis (e. g. what is mental illness), I ended up describing interactions related to food or to non-verbal activities as these have shown to have big impact on my interlocutors and the care they worked for in the units.

4.4 Eliciting dialogue

Regarding the ethical question of eliciting dialogue, having known very different people, some more friendly, others less talkative, indifferent or disapproving, it became important to guarantee that I would not pay more attention to those with whom I felt more empathy or had an easier interaction. How to manage a relation with someone that is less open to dialogue[16]? In my case, I chose to make an effort of communicating and interacting as much as possible in an equitable way and knowing as much as I could the people I worked with every day for more than 6 months. How this is done in a context where you do not control most of the time and activities? I did it, depending on the situation: (i) by using a verbal and bodily posture of conscious and deliberate attention, not only to those that were talking in a given group/activity, but also to those that were not talking; (ii) by examining their reactions to

---

[15] At a later stage of data producing, I used the strategy of asking two psychiatrists to introduce me to and ask their patients to talk to me in private after their appointments, so to explain them that I wanted to interview them and why for. The test proved an equally higher number of refusals, even with the doctors' referrals, which actually seemed positive and congruent with my concern of reinforcing and respecting others' autonomy.

[16] On finding new ways of understanding what people tell us without using words, please do not miss Jeanette Pols' article on enacting appreciations (Pols, 2005).

what was being said and showing that I was available to listen to them; (iii) sharing some of the available time free of activities with them – i.e. going to have coffee or a cigarette, waiting while the lunch did not arrive, or having lunch with, etc. – always asking if they would mind me going/staying[17].

It can be frequently challenging to ask people to talk to you, but that is the main part of a social researcher's work, because you cannot only know what people think or want from observing their behaviour – you have to ask them. In the case of reaching those that are more difficult to talk to, an ethical interest in a more just distribution of the different experiences I would portray has also an impact on the usefulness of my work – because it shows the experiences of people that usually are not depicted, which is not only new but also allows their experience to shape knowledge and its consequences, in some way.

As I have presented the main ethical dilemmas I was concerned with during my research, and the ways I addressed them, the next final point sums up the consequences for the researcher and the science s/he does.

5. Conclusions: implications of ethical reflexivity for the researcher and in science

Picking up on an argument I have started earlier in this paper, when recognising the power of the images we produce about reality, one should pause and contemplate the moral implications of our job, as Gross *et al.* (1988) suggested. What the previous practical examples show, I hope, is how ethical reflexivity is inevitably intertwined with methodological reflexivity and weighting our work's impact.

We know that the information (commonly known as data) we use is filtered by a series of social and psychological constraints of our own and of the people we inquire or observe. We know it is a version of reality, even if a scientific one, and most likely a temporary one. Yet, dominant scientific practice insists in not sharing a major amount of information, about the type of knowledge one aims to produce, with the people about which that knowledge is allegedly about. For example, when one decides to withhold information on the goal of the

---

[17] This insistence made way to some comic moments where my interlocutors would make jokes about these concerns of mine.

questions you are asking in a questionnaire ‘so not to influence the answers’ and to obtain objective data/knowledge. Not ignoring or denying the importance of social desirability when collecting data, and the usefulness of minimising it, one shall not ignore that these options may be a mark of a scientific way of working that sees subjects as objects and, frequently, as not collaborating. Moreover, this happens not only ‘during’, but also ‘after’ knowledge is produced – since it is most often shared in academic terms, be it in the so valued journal papers or in expensive conferences. I sustain that we shall find smarter ways to minimize social desirability than just simply hiding information on what we want to know; and that it is our duty to find more accessible ways to share the knowledge produced. These ways of working are not ethically justifiable and have become less and less acceptable, as discussed earlier.

On one hand, the fact of seeing people as collaborators, who share information about their experience freely and willingly (although not always spontaneously, once in many cases we are the ones asking for information), does not imply believing blindly in everything they tell us. One must (i) keep a critical attitude when analysing data, (ii) collect enough data, and (iii) if possible triangulate data. On the other hand, the foundation of ethics in science, namely in the health field, stands on the obligation of informing people that are sharing information with us, so that they can actually give an informed consent.

These ethical questions imply several philosophical considerations. However, they may represent an unsolvable debate because they are placed more in the realm of thoughts than in the realm of empirics. Again, it would be more useful for social sciences thinking these questions in operative terms. As Becker says, one cannot think about ethical problems in an organizational void, that is without thinking about who makes ethical claims, which claims are made and whether they are successful (1988: xiv). Hence, it is not as useful (or even possible, but that would be another discussion) to think ethically in abstract as to do it as a way of addressing problems that we face in any moment of research. This habit of reflecting ethically could foster a collection of guiding experiences, for ethical situated conducts in social research. Thus, the habit of asking ‘is this good?’, ‘to whom is this good?’, ‘why is it good?’ should be practised on a daily basis.

Being aware of the importance that experts have in contemporary societies (cf. Giddens, 2002; Eizagirre, 2017), our professional ethics should argue for a movement of revaluating scientific precepts also according to the impact they may have in people's lives, rejecting *ab initio* the idea that scientific validity is above people's tranquillity, moreover in normal circumstances (i.e. in non-criminal investigation, or when not at war). That is equivalent to defending that ethical problematization must have deontological consequences, and aim to establishing some instructions that might promote ethical questioning, influence methodological rules, and propose epistemological limits to scientific work.

In this perspective, ethical questions are not only established and resolved in a logical way or according to rationally derived principles, but also through negotiations and compromises influenced by different levels and types of power (Becker, 1988: xiv-xv). Generally, those asking information and complaining about scientific results are those that know more about how to protect themselves and those that have more power in a given social interaction. Ultimately then, claims against scientists are resolved according to the amount of power of each intervenient, and the researcher should be ethically obliged not to abuse of his power as a producer of truth (Foucault, 2003). The conclusion is that one should be more of a partner in producing knowledge, as Pols argues on her article on patient knowledge (Pols, 2013).

In the many examples involving image production presented in the volume compiled by Gross *et al*. (1988), when it comes to informed consent it is often concluded that someone can only be truly informed when s/he knows at least as much about photographic processing as the professionals who produce and use photographs. One could say that this problem would only affect those that actually produce images, as photographers, movie directors, advertisers, unless one would not admit that social sciences also produce images. However, in fact, it is the very production of certain ideas on reality that allows certain questions to be asked and certain explanations to be given (Quijano, 2001: 67), which has ethical and methodological consequences. Science is not neutral, as I have elaborated before, and it has a greater responsibility towards those (people, animals) it allegedly studies, since it may have real consequences on their lives, albeit undesired by the scientist:

> Whether he wants it or not, or whether he is aware of it or not, anyone who spends his life studying society and publishing the results is acting morally and usually politically as well. The question is whether he faces this condition and makes up his own mind, or whether he conceals it from himself and from others and drifts morally. (Mills, 2000:79)

Acknowledging and reflecting on those consequences is important, not only to ensure that research does not harm those involved, but also that researchers can design more useful projects to people involved in the field. The question will not be resolved with an affirmation of the usefulness and indispensability of scientific knowledge *per se* or that if the work is worth doing, because it has a social value, doing it is a good thing, as suggested by Becker (1988: xi). Both affirmations reflect a determined cosmovision, one that may not be exempted from finding out what our interlocutors think is best for them. In order to enact another cosmovision, one must give them at least as many information as the researcher has, and wait for them to accept participating in a work that we claim to have scientific and social value.

Even admitting that researchers may honestly affirm that they do not know and cannot predict with absolute certainty the total course of their investigation, they can still bind themselves to tight revision of any detail that might damage anonymity, to not using the database for any other purpose, and to give as much information as possible to the people they ask information from. However, if those concerns are only voluntary and given little reflection while scientists are being trained, that is if there is no negative repercussion of doing unethical science, scientists will not only be unaware of it but also will continue to work as they always have. As Becker puts it:

> social scientists won't give up methods that produce worthwhile scientific results unless the codes requiring them to do so have real teeth. (Some people in both these groups, of course, will take advantage of the possibility of doing work that just doesn't address these issues: still lives, research on innocuous topics). (Becker, 1988: XII)

Addressing these dilemmas might not only be an argumentative issue, but a political one. Ethical discussion is not sterile and should raise important epistemological challenges to scientists, namely those that, as many sociologists, work about and with people. In this sense, ethical rules guiding sociology cannot be limited to a set of declarations of intents, stipulated in deontological codes frequently out of date and with no juridical bond. While sociology and its scientific production gains social visibility, greater is its responsibility in bringing ethical concerns to the centre of methodological and epistemological debate and in showing ‘epistemological vigilance’. The latter, so frequently demanded and exalted, should be extended to supervising scientific work and assuming a scientific position ruled by ethical values advocated inside the discipline, conscious of its social responsibility.

That goal implies, finally, that scientific community should gather around these concerns and define effective sanctions for those who would not abide to those guidance rules. Against a frequent position, nowadays, of valuing said scientificity above the production of a scientific knowledge that, even if more limited (e.g. because it is not able to persuade as many people to participate in the study as it would without telling them our real goals) could be more cohesive, ethically pondered and responsible. That position could imply using methodologies or work plans that would take longer and demand a renewed ability for doing scientific work, but that seems to be the only ‘good’ position for a science that wants to be useful to the community in which is integrated. Because it is built in collaboration with that community and respects those that generously give us data about their lives. It is, in my opinion, a matter of choosing between a collaborative science or a usurper science.

The ethical need for a collaborative science is also justified with the urgency of bringing to the table, where one writes ‘the knowledge about reality’, those about whom that knowledge is produced. Only then may they be able to influence scientific agendas in terms of research priorities, and can researchers engage in a more productive dialogue with them. In the case of mental illness, for example, so seldom studied scientifically within Portuguese social sciences (and not only), secularly ignored in effective public policies, and traditionally demonized in public opinion and common sense, it is fundamental to design research projects that might give some space to ‘currently talk’ to people with an experience of mental illness – as long as they want to talk. Allowing them a place in the construction of the social narrative that is made about them is a fundamental way for enhancing their autonomy and citizenship in a democratic context, but also is an ethical imperative in terms of a social scientist‘s job. And even if sometimes it is not possible to have people talking to you in an interview, as it happened to me, still the researcher can find ways of listening to them, as I believe I did during participant observation. Perhaps, I like to think, as I did not influence their talk with my questions, the stories I collected are ever closer to what they wanted me to know and show about them.

References

Agger B. (2007) *Public Sociology: From Social Facts to Literary Acts*. New York: Rowman and Littlefield.

ALLEA [All European Academies] (2017) *The European Code of Conduct for Research Integrity. Revised Edition*. Available at: http://www.allea.org/wp-content/uploads/2017/05/ALLEA-European-Code-of-Conduct-for-Research-Integrity-2017.pdf.

APS [Associação Portuguesa de Sociologia] (2008) *Código Deontológico*, available at: https://aps.pt/pt/codigo-deontologico/.

Beauchamp T.L., and Childress J.F. (2009) *Principles of biomedical ethics*. New York: Oxford University Press.

Becker H. (1988) "Foreword: Images, Ethics, and Organizations". In Gross L., Katz J., and Ruby J. [Eds.] *Image ethics: The Moral Rights of Subjects in Photographs, Film, and Television*, xi-xvii. New York and Oxford: Oxford University Press.

Beckert C. (2002) "O conceito bioético da pessoa: entre o indivíduo biológico e o sujeito ético-jurídico". In da Silva R.J., Barbosa A., and Vale F.M. [Eds.] *Contributos para a Bioética em Portugal*, 15-31. Lisbon: Cosmos.

Bourdieu P. (1999) "Understanding". In Bourdieu P. *et al.*, *The Weight of the World: Social Suffering in Contemporary Society*, 607-26. Cambridge, UK: Polity Press.

Cascais A.F. (2002) "Genealogia, Âmbito e Objecto da Bioética". In da Silva R.J., Barbosa A., and Vale F.M. [Eds.]*Contributos para a Bioética em Portugal*, 47-136. Lisbon: Cosmos.

CNECV (2018) *Integridade Na Investigação Científica. Recomendação*. Conselho Nacional de Ética para as Ciências da Vida, available at: http://www.cnecv.pt/admin/files/data/docs/ 1523888172_IntegridadeCNECV2018.pdf.

Coelho Y., Guerriero Z., Schmidt M.L., and Zicker F. [Eds.] (2008) *Ética nas Pesquisas em Ciências Humanas e Sociais na Saúde*. S. Paulo: Aderaldo & Rothschild Editores.

Correia T. (2013) "Interpretação e validação científica em pesquisa qualitativa". *Comunicação Saúde Educação*, 17(45): 263-74.

Dawson A., and Garrard E. (2006) "In defence of moral imperialism: Four equal and universal prima facie principles". *J Med Ethics*, 32: 200-4.

Denzin N.K. (2004) “Reading Film: Using Photos and Video as Social Science Material“. In Flick U., Kardorff E.V., and Steinke I. [Eds.] *A Companion to Qualitative Research*, 234-47. London: Sage.

Eizagirre A. (2017) “Investigación e innovación responsables, Retos teóricos y políticos“. *Sociologia, Problemas e Práticas*, 83: 99-116.

Ewick P., and Silbey S. (1995) “Subversive stories and hegemonic tales: toward a sociology of narrative“. *Law & Society Review*, 29(2): 197-226.

Feyerabend P. (1977) *Contra o método*. Rio de Janeiro: Francisco Alves Ed.

Foucault M. (2003) *Microfísica do poder*. São Paulo: Perspectiva.

Goffman E. (1969) *Strategic Interaction*. Philadelphia: University of Pennsylvania Press.

——— (1993 [1959]) *A apresentação do eu na vida de todos os dias*. Lisbon: Relógio d’Água.

Goldfarb B. (2008) “The effect of government contracting on academic research: Does the source of funding affect scientific output?”. *Research Policy*, 37: 41-58.

Grimpe C. (2012) Extramural research grants and scientists’ funding strategies: Beggars cannot be choosers?”. *Research Policy,* 41: 1448-60.

Gross L., Katz J., and Ruby J. [Eds.] (1988) *Image ethics: The Moral Rights of Subjects in Photographs, Film, and Television*. New York and Oxford: Oxford University Press.

Guerra I.C. (2006) *Pesquisa Qualitativa e Análise de Conteúdo*. Lisbon: Príncipia.

Harper D. (2004) Photography as social science data. In Flick U., Kardorff E.V., and Steinke I. [Eds.] *A companion to qualitative research*, 231-6. London: Sage.

Harris J. (2003) “In praise of unprincipled ethics“. *J Med Ethics*, 29: 303-6.

Hostetler J.A., and Kraybill D.B. (1988) “Hollywood markets the Amish“. In Gross L., Katz J., and Ruby J. [Eds.] *Image ethics: The Moral Rights of Subjects in Photographs, Film, and Television*, 220-35. New York and Oxford: Oxford University Press.

Latour B., and Woolgar S. (1986) *Laboratory Life: The Construction of Scientific Facts*. Princeton, NJ: Princeton University Press.

Law J. (2004) *After Method. Mess in social science research*. London and New York: Routledge.

Lopes N. [Ed.], Zózimo J.R., Ramalho J., Pegado E., and Pereira P. (2016) *Geração Sénior de Almada no século XXI: um retrato social*. Lisbon: Deriva Editores.

Maclean M., Anderson J., and Ben M.R. (1998) “Identifying research priorities in public sector funding agencies: mapping science outputs on to user needs“. *Technology Analysis & Strategic Management*, 10(2): 139-55.

Mills C.W. (2000) *The Sociological imagination*. New York: Oxford University Press.

Nunes J.A. (2011) “Sobre a ética (e a política) da investigação social em saúde“. *Sociologia On Line*, 3, available at: https://ces.uc.pt/myces/UserFiles/livros/1097_%C9tica%20e%20Pol%EDtica%20JAN.pdf.

Nunes J.A [Ed.] T.S., Brás O.P., and Matos A.R. (2013) “Biographies of Objects and Narratives of Discovery in the Biomedical Sciences. The case of the Helicobacter pylori“. *CesContexto*, available at: https://www.ces.uc.pt/publicacoes/cescontexto/ficheiros/cescontexto_estudos_ii.pdf.

Oliveira N.M.P., and Mac Crorie B. [Eds] (2016) *Pessoa, Direito e Direitos, Direitos Humanos.* Braga: Centro de Investigação Interdisciplinar da Escola de Direito da Universidade do Minho, available at: http://repositorium.sdum.uminho.pt/handle/1822/47171.

OECD (2018) *Higher Education, Research and Innovation in Portugal Perspectives for 2030*, available at: https://www.dges.gov.pt/sites/default/files/portugal_teri_system_rev_v14fev 2018_v3_com_capa-compressed.pdf.

Pols J. (2005) “Enacting Appreciations: Beyond the Patient Perspective“. *Health Care Analysis*, 13(3): 203-21.

——— (2013) “Knowing Patients, Turning Patient Knowledge into Science“.*Science, Technology, & Human Values*, 39(1): 73-97.

Quijano A. (2001) “El regresso del futuro y las cuestiones del conocimiento“. *Revista Crítica de Ciências Sociais*, 61: 63-77.

Raposo H. (2016) “Apreciação ética de projectos de investigação em saúde: uma reflexão situada a propósito da ética de investigação em ciências sociais“. *Sociologia On Line*, 12: 22-48.

Roy R. (1985) “Funding Science: The Real Defects of Peer Review and an Alternative to It“. *Science, Technology & Human Values*, 10(3): 73-81.

Ten Have H.A.M.J., and Jean M.S. (2009) “The UNESCO Universal Declaration on Bioethics and Human Rights. Background, principles and application“. *Ethics series*, UNESCO Publishing, available at: http://unesdoc.unesco.org/images/0017/001798/179844e.pdf.

UNESCO (2005) *Universal Declaration on Bioethics and Human Rights*, available at: http://unesdoc.unesco.org/images/0014/001461/146180E.pdf.

Van Dijk D., Ohad M., and Lucas C.B. (2014) “Publication metrics and success on the academic job market“. *Current Biology*, 24(11): R516-17..

Walker H.J. (2013) *A Mile in My Shoes: A Prolegomenon for an Empathic Sociology*. Master Thesis in Sociology, University of Western Ontario, Canada, available at: https://ir.lib.uwo.ca/etd/1292/.

Zózimo J. R. (2018) “Empatia e intuição: sobre a função heurística das emoções no estudo da doença mental“. In Raposo *et al.* [Eds.] *Utopia, Anarquia e Sociedade. Escritos Em Homenagem A José Maria Carvalho Ferreira*, 915-40. Coimbra: Almedina.

Autonomy and dementia. The problematic freedom of health care of Alzheimer’s patients

Stefano FUSELLI
Department of Private Law and Critique of Law - University of Padua
Letizia MINGARDO*
Department of Private Law and Critique of Law - University of Padua

ABSTRACT: The effects of Alzheimer’s disease are disruptive on a practical level for patients and their families, as well as for the healthcare system. They are also disruptive on a conceptual level because they challenge the traditional notion of identity and autonomy of the subject. The consequences are primarily relevant from a theoretical point of view, before one considers the practical one. By considering the current debate in bioethics and biolaw, this contribution aims to shed light on what Alzheimer’s disease can reveal about the notions of identity and autonomy. As many scholars recognize, there is a need for a relational turn in using these concepts. In light of this relational turn, the idea of being autonomous does not mean being sovereign of the self and exclusive authors of our own life and identity. In accordance with this new trend in bioethics, the autonomy of people with dementia is promoted, and not cancelled, through the responsibility of their doctors and care-givers, by respecting their margin of agency.

1. Human, all too human

> As far as is known, AD is a distinctly human disease; although limited AD pathology (…) has been reported in brains of nonhuman primates (…), there is no evidence for an equivalent, full-blown disease process in any but the human species (Rapoport, 1992: 88)

Although these words were written by Rapoport more than twenty years ago, they still seem appropriate to put into light one of the most dramatic features of Alzheimer’s Disease

---

* Corresponding author: Letizia MINGARDO | letizia.mingardo@unipd.it

Stefano Fuselli is author of paragraphs 1, 3 and 4; Letizia Mingardo is author of paragraphs 2 and 5.

(AD). Beyond its neurological profile, AD is a specifically human disease, insofar as it affects what is considered specifically human, that is those functions and capacities, like language, memory, or conscious self-determination by means of which the human species has distinguished itself from other species.

If there is a specific human way to be aware – and therefore to communicate and to decide – AD is one of its most devastating forms of erosion and decay. Patients progressively lose their memory in all its aspects and components (Gambina, 2008). Therefore, they do not lose only their capacity to retain or to recall who they were and what they were like, but they also lose the capacity of thinking of themselves as the subject, the main character of a narrative which develops in time, and which is articulated into past, present and future. This capacity of putting things and themselves in a temporal order, which is a structural feature of our awareness, has been recognised as a specific trait of human intelligence since Aristotle[1].

Because of AD progression, patients gradually but relentlessly withdraw from the world that was their environment, which is not only a collection of 'things' but a totality of relationships and meanings, on the basis of which they could shape their behaviour, their expectations, their choices. The progressive decay of their cognitive capacities causes not only the loss of relationships established with the world, but it also causes the progressive loss of the capacity itself of establishing those relationships with the world. From this point of view, a radical detachment from everything takes shape in the decay process. In fact, what is compromised is the capacity which makes possible every usual, familiar, daily way of establishing a relationship with something. This detachment is total and totalising to the extent that it involves patients who, in the progressive loss of awareness, withdraw not only from the world, but even from themselves.

This is the reason why, according to some scholars, Dementia and AD offer a special point of view which helps to grasp the difference between being 'somebody' and being 'something'[2], and therefore to test those bioethical theses that consider awareness to be not only the condition for an individual's psychological identity – i.e. his/her being or not the same person – but also for his/her ontological identity, that is his/her being a person or even a

---

[1] Aristotle, Phys., IV, 223 a 25-ff.

[2] The reference is to Spaemann (1996). AD is a particular stimulating testing-bench for philosophical research, as attested by some essays collections like Churchland (1992), and the more recent Carlson & Kittay (2009).

human being (Gazzaniga, 2005). Of course, this has immediate and disruptive consequences in biolaw debate about the decision-making capacity of patients. Some well-known issues are at stake. To what extent are they still autonomous? To what extent should their residual autonomy be preserved and respected? What does it mean to respect the autonomy of an AD patient?

The two main views developed in this context – the Substituted Judgement Standard and the Best Interest Standard – both imply a previous assumption about that particular entanglement of personal identity and autonomy, shaped in decision-making capacity (Jaworska, 2009). From Informed Consent to Living Will issues, the question about 'who' is choosing is implied in the question 'whether' someone is capable to do it and 'to what extent' he/she can do it. After all, the word 'autonomy' implies the reference to *autos,* self.

2. Alzheimer's and legal tools for self-determination in health care

From a legal point of view, AD makes it very difficult to evaluate the validity of will and wishes of the patients (Fethersonhaugh *et al*., 2016; Fethersonhaugh *et al*., 2013), with particular reference to informed consent for medical treatments (Salvaterra, 2011).

In Italy, before 2004, such difficulties could be resolved by means of particular legal measures for the protection of the incapacitated: full guardianship for the totally incapacitated (in Italian, *interdizione*), as ruled in article 414 of the Italian civil code; curatorship for the partially incapacitated (in Italian, *inabilitazione*), as ruled in article 415 of the Italian civil code. According to those measures, legal representatives, who are the guardians for the totally incapacitated and the curators for the partially incapacitated, substitute for the will and capacity of those entrusted to their care. These legal measures are still available nowadays; however, they consider people simply in terms of a straightforward dichotomy of presence or absence of will, capacity or autonomy, without considering possible (and even probable) grey areas. The idea of simply substituting the will of incapacitated subjects is clearly a legalistic approach with a stamp of paternalism, which contemporary legal culture regards as obsolete and unworkable.

Furthermore, using these instruments was not universally acceptable for those issues concerning the person, and not the heritage, of the incapacitated, such as medical decisions. In fact, the major part of the legal doctrine underlined the fact that those measures were designed for the protection of heritage rather than the wellbeing of the individual. This debate was still active in the 90's, when the Englaro case arose with its force for change. This case, eventually ruled by the Italian Cassation Court in 2007, was the first to introduce in Italy the so called 'substituted judgement test' and it succeeded also in changing this set of opinions, by permitting legal representatives to decide about the health care and medical needs of the incapacitated (Mingardo, 2012).

In 2004, an additional level of protection for the incapacitated, called 'support administration' (in Italian, *amministrazione di sostegno*), was added by law n. 6/2004, given that the legal measures of the day were inadequate to the proper management of the semi-incapacitated, not to mention the management of those with intermittent conditions, such as AD. As was set out, the purpose of the law was (and is) to safeguard, with the minimum possible limitation of their legal capacity (that is the capacity referred to the age of majority), people who lack, totally or partially, the autonomy and ability to manage their lives, through means of permanent or temporary intervention. Article 404 of the Italian civil code states that such interventions call for the designation of a support administrator: "The subject who, by reason of an infirmity or a physical or psychological reduction of capacity, finds it impossible, either partially or totally, to provide for his/her proper interest, may be assisted by a support administrator, appointed by the judge".

Much use of such legal measures is made in the field of the mentally disturbed and for those with degenerative diseases even where health decisions are concerned. In fact, support administrator is regarded as a health care proxy, endowed with power to decide with, and not for, the incapacitated person, and refer such decisions to doctors.

The law grants everyone the right to designate in writing his/her choice of a support administrator in case of future incapacity, thus permitting the appointment of a health care proxy, who may be supplied with instructions to be put into practice at the appropriate time. This right was interpreted as a possibility to draft a proxy directive, despite the fact that there was no specific law on informed consent and health care directives (Defanti *et al.*, 2007).

In the absence of a specific law on health care directives, such possibility has been much discussed in legal doctrine and in jurisprudence, but it may well be overtaken by the approval of law n. 219/2017 in the matter of informed consent and health care directives. Such law prescribes that the person incapacitated has the right to a proper evaluation of his/her capacity to understand and decide upon, and to receive information relative to his/her own health choices in relation to his/her capacity to understand, in order to be able to express his/her wishes. Within this general principle, guardians or curators, and support administrators, are expressively endowed with the task of a health care proxy, at the service of the will of the person incapacitated.

As specific tools safeguarding freedom in health care, advance health care directives and advance care planning have been established, in conformity with articles 4 and 5. Advance health care directives, ruled in article 4, permit anyone with normal capacity to indicate such health care treatments as would or would not be applied to future cases of incapacity, and to appoint a health care proxy with the task of representing his/her wishes to the doctors and entering into relations with health care staff. Advance care planning, ruled in article 5, which is more suited to illnesses, amongst which AD should be considered, allows for programming of a health care plan in cases of chronic diseases, invalidity, or illnesses characterized by a progressive and terminal condition. This plan, which should be agreed between doctor and patient, would be mandatory for doctors and medical staff, when the patient finds himself/herself in a situation where it is impossible to express his/her wishes or give his/her informed consent, or where he/she is in a condition of total incapacity.

In dialogue with doctors, the patient and his/her relatives or trusted partners should be well informed about the progression of the illness, the quality of life he/she may expect, the clinical possibilities of treatment, surgery, or palliative care. As a result of this consultation, the patient may give his/her informed consent to the plan proposed by the doctors, express clearly his/her wishes for the future and even appoint a proxy.

It would seem therefore, that from a legal point of view, these are suitable instruments to deal with and safeguard the freedom of patients suffering from Alzheimer’s disease as well, through the appointment of a support administrator, advance health care directives and advance care planning. However, things are not that simple. The way in which the rules and norms for the incapacitated are applied depends, on the one hand, on the specifics of the case and the nature of the persons involved, and, on the other hand, on the culture (not only legal, but also social and ethical) of the context in which the norms are applied.

In other words, when it is necessary to admit patients to hospitals or residential care facilities for the aged, they enter places where, although sensitivity to patient’s autonomy is hugely stronger than in the past (CNB, 2014), they are nevertheless subjected to bio-political power (Foucault, 2012; 2006; 2003; 1995).

In such environments, it is easier to find new forms of medical paternalism that originate from modern culture and its presumptions (Zanuso, 2013; 2005; Fuselli, 2016; 2014; Moro, 2004), in particular from its idea of solipsistic freedom (that is, as complete absence of obstacles), and its idea of solipsistic autonomy (that is, as complete independence of the individual). Such aporetic concepts of liberty and autonomy influence many of the contemporary ideas and theories of personal identity; maybe in a less evident way than in the past, but nonetheless persuasive (and violent), as the following pages will show.

3. Alzheimer's and identity

The debate about the loss of 'identity' or 'self' in AD patients often overlooks that these notions are all but univocal even in the clinical context itself. Some years ago, a study by Caddell and Clare put into light that in clinical literature there is a wide range of methods currently used to investigate self and identity in people with dementia. This methodological variety implies a corresponding conceptual variety, because the notions of self and identity underlying the different approaches are not the same (Caddel & Clare, 2010). The most relevant consequence of it is that:

> it is still not known whether the self as a whole is affected by disease, or whether isolated components of self are affected independently of each other. In addition, it is unclear how the self changes over the disease course, and if the self persists in dementia, whether it is a current or outdated sense of self (Caddel & Clare, 2010: 125)

Bioethical and biolaw literature too offers different accounts of personal identity - psychological, biological, narrative or anthropological - each of which implies a certain idea of continuity (Shoemaker, 2015; Reichlin, 2012). It is worth noticing that each of these models is the result of a multi-century-long philosophical debate aimed at going beyond that 'metaphysical' view according to which the self is a substrate, an essence that persists beyond any changes, even those extreme forms of changes which are birth and death (for instance, this is the case with a traditional idea of 'soul').

Although these accounts reject the metaphysical notion of ‘substance’ or ‘essence’, they assume that there is a persisting ‘real self’ which provides the continuity – the personal identity – of the individual beyond any changes. It is clear that on the basis of these assumptions, because of the radical transformations caused by the disease, an AD patient could not be seen otherwise than as someone who is not anymore, someone who is no longer that same ‘self-aware subject’[3] who was recognisable by him/herself and the others.

In addition, this ‘hard core’ of personal identity is thought to be structurally self-sufficient, because the ground of its being one and the same is an exclusive self-relationship. Even the idea of a self that is committed to a stable set of identity-defining values and convictions and therefore capable of expressing continuity over time – like, for instance, in Dworkin’s theory (Dworkin, 1993) – presupposes “a self that is separate from all other selves and that essentially decides alone” (Koppelman, 2002: 70).

As an alternative to this approach, according to which patients’ identity is fixed in the then self, that is the self which, before the onset of the disease was identified by a stable set of values, a different approach has been provided. It focuses on the now self, characterized by the patients’ abilities, interests and expectations in the present. According to the now self approach, the new interests or desires of AD patients should be taken into account, even if they are not or seem to be not compatible with past choices (Koppelman, 2002).

In contrast to the idea of identity as stability and continuity, this approach provides a view of the self which can be called ‘punctiform’, because it can be entirely identified with interests that are circumstantial or even episodic. However, it overlooks the fact that what makes the existence of one’s self unique – and therefore provides a necessary feature of personal identity – is the particular way in which its experiences and decisions are entangled. In the now self approach, the self is not only separated from all other selves, but even from itself.

Therefore, it seems to be more fruitful to take into account those positions which challenge a monadic and solipsistic view of personal identity (Quante, 2007; Meini, 2017). After all, as highlighted by Ricoeur, the idea of narrative identity has to take into account the fact that the subject of this narration – the narrating self – does not dominate the beginning

---

[3] In Italy, the National Bioethics Committee (CNB) distinguishes among self-recognition and self-detection; self-monitoring and self-agency; self-recognition and self-ownership; and self-knowledge (CNB, 2014); see also Thompson (2007), and Rodotà (2012).

nor the end of the whole story, which are by necessity referred to narrations provided by others (Ricouer, 1990).

This seems to be the reason why a different conceptual frame is required (Nizzi, 2012, 2013), one that takes into account a more dynamic and plastic view of identity. For example, Hilde Lindemann, provides a notion of identity as a ‘representation of self’, which is “a tissue of stories, constructed from not only first-person but also many third-person perspectives, depicting the more important acts, experiences, relationships, and commitments that characterize a person” (Lindemann, 2009). If the contribution of third-person voices is fundamental not only for the process of constructing a child’s identity but also throughout a person’s adulthood, it could be helpful for AD patients too, in order to preserve their identity.

On the other hand, according to Bruce Jennings a relational account of personal identity prevents from equating it with the set of performances that somebody is capable of at the present moment. This is possible by adopting a specific account of personal identity based on the ‘memorial personhood’ notion: “To be a memorial personhood is to be a self in the imagination and memory of others” (Jennings, 2009: 430). We all need others to recall some events of our story. On this basis, dementia care could be seen as a form of reminding that is not only recalling, but also a form of reconstructing the subject, of hindering the erosion of the mind of a patient. In fact, having a mind – this is the backing assumption – implies the capacity of establishing semantic relationships with other individuals by means of which someone can make, interpret, and exchange meanings. Of course, communication is not limited only to verbal or usual semiotic communication, but it could also be performed by means of touch, gesture or eye contact. Therefore, the decay of the main cognitive functions does not imply the loss of semantic agency tout court, nor the loss of personal identity.

To sum up, the steadily progressive decline in several cognitive domains like memory, language, time perception, which is typical for AD patients, is not reducible to a mere loss of personal identity or self. Rather, it seems to call for dealing with the source of personal identity, the background for the shaping of the individual self.

The falling apart of that set of abilities, performances, competences which features and concretizes the identity core of the conscious individual self is not only a dissolution, a loss, but so to say a going back to that pure and therefore also considered extremely poor and meagre communicative competence which underlies all kinds of relationships the self is capable of and is woven from. The progressive sinking of consciousness into unconsciousness is like a backwards walk that shows what lies behind consciousness, what makes its arising possible, and what therefore does not exhibit the same features of consciousness itself or of its most typical activities.

The withdrawing from everything is the going back to that point from which the identity of a conscious self has originated. The poorest but therefore most essential core of personal identity requires a certain way of being in relationship, which is the dialogical way: to be in dialogue and for the dialogue beyond the words.

4. Alzheimer's and autonomy

According to some scholars, if there is a residual communication capacity – even if not verbal – the aim of caring is to support the agentivity of patients, their ability to make choices and decisions. Research on AD patients shows that the possibility of remaining central in everyday decision-making plays a crucial role in maintaining their sense of self and identity (Fetherstonaugh *et al.*, 2013).

Of course, the range of decisions which AD patients are capable of is progressively reduced to those that are meaningful to them, to those decisions that belong to the semantic level which they are capable of. Nevertheless, if "autonomous decisions (…) are decisions that reflect the self which makes them" (Koppelman, 2002: 65), a certain degree of autonomy has to be recognized to AD patients too.

Autonomy, like identity, is not a univocal notion. For instance, in legal contexts, the interest is focused on determining the kind of decision-making ability needed to be competent as well as on measuring its degree (Defanti *et al.*, 2007). Clinical tests are administered to evaluate to what extent a patient can communicate relatively consistent or stable choices, to what extent he/she can understand basic information about choices, his/her ability to evaluate the probable consequences of available choices or to rationally assess risks and benefits of choices (Woods & Pratt, 2005). But this calls for a particular notion of autonomy as specific competence (White, 1994).

Different meanings imply different approaches also in bioethics. According to a well-established approach, being an autonomous person implies being an individual of normal competence who has the right to make important decisions defining one's own life for him/herself. Autonomy calls for “the capacity to express one’s own character (…) in the life one leads” and therefore “makes self-creation possible” (Dworkin, 1993: 214). Thus, autonomy is connected to the conceptual field of self-determination, of full independence of the agent’s will from any external factor, a kind of full self-sovereignty (Rodotà, 2012: 272) of an ‘insular individuality’ (Azzoni, 2012; Mingardo, 2015), according to which the agent – on one’s own - can shape his/her personal individuality.

Therefore, it could be interesting to take into account a different point of view. In contemporary bioethics, the ‘relational turn’ (Jennings, 2016) challenges the assumption that being autonomous implies being the self-sovereign creator of one’s own life and identity. The claim is that one cannot be autonomous without nesting in a relational context. Therefore, being autonomous calls for the flourishing of a relational self. On the other hand, emphasis is laid on the fact that not even the most individual choice is made in a social vacuum, because it is always oriented by the set of values or preferences that each of us has developed in a certain historical-cultural context.

Some effects of this relational turn seem to be recognisable also in the debate about autonomy of AD patients and how to respect it. Some scholars argue that awareness is not something private which declines with the cognitive decline due to the disease, but it is something multi-faceted, to be understood in the context of the interaction of cognitive functioning, individual response and social context[4]. Therefore, the notion of autonomy of AD patients and of the respect of it has been reconsidered and reconceptualised. In fact, if awareness is related only to the demented person, the expression of patients’ personal autonomy may be hindered even in daily decision-making. On the other hand, if awareness is understood as multi-faceted and context-related, the manifestations of autonomy in daily life should be supported as much as possible.

From this point of view, preserving AD patients’ agency, their being moral subjects by means of the context, becomes the goal of treatments. Care-givers should consider what patients care for. Patients’ capacity of caring, that is their capacity of focusing on a set of values that underlies those particular interests and choices in which they feel primarily engaged, and on the basis of which they can grade their preferences, could be seen as a particular form of autonomy (Jaworska, 1999; 2007). By virtue of the endogenous character

---

[4] See Clare (2004), reported by Woods & Pratt (2005).

of this capacity of having values and of caring, a form of autonomy takes shape that does not decline even if one needs other people to help him/her in performing what he/she feels essential. Therefore, AD patients’ autonomy could be seen as the capacity of taking active part in a process that involves many people, who care for making it possible that patients should choose, in those situations which they feel are decisive for themselves. Nevertheless, it is worth highlighting something that lies in the background of the AD patients’ autonomy issue, something that lies at the root of humanity. Behind the capacity of decision-making there is a previous act, which comes before the one performed by choosing among given possibilities, that is the act of originating different possibilities by opening the field of the possible.

According to Damasio, “our attitudes and our choices are, in no small part, the consequence of the “occasion of personhood” that organisms concoct on the fly of each instant” (Damasio, 1999: 225). This uninterrupted opening of possibilities, this continuous concocting of possibilities is what provides the conditions for the developing and the implementing of the choice-making capacity. From this point of view, something more radical takes shape behind the progressive diminished capacity for decision-making or putting decision into practice and carrying choices out, which is the diminishing of the capacity to provide alternatives, to model the possible. This capacity can be stimulated by relationships, and insofar it had been educated, developed, nourished and enhanced before the onset of the disease, it could be supported or protected in AD patients too.

The role of the different care-givers (professionals or family members) appears to be here really crucial. Their primary function is not to carry out a previous will or past decisions, nor to act according to an abstract best interest standard. Rather, their primary function is to provide conditions for a choice that is to figure out alternatives which are not only abstractly possible, but also meaningful for the patients[5]. Of course, this calls for a constant dialogue among the different care-givers. The aim of the dialogue is not only to come to a decision, but primarily to open the space for the possible and to keep it open. So, there are no pre-established solutions to the question concerning the right course of actions, because the answers should be case-related, since they emerge as a result of the concrete constantly evolving dialogical relationship.

---

[5] In Fethersonhaugh *et al*. (2016), it is used the taxonomy proposed by Thompson (2007).

5. Alzheimer’s and freedom of health care

If we want to improve our way of living, thus to make our societies more innovative, inclusive and reflective, it is essential to find a way to really respect the margins of ‘agency’ of people with dementia. As demonstrated, this change can happen only if we rethink in depth the concepts of ‘identity’, primarily, and ‘autonomy’ and ‘freedom’, secondly.

In light of the relational turn above discussed, the idea of ‘being autonomous’ does not mean being sovereign of the self and being exclusive authors of our own life and identity. On the one hand, the idea is that we are autonomous only in the relational context in which, and thanks to which, we live. In this way, to be autonomous is to realize this ‘relational self’. On the other hand, we have to consider that even the most individualistic choice never arises in a social vacuum, but is always orientated by the set of values or preferences of a certain historical-cultural context.

As above mentioned, in accordance with this new trend in bioethics, autonomy of people with dementia is promoted, and not nullified, by changing the responsibilities of their doctors and care givers, by respecting their margin of agency. In this sense, it is possible to reconsider the convenience of advance health care directives and advance health care planning in the context of Alzheimer’s disease.

For the first, we need to consider, not only the health care directives as generally understood, which are written by fully competent people providing for future incapacity, but also those special types of directives born in North America and called ‘Ulysses contracts’.

Here we call to memory the tale of Odyssey, in which Ulysses encounters the Sirens, monstrous creatures, who, hungry for human flesh, sing to attract their prey. In order to listen to their song, which reveals the mystery of the universe, and in order to avoid sailing his ship onto the rocks, Ulysses asks his companions to tie him to the mast and not to release him, even if he implores them so to do. Among bioethicists, Ulysses’ request to his companions is considered to be the archetype of advance directives.

The special characteristic of the Ulysses contracts, also known as ‘mental health advance directives’ or ‘psychiatric wills’, is that they can be written by a person with reduced capacity but who can still be considered competent, where decisions about his/her own health care are required (as may be the case of a patient in the early stages of AD). Clearly, the individualization of this margin of competence should be made consciously, adjusted on a case-by-case basis, in the light of and in respect of the individual patient's margin of agency, as above mentioned. Although they are much discussed (Dresser, 1984; Wicklin, 1987; Widdershoven & Berghmans, 2001), they could, and should be an opportunity to improve the dialogue between the patient and his/her doctors or care givers and, therefore, to respect his/her 'relational dignity' and his/her 'relational identity' (Mingardo, 2015; Van Willigenburg & Delaere, 2005). These tools are, without doubt, an invaluable opportunity only if they are properly considered and applied as a means to open a space for shared decision-making. Of course, we must avoid falling into that mentality Mingardo called the 'paradigm of patient's sovereignty' (Mingardo, 2015). In conformity with this cultural model and widespread trend, the right to freely choose health care is conceived as absolute, and as the patient's claim to be master of his/her own life and decisions.

Confronted with the sovereign-patient, the presence of the subject-doctor (or care giver), endowed with the power of performing the orders received, as an automaton, is obligatory. Within this paradigm, the space for an authentic communication, which implies not only passing of information, but also sharing of experience and emotions, is reduced to the minimum, if not nullified. Implicit in this fact is the conception of personal relationships only in terms of utilities, while the other is seen as a mere instrument, useful for achieving prefixed goals. In other words, this fact seems to be condemning others, and, therefore, even themselves, to solitude.

That is why, in the context of dementia, it is better to prefer advance health care planning rather than simple advance health care directives. Within advance health care planning, in fact, the risk of falling into the solipsistic upshot, just described, is minor. Advance health care planning ensures, with major certainty, the opening of a space to have dialogue and share information, experiences and emotions, by creating a net for supporting the patient from the first moment.

Ulysses himself, when he faces the Sirens and their mortal danger, understands that the only way to face, as a man, the risk of death, is to trust his faithful companions, those who found themselves living the adventure of living with him. The hero, confronted with death, chooses life, recognizing the need to place his confidence in others, and further. This trust calls for respect for the liberty of others and the acknowledgement of our own frailty and, at the same time, of our own transcendence over the world of phenomena.

By recognizing this fact, having the opportunity to accept the tragic nature of life means grasping ‘freedom’:

> Life does not necessarily have to be destructively painful; in life we cannot find perfect criteria, already established, to follow in every case. However, the uncertainty [of freedom] reveals a surprising message: Oh man, your pain is witness that your destiny is not reduced to the world of phenomena (Cavalla, 2000: 241)

References

Azzoni G. (2012) “Dignità umana e diritto privato”. *Ragion Pratica*, 38: 75-98.

Caddel L.S., and Clare L. (2010) “The impact of dementia on self and identity: A systematic review”. *Clinical Psychological Review*, 30: 113-26.

Carlson L., and Kittay E.F. [Ed.] (2009) “Cognitive Disability and Its Challenge to Moral Philosophy”. *Metaphilosophy*, 40(3-4): 307-632.

Cavalla F. (2000) “Libertà da, Libertà per: ordine e mistero”. In AA.VV., *L’insopportabile peso dello Stato*, 216-42. Treviglio: Facco.

Churchland P. [Ed.] (1992) *Neurophilosophy and Alzheimer’s Disease*. Berlin: Springer.

Clare L. (2004) “The construction of awareness sin early-stage Alzheimer’s disease: a review of concepts and models”. *British Journal of Clinical Psychology*, 43: 155-75.

CNB [Comitato Nazionale per la Bioetica] (2014) *Le demenze e la malattia di Alzheimer: considerazioni etiche*, Opinion of the 20th June 2014, available at: http://bioetica.governo.it/media/170730/p117_2014_demenze_malattia_alzheimer_it.pdf.

Damasio A.R. (1999) *The Feeling of What Happens. Body and Emotion in the Making of Consciousness*. Orlando: Harcourt.

Defanti C.A, Tiezzi A. Gasparini M., Gasperini M., *et al.* (2007) “Ethical questions in the treatment of subjects with dementia. Part I. Respecting autonomy: awareness, competence and behavioural disorders. *Neurological Sciences*, 28: 216-31.

Dresser R. (1984) “Bound to Treatment. The Ulysses Contract”. *The Hasting Center Report*, (3): 13-6.

Dworkin R. (1993) *Life's Dominion. An Argument about Abortion, Euthanasia, and Individual Freedom*. New York: Knopf.

Fethersonhaugh D., Tarzia L., Bauer M., Nay R., and Bettie E. (2016) "The Red Dress or the Blue? How Do Staff Perceive That They Support Decision Making for People With Dementia Living in Residential Aged Care Facilities?". *Journal of Applied Gerontology*, 35 (2): 209-26.

Fetherstonaugh D.,Tarzia L., and Nay R. (2013) "Being central to decision making means I am still here! The essence of decision making for people with dementia". *Journal of Aging Studies*, 27: 143-50.

Foucault M. (1995) *Discipline & Punish: The Birth of the Prison*. New York: Vintage.

——— (2003) *Le pouvoir psychiatrique: Cours au Collège de France (1973-1974).* Paris: Gallimard-Seuil.

——— (2006) *History of Madness*. London: Routledge.

——— (2012) *Du gouvernement des vivants: cours au Collège de France (1979-1980)*. Paris: Gallimard-Seuil.

Fuselli S. (2014) *Diritto, neuroscienze, filosofia. Un itinerario*. Milan: Franco Angeli.

——— (2016) *Neurodiritto. Prospettive epistemologiche, antropologiche e biogiuridiche*. Milan: Mimesis.

Gambina G. (2008) "La malattia di Alzheimer". In Gambina G., and Pasetti C. [Eds.] *Introduzione alla malattia di Alzheimer e alle altre demenze. Dalla clinica alla bioetica*, 211-40. Verona: Cortina.

Gazzaniga M.S. (2005) *The Ethical Brain*. New York and Washington: Dana Press.

Jaworska A. (1999) "Respecting the Margins of Agency: Alzheimer's Patients and the Capacity to Value". *Philosophy and Public Affairs*, 28(29): 105-38.

——— (2007) "Caring and Internality". *Philosophy and Phenomenological Research*, 74(3): 529-68.

——— (2009) "Advance Directives and Substitute Decision-Making". In Zalta E.N. [Ed.] *The Stanford Encyclopedia of Philosophy*, available at: https://plato.stanford.edu/archives / sum2017/entries/advance-directives/.

Jennings B. (2009) "Agency and moral relationship in dementia". *Metaphilosophy*, 40(3-4): 425-37.

——— (2016) “Reconceptualizing Autonomy: A Relational Turn in Bioethics”. *Hasting Center Report*, 46(3): 11-6.

Koppelman E. (2002) “Dementia and Dignity: Towards a New Method of Surrogate Decision Making”. *Journal of Medicine and Philosophy*, 27(1): 65-85.

Lindeman H. (2009) “Holding one another (well, wrongly, clumsily) in a time of dementia”. *Metaphilosophy*, 40(3-4): 416-24.

Mingardo L. (2012) “Osmosi tra ordinamenti giuridici. Un caso per il biodiritto: il giudizio sostitutivo”. In Moro P., Sarra C., [Eds.] *Positività e giurisprudenza. Teoria e prassi nella formazione giudiziale del diritto*, 253-78. Milan: Franco Angeli.

——— (2015) *Incontro alle sirene. Autodeterminazione e testamento biologico*. Naples: ESI.

Meini C. (2017) “Guardarsi dentro. Il ruolo della relazione nella formazione della coscienza introspettiva”. *Sistemi intelligenti*, 1: 109-28.

Moro P. (2004) *I diritti indisponibili. Presupposti moderni e fondamento classico nella legislazione e nella giurisprudenza*. Torino: Giappichelli.

Nizzi M.C. (2012) “La maladie d’Alzheimer et son impact sur l’identité de la personne”. In Hirsh E., Gzil F. [Ed.] *Alzheimer, étique et societé*, Paris: Erès.

——— (2013) “La notion de perte d’identité dans la représentation sociale de la maladie d’Alzheimer”. *Klesis-Revue Philosophique*, 27: 263-87.

Quante M. (2007) “The Social Nature of Personal Identity”. *Journal of Consciousness Studies*, 14(5-6): 56-76.

Rapoport S.I. (1992) “Alzheimer’s Disease: Disruption of Mind-Brain Relations”. In Churchland P. [Ed.] *Neurophilosophy and Alzheimer’s Disease*, 86-107. Berlin: Springer.

Reichlin M. (2012) *Etica e neuroscienze. Stati vegetativi, malattie degenerative, identità personale*. Milan: Mondadori.

Ricoeur P. (1990) *Soi-même comme un autre*. Paris: Le Seuil.

Rodotà S. (2012) *Il diritto di avere diritti*. Rome and Bari: Laterza.

Salvaterra E. (2011) “Capacità e competenze”. In Lenti L., Palermo F.E., and Zatti P. [Eds.] *I diritti in medicina. Trattato di biodiritto*, 341-60. Milan: Giuffrè.

Shoemaker D. (2015) “Personal Identity and Ethics”. In Zalta E.N [Ed.] *The Stanford Encyclopedia of Philosophy*, available at: https://plato.stanford.edu/archives/win2016/entries/identity-ethics/.

Spaemann R. (1996) *Personen. Versuche über den Unterschied zwischen "etwas" und "jemand"*. Stuttgart: Klett-Cotta.

Thompson A. (2007) "The meaning of patient involvement and participation in health care consultations: a taxonomy". *Social Science & Medicine*, 64: 1297-310.

Van Willigenburg T., and Delaere P.J.J. (2005) "Protecting Autonomy as Authenticity Using Ulysses Contracts". *Journal of Medicine and Philosophy*, 4: 395-409.

Wicklin A. (1987) "Bound to Freedom: the Ulysses Contract and the Psychiatric will". *University of Toronto Faculty of Law Review*, 1: 37-68.

Widdershoven G., and Berghmans R. (2001) "Advance directives in psychiatric care: a narrative approach". *Journal of Medical Ethics*, 2: 92-7.

White B. (1994) *Competence to Consent*. Washington DC: Georgetown University Press.

Woods B., and Pratt R. (2005) "Awareness in dementia: Ethical and legal issues in relation to people with dementia". *Aging & Mental Health*, 9(5): 423-9.

Zanuso F. (2005) *Neminem Laedere. Verità e persuasione nel dibattito bio-giuridico*. Padua: Cedam.

——— (2013) "Autonomia, uguaglianza, utilità. Tre paradossi del razionalismo moderno". In Zanuso F. [Ed.] *Custodire il fuoco*, 15-81 Milan: Franco Angeli.

Completing the picture of informal caregiving to individuals with mental illness: An interdisciplinary outline

Anna PROKOP-DORNER[*]

Department of Medical Sociology - Jagiellonian University Medical College

Institute of Sociology - Jagiellonian University in Krakow

ABSTRACT: Despite the particularity of the social context of family caregivers of individuals with mental disorders, most of the existing studies inquiring their situation apply a limited scope of conceptions such as adaptation, burden or emotional management. These are typically applied when studying other categories of informal caregivers. The article discusses the theoretical perspectives, which by shifting from the deficit orientated perspective of an individual in a disadvantageous situation to a strength-orientated one could valuably expand the current discourse and help understand new dimensions of the subjective experience of this category of family caregivers.

1. Introduction

The negative impact of mental illness related stigma on various life domains of individuals afflicted with mental ill-health, as one of the most significant social dimensions of mental health, has received more attention in the academic and clinical discourse in the last three decades. Experiencing stigma due to mental health status results in internalizing negative stereotypes by the afflicted individuals (self-stigma), hinders quality of life (Corrigan *et al*., 2005; Rosenfield, 1997), poses threats to their physical health (Wahlbeck *et al*., 2011), and to their academic achievements (Yang *et al*., 2007) and employment prospects (OECD, 2012). The spoiling consequences have been noted also in the studies of families of individuals with mental health problems (Angermeyer *et al*., 2003; Birenbaum 1992; Muhlbauer, 2002; Phillips *et al*., 2012). Family caregivers accompanying their close ones with mental illness were found to suffer not only from watching the ill relative being

---

[*] Corresponding author: Anna PROKOP-DORNER | anna.prokop@uj.edu.pl

discriminated, but also from being assigned the guilt for their relative's illness, being ashamed or socially excluded (Angermeyer *et al.*, 2003) which makes their experience different from other categories of caregivers.

Two thirds of family caregivers participating in a peer-to-peer taught educational program 'Family To Family' (FTF) from the United States of America (USA) reported thinking about stigma-related caregiving experiences at least sometimes (Muralidharan *et al.*, 2016). In a study performed on a sample of family members of first-admission psychiatric patients (parents living with patient, parents not living with a patient, spouses), more than half of the respondents reported making some effort to conceal the hospitalization of an ill relative (Phelan *et al.*, 1998). Those who most likely somehow managed the information were parents not living with the patient. Only every twelfth of all respondents spoke about the psychiatric hospitalization with a number of people: these were most often parents living with patients and spouses (Phelan *et al.*, 1998).

Despite the above-mentioned particularity of the social context of family caregivers of individuals with mental health problems, most of the existing studies conducted to outline their experience adopt concepts typical for studying other categories of informal caregivers. Social science discourse on family caregivers of individuals with mental disorders has been limited to a few conceptions, such as adaptation, burden or emotional management. Less empirical and theoretical interest has been dedicated to understanding coping strategies, stigma management, factors of resilience or empowerment of individuals accompanying their ill close ones.

By referring to the most informative empirical studies from various countries[1] and contemporary interdisciplinary theoretical works, this article offers a thorough outline of the dominant perspectives used in academic discourse to problematize the experience of providing care to a relative with mental ill-health. Moreover, the article identifies the theoretical perspectives that could valuably expand the current discourse and help understand new dimensions of the experience of this group of family caregivers.

The application of the proposed framework informed the author's doctoral study aimed at reconstructing the subjective experience of courtesy stigma among family members of

---

[1] Due to difficulties in accessing the research populations and creating a sampling frame, available studies on families of individuals with mental health problems are all based upon non-probability purposive sampling. Therefore, results taken from the available research cannot be easily generalized for the whole population.

individuals with schizophrenia, engaged in non-governmental organizations devoted to mental health, as well as exploring their positive coping. The concepts hereby presented provided a broad theoretical context enabling the researcher to approach the research problem in an innovative manner by looking at the experience of stigmatization as well as at resources facilitating coping with difficulties that result from adverse social surroundings. Moreover, the conceptual framework helped to grasp the complexity of the studied phenomena with a usage of qualitative methods and analyse the gathered data covering various components of caregivers' experience[2].

2. The processual perspective on accompanying a relative with mental illness

The processual approach to describing the experience of accompanying a relative with mental problems delivers an understanding of how families' attitudes, opinions and emotional responses change over time as the processes of defining their relative's psychiatric diagnosis and treatment progress. This sub-section presents the most noteworthy findings from the available studies whose processual interests were focussed on various aspects of family experience.

Based upon rich material from in-depth interviews with US children, spouses, parents or siblings of individuals with major mental illnesses (uni-polar depression, manic-depression or schizophrenia), David Karp and Valaya Tanarugsachock (2000) argue that there is a predictable schema of feeling frames determining the affective state of family caregivers, as they accompany their relative through time. The researchers claim that this specific dynamics of emotion management is parallel to a discernible career path that a family member follows over time, and that the shift in a caregiver's emotional response transforms as their perception of obligation to the ill relative alters. The dynamics of emotional management comprised four emotional phases: emotional anomy, empathizing with the ill relative, frustration and acceptance. The initial phase entails a strong emotional response to the occurrence of highly confusing behaviour by a relative, and features great uncertainty, anxiety and sheer confusion. A strategy to cope with the emotional anomy that appeals to many family

---

[2] At the time of writing this article, future publications of the study's results are still being prepared.

caregivers is to deny the possibility that the relative is mentally ill. The collected material urged the researchers to introduce the metaphor that a psychiatric diagnosis thrusts the whole family into a different culture, which proposes a new perspective for the functioning of the relative and organizes the situation according to its particular norms. The process of ambiguity ends with diagnosis, which provides a feeling of release, greater efforts to learn about mental health, and a strong commitment to finding a cure for the patients by many of their caregivers. No matter how challenging it is, due to the particular difficulties the diagnosed family member experiences, the care-giving relatives try to empathize with him/her. An ill relative's lack of an ability to reciprocate to family caregivers leads to negative emotions. As time passes by, the loss of expectation from before the diagnosis leads to intense frustration and anger. Only the realization that the relative's fate is not the caregiver's fault, and so it is not in their power to fully control the situation, enables the caregiver to renegotiate the boundaries of obligation and once again accept their child, spouse, parent or sibling's situation (Karp & Tanarugsachock, 2000).

A similar dynamic of the phenomenon of accompanying a relative afflicted with mental illness is presented by Monika Frąckowiak-Sochańska (2015) in her analysis of biographical accounts of Polish and German relatives of people with mental illness. She describes the process of affective-cognitive adaptation to the situation of mental illness that relatives experience over time. The process involves four stages. The first relates to early cognitive and affective reactions to the disturbing behaviour of a relative. The stage is also characterized by anxiety at various levels of consciousness, as well as an overt or latent frustration and anger. The inability to remove the cause of those reactions leads to sadness, loss in mental and physical strength, as well as a tendency towards isolation. In order to decrease the level of anxiety, at the second stage of adaptation, relatives make efforts to sustain family life's status quo by denying the fact of a family member's mental problems. A mechanism useful in the second stage is therefore denial. The third stage of the adaptation process involves confrontation with the illness, and introduction of changes in relation to the afflicted relative and the whole family system. It becomes possible only after the conscious experience of losing feelings of security, expectations of the afflicted relative's and one's own future, and one's own vision of the family. As the tension of the third stage is released, the final stage of the proposed adaptation process can commence. As in Karp and

Tanarugsachock's analysis of emotional framework, Frąckowiak-Sochańska also observed the emergent acceptance of their inability to rewind the past (Frąckowiak-Sochańska, 2015).

Another valuable account of family caregiving was provided by Patricia Howard in her qualitative study from the early 1980s in the USA. Owing to the fact that a number of individuals who had schizophrenia diagnosed in their twenties became chronic sufferers, a family's need to accompany them may last decades. A frequently observed pattern of providing care in the family is that parental dedication to the child's needs is prolonged and extended. Care for an adult with schizophrenia is therefore often provided by parents of an advanced age, mainly mothers who dedicated their lives to an adult child. Howard (1994), based on a lifespan perspective and qualitative data from in-depth interviews and respondents' diaries on caregiving, described mothers' perception of engagement in caregiving, from the onset of the child's illness to the time of the research. The material obtained led to conclusion that mothers perceived their prolonged maternal care as consisting of watching (intense vigilance), working (the physical and mental tasks of care giving increased the period normally ascribed to parenting) and waiting (worrying about a child's future after the parents' death). Howard also proposed a model of learning to live with a child who has schizophrenia. It refers to a forward movement of the lifespan trajectory, with possible temporal regression to earlier stages. The process compromises four stages: perceiving the problem, searching for solutions, enduring the situation, and surviving the experience.

The first stage is the period when non-specific signs of the problems are observed and their severity realized, causing a feeling of bewilderment and uncertainty. The next phase has, for most mothers, been the moment of receiving the diagnosis but few details about the disorder. While the lack of information about the illness contributed to tension among the mothers, the second stage typically involved the searching out of information and efforts to understand the nature of schizophrenia. Mothers described their conscious experiences at this stage as 'anguish' and 'living grief' concerning the state of the illness. A daily struggle with the illness required great endurance on the part of the mother. As time passed, and with continual care giving, the mothers experienced progress in managing the situation. The turning point in the third stage is, however, acknowledging the biological aetiology of schizophrenia. The final stage in the model covers accepting the situation and regaining hope, as well as stimulates determination in facing the challenges of caregiving. One of the participants of the study explained that one constant challenge is the pervasiveness of sorrow connected to accompanying a relative with schizophrenia: “When someone dies, you grieve and then you go on. With schizophrenia, you grieve so many endless griefs” (Howard, 1994: 112). Hope and acceptance occur after a reduction of feelings of guilt, and a reinforcement in mothers’ determination with their care giving efforts (Howard, 1994).

An analysis of family caregivers’ experiences influenced by having obtained institutional help has been covered in studies by Susan Muhlbauer (2002) and Anita Pejlert (2001), conducted in two settings with differing medical care setups. In her qualitative study, Muhlbauer investigated experiences of families of individuals with schizophrenia or bipolar disorders living in the USA, who participated in psycho-educational programmes. The experience of 26 interviewed family caregivers was reconstructed in six phases and presented as an analogy of ‘navigating through the hurricane’. It starts with a phase of developing awareness, which incorporates increasing concerns about problematic behaviours of a relative and inefficient effort to seek help. Next, relatives move on to a phase of crisis.

The second phase is characterized by traumatic episodes and entering mental health services. Institutional care is connected to encountering various inconveniences, such as financial troubles resulting from the cost of medical help, as well as insufficient and/or inadequate provision of information by medical professionals. On the other hand, getting a medical diagnosis seems to be a relief for the relatives. Further experiences of families were metaphorically presented as ‘a drift on perilous seas’, which reflects continuous instability, failure to search for explanations, further financial problems, dissatisfaction with mental health services as well as experiences of stigma (Muhlbauer, 2002).

The other study illuminates parental experience of care giving to an adult child with a severe mental illness in a Swedish community-care setting. Using a phenomenological hermeneutic perspective, Pejlert analysed parents’ narratives regarding placing their ill children in a group residence/flat. Her study revealed components of the experience of being a parent of a child receiving professional care: living with sorrow, anguish and constant worry, living with guilt and shame, relating with carer/care; comfort and hardships; coming to terms with difficulties and hoping for a better life for the adult child.

The first element of the pattern consisted of grieving for the lost child and being constantly worried about the child's poor health condition. It was also typical for parents to blame themselves of being responsible for their offspring's illness and experiencing shame due to rule-breaking behaviour of the ill child.

The second component of Pejlert's respondents' experience was ambiguity towards formal carers: on the one hand they were satisfied with their work, on the other hand, the lack of full control over the process of care giving caused feelings of dissatisfaction. Pejlert pointed out that parents dealt with the situation in different ways: either by concentrating on the advantages of the situation, or on the drawbacks and efforts to take hold of some actions and influence them. Finally, the year-long experience leads to the development of a hopeful attitude and concentrating on the positive moments while accompanying the ill child (Pejlert, 2001).

3. Family Burden

The processual perspective on the experience of families accompanying their relatives with mental health problems exposes a long-term struggle to accept a relative's mental condition and how burdensome this experience may be. Even in cases of receiving substantial support in caring for an ill adult child, parents termed their involvement 'endless parenting' (Pejlert, 2001). The costs of prolonged care and dedication of parents or other family members, has been studied as family burden. It is conceptualized as the sum of objective losses and disruptions to family routines and subjectively experienced worries and tensions related to the process of caring (Schene *et al.*, 1998). Numerous studies on this phenomenon demonstrate that, for a significant proportion of relatives, care giving to a family member with a mental disorder results in the emergence of feelings of loss, worries about the ill relative's future and feelings of not being able to bear the situation any longer (Hadryś *et al.*, 2011; Magliano, 1998).The most recent exploration of this problem among families of individuals with mental illness was accomplished in 2015 within "The Caring for Carers Survey"[3]. The burden of care was conceptualized here as occurring in several life domains:

---

[3] The study was conducted by an academic research team from the Centre for Care Research and Consultancy of KU Leuven in cooperation with EUFAMI with a self-completion questionnaire administered on paper, by

emotional, social, physical, financial, concerning safety, and relationships. For a large number of family caregivers, the relationship with the person they care for was of serious concern. More than half of all respondents in the survey worried that the ill relative would become too dependent on them in the future. Around four out of ten family members worried that he/she was too dependent at that moment and were distressed with strains in the relationship with the ill relative or with upsetting things he/she said. Around one-third of families were concerned about reaching a ‘breaking point’ when one cannot carry on with the situation or felt irritable with the ill relative. The second most bothering aspect of care giving for a relative with mental health problems were financial issues, including the situation of the ill relative, of the caregivers themselves and the extra costs connected with caring.

Another life domain in which they experienced a sense of burden regarded emotional coping. More than one third of the respondents reported that constant caring, lack of sleep due to stress or worrying, feelings of depression, and the negative effect of exhaustion of one’s ability to function were all troublesome. A less common tendency was to perceive things negatively and to lack sleep because of having to provide care to the ill relative at night.

Physical burden was also declared as causing serious concern by one in three family caregivers. Moreover, some of the relatives’ worries regarded safety. Nearly one in four caregivers had concerns about a relapse or deterioration that could put a relatives’ safety in danger, and nearly one-third worried about their close ones getting themselves into dangerous situations or self-harming. Less family caregivers declared being concerned about the ill relative becoming aggressive towards the caregivers or accidentally doing something dangerous to them.

Finally, every third family member who provided care to his/her ill relative worried about feeling isolated, not getting the support needed from their close ones, or losing contact with family and friends because of their responsibilities. One in five was concerned about conflicting roles as a result of the caregiver’s duties. Burden from at least two domains is experienced by nearly four out of ten family caregivers, while burden from three or more domains is experienced by every third. Only 28% of the respondents in the study did not

---

email and online in Australia, Austria, Belgium, Canada, Cyprus, Denmark, Finland, France, Germany, Greece, Ireland, Israel, Italy, Malta, Netherlands, Norway, Portugal, Russia, Spain, Sweden, Switzerland and UK (Vermeulen *et al*., 2015).

report any burdening experience. Some particular characteristics of family caregivers are associated with a higher level of experienced burden, such as being female, of a young age, not getting by financially, a higher number of hours of care giving in the previous week, and being the only caregiver (Vermeulen *et al.*, 2015).

A study conducted by Tomasz Hadryś and colleagues (2011) on burden of caregiving, describes the situation of families in Poland. In the inquiry, burden was operationalized as a sum of the subjective burden covering worrying and tension, and the objective burden covering supervision and advice. A vast majority of the responding family caregivers reported worrying about a relative's general health (82%), his/her future (74%) and financial status (66%). A substantial proportion of the caregivers (65%) struggled with urging relatives to undertake any kind of activity during the day. Another study conducted in Poland reported that, due to the mental burden, 22% of the caregivers needed professional support from a psychologist and/or psychiatrist (Wojciechowski *et al.*, 2015). The type of psychiatric diagnosis was proven not to be associated with the level of family burden of caregiving. Caring for patients with anxiety or personality disorders was just as burdensome as caring for patients with schizophrenia or depression (Hadryś *et al.*, 2011).

However, a difference in the experience of burden was observed when comparing family caregivers of individuals with mental disorders with those caring for individuals with intellectual disorders.

A study from the USA tested the impact of mental disorders and intellectual disabilities in adults on the experience of lifelong caregiving responsibility among mothers aged 64 and over. It demonstrated that mothers who have taken care of their adult children with either mental (mainly schizophrenia) or intellectual (mainly Down syndrome) disabilities, tended to use the same coping strategy, i.e. problem-focused coping. However, those two groups of mothers differed in their ability to reduce their risk of depression. While the mothers of adult individuals with intellectual disabilities were able to decrease the risk, mothers of adult individuals with mental illnesses were not.

The researchers pointed at the context of caregiving as a significant variable here. They claim that little control over stress related to the irregular, cyclical nature of mental illness, in comparison to the stability of the states of adult children with intellectual disabilities, determined the difference (Seltzer *et al.*, 1995). Moreover, the mothers of individuals with mental illnesses had a smaller social network, and their close relations were more often established with other women with mentally ill children. Nearly seventy percent (65.7%) of their friendship network represented women with a similar family situation, as compared to a half (51.1%) of friendship network of mothers of individuals with intellectual disabilities (Greenberg *et al.*, 1997).

Additionally, some later studies revealed that mothers of adults with mental illnesses felt significantly more pessimistic about their children's future. They also reported greater caregivers' burnout than in mothers from the other group (Greenberg *et al.*, 1997). What also determines family burden is the patient's degree of impairment in daily life, as well as the carer's characteristics (Wittmund *et al.*, 2002).

Furthermore, the contextual factors connected to healthcare systems in various countries, including accessibility, scope and quality of institutional assistance provided to an individual with mental health problems, as well as different levels of mental health awareness and culturally varying coping strategies, have been discussed as crucial factors impacting the international variations in the level of burden on caregivers. The available research on family burden revealed that Polish families of individuals with mental health conditions are distinct in this respect from families in Western European countries. Namely, in Poland family caregivers experience more burden of caregiving when compared to those in Western European societies.

In case of caring for individuals with schizophrenia, the difference is 13% (74% caregivers in Poland and 61% in Western Europe reported burden) and in cases of caring for relatives with depression, 22% more Polish families declared experiencing burden (66% vs. 44% respectively) (van Wijngaarden *et al.*, 2004; Hadryś *et al.*, 2011). The researchers interpret this dissimilarity mainly as resulting from the worse accessibility to community services and extensive institutional neglect of patient's family needs in Poland, compared to societies with a better-developed Welfare state (Hadryś *et al.*, 2011). Moreover, research from the United Kingdom indicates that the support offered to family carers needs to be of an adequate quality. A lack of cooperation, reciprocal distrust and disrespectful treatment by mental health professionals towards the family caregivers increases a sense of burden and distress, and causes feelings of being ignored and marginalized amongst the carers (Askey *et al.*, 2009).

Another conceptual approach to describe the particularities of this caregiving experience emphasizes this activity’s stressfulness. This particular research perspective discusses parents’, spouses’ or children’s experiences of taking care of their ill relatives either as a chronic stressor – some symptoms are maintained over a long period of time, or as discrete life events – when a specific situation, i.e. hospitalization or encounters with the police, is taken into account (Avison & Comeau, 2013).

In the Polish study from 2015, taking care of a relative with schizophrenia has been indicated as one of the strongest sources of stress. On a scale from 0 (not stressful at all) to 10 (the most stressful) the responding relatives assessed their situation of providing care on average at 7.9 (Wojciechowski *et al.*, 2015). Chronic stress and strain connected to caregiving of individuals with another mental disorder – bipolar disorder – has been analysed by Deborah Perlick and colleagues in relation to the caregivers’ risk of developing depression. It has been found that 40% of family caregivers reported experiencing some depressive symptoms. Depression in caregivers was then associated with the perception of courtesy stigma. Families anticipating rejection and/or embarrassment tend to adopt ineffective coping strategies, such as avoidance, or retreat from social support, which may lead to depression as a result (Perlick *et al.*, 2007). Experience of courtesy stigma among family caregivers of individuals with Alzheimer’s disease was also found to increase caregivers’ burden (Werner *et al.*, 2012). Also the caregivers’ thoughts about stigma-related experiences, i.e. secrecy, concealment and being stigmatized, were associated with caregivers’ distress (Muralidharan *et al.*, 2016).

4. Managing stigma and positive adaptation

The concepts of stigma management, coping strategies or caregiving satisfactions provide a different perspective on the experience of accompanying a relative with a highly stigmatizing condition. Erving Goffman (1963) argued that the management of stigma depends on the visibility of the stigmatizing attribute. Management strategies typical for discredited individuals are those particular daily arrangements, undertaken by stigma carriers, to reorganize their engagement mainly in a public life, interactions with strangers or mere acquaintances. Relations characterised by intimacy, i.e. within a close family, are typically free from those additional efforts. Since these easily visible attributes are particularly crucial for interactions with strangers, a strategic breaking through aims at the normalization of the discrediting characteristic by reaching more personal levels between stigmatized and stigmatizing. Gradually, the discredited individuals start to feel sheltered among those with whom they interact on a regular basis.

Goffman (1963) illustrated the variety of stigma management strategies by drawing a continuum between stigmata that are unknown to anyone, including their carriers, at the one end, and stigmata that are familiar to everyone associated with the carrier, at the other. On the continuum between those extremes of complete secrecy and full transparency, there are stigmatized individuals who pass their stigmatizing attribute from one social group, and expose it to another. There are also others whose tabooed traits are generally firmly concealed, but which are shared within some very close relations. There are also others whose stigmatizing attributes are apparent, yet in certain situations some of those who encounter the individual do not realize the stigmatized status.

The dominant tendency is, however, to conceal the secret of the carried attribute. Independent from the scale of passing, it requires having a double life, which consists of contact with those to whom the stigma was disclosed and with those who, lacking this knowledge, assume the individual’s normalcy. The individual biography available to each of these groups differs. Concealment carries the risk of being discredited should the individual have a slip – a shameful incident. Goffman (1963) also noticed that passing is connected with high personal costs, including experiencing the anxiety associated with the danger of others learning about the concealed truth. On the other hand, Goffman discusses that deciding on a strategy of passing could be the result of an individual having problems identifying with a new group, and at the same time disdaining themselves for not reacting to insulting comments addressed at the category of people that individual may belong to. A positive stigma management strategy in Goffman’s theory is one that results in positive outcomes, understood as gaining social acceptance as well as regaining some degree of normalcy:

> After laboriously learning to conceal, then, the individual may go on to unlearn this concealment. It is here that voluntary disclosure fits into the moral career, a sign of one of its phases. It should be added that in the published auto-biographies of stigmatized individuals, this phase in the moral

> career is typically described as the final, mature, well-adjusted one – a state of grace (Goffman, 1963: 124)

Yet, Goffman's elaboration on the techniques of controlling, hiding and passing does not cover individual's ability to challenge the consequences of unequal treatment resulting from the processes of labelling and stigma theory.

In psychology, on the other hand, a great body of research addresses the problem of external and internal requirements by applying the concept of coping, typically defined as strategies aimed at tackling hardships and handling stressful events (Heszen, 2013: 61). The majority of psychological research on coping suggests that measures applied in response to stressful events are emotion-orientated or task-orientated (Lazarus & Folkman, 1984). Reactions to particular life events, i.e. the loss of a spouse, comprise loss-orientated coping and restoration-orientated coping, as for example the death of a wife or husband causes both emotional and cognitive challenges to the widower or widow, as well as financial, legal and organizational difficulties.

Classical psychology approaches coping as an individual's disposition to behave in ways that extend the regular possibilities of that individual. Individuals respond to stressful events by applying different coping styles or strategies, which have been categorized as: information seeking or information avoidance strategies (Carver *et al.*, 1989); task-oriented, emotion-orientated or avoidance-orientated styles of coping (Endler & Parker, 1994), as well as active coping, planning, instrumental seeking of support, seeking emotional support, concentration on emotions, disengagement, denial, acceptance, religion or humour (Miller & Kaiser, 2001). In the rich body of psychological research on coping strategies, psychologists confirm that some particular conditions determine the probability of applying particular strategies. For example, having control over a stressful situation brings about a more confrontational coping style, compared to uncontrolled situations, in which individuals tend to apply avoidance coping strategies (Heszen, 2013).

In the last decades, the discourse has broadened the conceptualization of care giving outcomes to advantages of engaging in caregiving. Some studies indicated the experience of gratification by family caregivers for providing assistance to their close ones (Bulger *et al.*, 1993). In the Polish study from 2015, the family caregivers reported seeing a positive impact of their assistance on the mental health state of their relatives. On average respondents evaluated it at 8.4 on a scale from 0 (no impact on the mental health state of the relative) to 10 (very positive impact on the mental health status of the relative) (Wojciechowski *et al.*, 2015).

This emphasis of internal and external resources supporting informal caregiving has attracted a relatively small number of studies so far. It is still unpopular to research a family's potential for – and resources that foster – empowerment in the encounter of various adversities in accompanying a relative with mental problems. For example, the factors of resilience, defined as "potential for recovery, repair, and growth in families facing serious life challenges" (Walsch, 2007: 399), facilitate positive coping and adaptation to hardships individuals encounter, as well as enabling recovery and growth.

The subject of resilience can be both an individual and a family unit. A single available study on resilience with regards to family caregivers of individuals afflicted with severe mental illnesses has been conducted recently by Melanie Bishop and Abraham Greeff (2015). They applied a mixed-method approach to explore factors supportive to families' adaptation after a member had been diagnosed with schizophrenia. The performed quantitative measurements suggest a relation between the ability to positively manage the situation of a relative's psychiatric diagnosis and relatives' psychological qualities, their soft-skills, family-life practices, environmental resources, as well as the family's social status. Moreover, the following nine quantitative measures relate positively with a family's resilience and its ability to adapt: family hardiness; style of communication during a crisis; commitment to the family; positive reframing; supportive communication patterns; special events and family time; degree to which the family finds support in their community; internal locus of control and family income.

The first factor, family hardiness, indicates how much a family is able to resist stress and endure a demanding situation, and has been found to be the strongest predictor of the ability to adapt after the psychiatric diagnosis of a relative. Secondly, since clarity of communication facilitates problem solving, an effective form of communication between family members is highly important to adapt to unknown conditions of crisis. Thirdly, being involved on behalf of a family group remains crucial for solving its problems and staying supportive for each other. Fourth, being able to learn about the new situation and approach it as a challenge has been found to be a vital cognitive feature of family caregivers. Fifth, sharing experiences and views among family members in stressful conditions enables the whole family group to remain together and support each other despite the crises. Sixth, customary family gatherings and spending time together unites the family and enhances its internal resources. Seventh, accompanying a relative with mental problems is so burdensome for a family that receiving support for the family caregivers themselves in the form of support and/or educational workshops is essential. Eighth, a psychological readiness to feel in control over the situation and perceive meaning in life fosters better coping. Finally, a psychiatric diagnosis may become a source of financial burden to family caregivers. Having financial support empowers family groups to better adapt to the challenge.

In the qualitative part of the inquiry, Bishop and Greeff (2015) found that there are also some factors related to functioning of a diagnosed individual, as well as his/her family's attitude toward the relative's health condition, that determine the level of a family's resilience. The former category includes: the extent to which the ill relative adheres to medication, independence, involvement in the community, having some responsibilities, certain routines and activities, as well as a positive attitude and attending support groups for people with schizophrenia. The other category covers the ability of a family to accept their family member's diagnosis. Other studies proved that the better the communication between community services and the patient's family, the stronger the resilience of the relatives (Bishop & Greeff, 2015).

Some studies, which I present briefly below, suggest that planned educational interventions can enhance coping capabilities with a relative's mental disorder. Recognition that therapeutic endeavours aimed at modifying dysfunctional families of individuals with symptoms of schizophrenia were ineffective gave birth to psycho-educational programmes addressed towards relatives. This change of therapeutic perspective required professionals to transition from an approach that excluded and blamed relatives for the destructive impact on an ill family member, to one of engaging families, sharing information about the illness with them, educating and teaching them how to cope with the burden of care giving. This new perspective evolved into various models of cooperation with relatives: individual family consultation, single-family and multifamily group formats, traditional family therapies, professionally-led family psycho-education or short term family education, as well as family-led information and support groups (Dixon *et al.*, 2001; McFarlane *et al.*, 2003).

A number of studies conducted since the 1980s have demonstrated that meeting the needs of a family improves patient’s prospects. A treatment that includes family intervention is clearly superior to the usual care of patients with schizophrenia. A meta-analysis of 25 studies, examining the effectiveness of intervention programs to educate relatives and help them cope better with patient's illness, has demonstrated that patient's relapse rate was reduced when his/her family caregiver/s participated in psycho-educational initiatives. A significant worsening of symptoms or re-hospitalization in the first years after hospitalization has been found to be reduced by 20 percent when family members have received support. The effect was especially evident when help to the family continued for more than 3 months.

Whether the effects of psycho-educational intervention remain stable over a longer period of time has not yet been established. Regardless of the orientation of the intervention (psycho-educationally or therapeutically oriented), significantly better results were observed when family intervention was offered additionally, compared to when standard medication-only treatment was provided ($p<0.0001$ and $p<0.001$) (Pitschel-Walz *et al.*, 2001). A recent experiment conducted in Jordan on a group of family caregivers of individuals with schizophrenia, demonstrated the benefits of psycho-educational intervention devoted to increasing awareness about neuroleptic medication. This finding proves that enhancing family caregivers’ understanding of the illness might help in the reappraisal of caregiving demands, and facilitate coping with problematic behaviour (Al-HadiHasan *et al.*, 2017).

5. Conclusions

Taking into account estimations from the WHO according to which one in four families has at least one member currently affected by mental or behavioural disorder (WHO, 2001), accompanying a relative with mental health problems is not a rare experience. However, despite the potential number of individuals related to somebody with mental illness, accompanying some close person struggling with mental illness remains a cultural taboo (Angermeyer & Matschinger, 2003; Coppens *et al.*, 2013), which might impact informal caregiving in a large part of the population. Therefore, further works on family caregivers’ experience are necessary in order to enrich our understanding of their situation.

The dominant approach to describe the experience of relatives accompanying their close ones concentrates on caregiving burden. Little theoretical and empirical attention has been given to the resources of the families and their potential to tackle the outcomes of mental illness related stigma. To complete the understanding of the experience of caregiving to individuals with mental health problems it is crucial to shift the approach from the deficit-orientated perspective of an individual in a disadvantageous situation to a strength-orientated one. Indeed, a perspective grasping relatives' involvement in non-governmental organizations and their efforts to tackle the adverse social context is beneficial for learning about factors facilitating families' empowerment and conditions conducing to constructive coping with the challenges brought up when accompanying individuals with mental health problems.

References

Al-HadiHasan A., Callaghan P., and Lymn J.S. (2017) "Qualitative process evaluation of a psycho-educational intervention targeted at people diagnosed with schizophrenia and their primary caregivers in Jordan". *BMC Psychiatry*, 17(1): 68. http://doi.org/10.1186 /s12888-017-1225-2.

Angermeyer M.C., and Matschinger H. (2003) "Public beliefs about schizophrenia and depression: Similarities and differences. *Social Psychiatry and Psychiatric Epidemiology*, 38(9): 526-34.

Angermeyer M.C., Schulze B., and Dietrich S. (2003) "Courtesy stigma - A focus group study of relatives of schizophrenia patients". *Social Psychiatry and Psychiatric Epidemiology*, 38: 593-602.

Askey R., Holmshaw J., Gamble C., and Gray R. (2009) "What do carers of people with psychosis need from mental health services? Exploring the views of carers, service users and professionals". *Journal of Family Therapy*, 31(3): 310-31.

Avison W.R., and Comeau J. (2013) "The Impact of Mental Illness on the Family". In Aneshensel C.S., Phalan J., and Bierman A. [Eds.] *Handbook of sociology of mental health*, 543-61. Berlin: Springer.

Birenbaum A. (1992) "Courtesy stigma revisited". *Mental Retardation*, 30(5): 265-68.

Bishop M.A., and Greeff A. (2015) “Resilience in families in which a member has been diagnosed with schizophrenia”. *Journal of Psychiatric and Mental Health Nursing*, 22(7): 463-71.

Bulger M.W., Wandersman A., and Goldman C.R. (1993) “Burdens and gratifications of caregiving: Appraisal of parental care of adults with schizophrenia”. *American Journal of Orthopsychiatry*, 63: 255-65.

Carver C., Scheier M., and Weintraub J. (1989) “Assessing coping strategies: a theoretically based approach”. *Journal of Personality and Social Psychology*, 1(56): 267-83.

Coppens E., Van Audenhove C., Scheerder G., Arensman E., Coffey C., Costa S., Koburger N., Gottlebe K., Gusmão R., O'Connor R., Postuvan V., Sarchiapone M., Sisask M., Székely A., van der Feltz-Cornelis C., and Hegerl U. (2013) “Public attitudes toward depression and help-seeking in four European countries baseline survey prior to the OSPI-Europe intervention”. *Journal of Affective Disorders*, 150(2): 320-29.

Corrigan P.W., Kerr A., and Knudsen L. (2005) “The stigma of mental illness: Explanatory models and methods for change”. *Applied and Preventive Psychology*, 11(3): 179-90.

Dixon L., McFarlane W., Lefley H., Lucksted A., Cohen M., Falloon I., Mueser K., Miklowitz D., Solomon P., and Sondheimer D. (2001) “Evidence-based practices for services to families of people with psychiatric disabilities”. *Psychiatric Services*, 52: 903-10.

Endler N., and Parker J. (1994) “Assessment of multidimensional coping: task, emotion and avoidance strategies”. *Psychological Assessment*, 6: 50-0.

Frąckowiak-Sochańska M. (2015) “Poznawcza i emocjonalna adaptacja do sytuacji choroby psychicznej w rodzinie”. *Przegląd Socjologii Jakościowej*, 11(4): 88-112.

Goffman E. (1963) *Stigma. Notes on the management of spoiled identity*. A Spectrum book. Englewood Cliffs, N.J., Prentice-Hall.

Greenberg J., Seltzer M., Krauss M., and Kim H. (1997) “The Differential Effects of Social Support on the Psychological Well-Being of Aging Mothers of Adults with Mental Illness or Mental Retardation”. *Family Relations*, 46(4): 383-94.

Hadryś T., Adamowski T., and Kiejna A. (2011) “Mental disorder in Polish families: Is diagnosis a predictor of caregiver’s burden?”. *Social Psychiatry and Psychiatric Epidemiology*, 46(5): 363-72.

Heszen I. (2013) *Psychologia stresu*. Warsaw: Wydawnictwo Naukowe.

Howard P. (1994) “Lifelong maternal caregiving for children with schizophrenia”. *Archives of Psychiatric Nursing*, 3: 107-14.

Karp D.A., and Tanarugsachock V. (2000) “Mental Illness, Caregiving, and Emotion Management”. *Qualitative Health Research*, 10(1): 6-25.

Lazarus R., and Folkman S. (1984) Stress, appraisal, and coping, New York: Springer.

Magliano L. (1998) “Burden on the families of patients with schizophrenia: results of the BIOMED I study”. *Social Psychiatry and Psychiatric Epidemiology*, 33(9): 405-12.

McFarlane W., Dixon L., Lukens E., and Lucksted A. (2003) “Family psychoeducation and schizophrenia: a review of literature”. *Journal of Marital and Family Theraphy*, 29(2): 223-45.

Miller C.T., and Kaiser C.R. (2001) “A theoretical perspective on coping with stigma”. *Journal of Social Issues*, 57(1): 73-92.

Muhlbauer S. (2002) “Experience of stigma by families with mentally ill members”. *Journal of the American Psychiatric Nurses Association*, 8(3): 76-83.

Muralidharan A., Lucksted A., and Medoff D. (2016) “Stigma: a Unique Source of Distress for Family Members of Individuals with Mental Illness”. *Journal of Behavioral Health Services and Research*, 43(3): 484-93.

OECD [Organisation for Economic Co-operation and Development] (2012) *Sick on the Job? Myths and Realities about Mental Health and Work*. Paris: OECD Publishing.

Pejlert A. (2001) “Being a parent of an adult son or daughter with severe mental illness receiving professional care: parents’ narratives”. *Health and Social Care in the Community*, 9(4): 194-204.

Perlick D.A., Miklowitz D.J., Link B.G., Struening E., Kaczynski R., Gonzalez J., Manning L.N., Wolff N., and Rosenheck R.A. (2007) “Perceived stigma and depression among caregivers of patients with bipolar disorder”. *The British Journal of Psychiatry* , 190: 535-6.

Phelan J.C., Bromet E.J., and Link B.G. (1998) “Psychiatric illness and family stigma”. *Schizophrenia Bulletin*, 24(1): 115-26.

Phillips R., Benoit C., Hallgrimsdottir H., and Vallance K. (2012) “Courtesy stigma: A hidden health concern among front-line service providers to sex workers”. *Sociology of Health and Illness*, 34(5): 681-96.

Pitschel-Walz G., Leucht S., Bäuml J., Kissling W., and Engel R.R. (2001) “The effect of family interventions on relapse and rehospitalization in schizophrenia: a meta-analysis”. *Schizophrenia Bulletin*, 27(1): 73-92.

Rosenfield S. (1997) “Labeling Mental Illness: The Effects of Received Services and Perceived Stigma on Life Satisfaction”. *American Sociological Review*, 62(4): 660. http://doi.org/ 10.2307/2657432.

Schene A.H., van Wijngaarden B., and Koeter M. (1998) “Family caregiving in schizophrenia: domains and distress”. *Schizophrenia Bulletin*, 24(4): 609-18.

Seltzer M.M., Greenberg J.S., and Krauss M.W. (1995) “A comparison of coping strategies of aging mothers of adults with mental illness or mental retardation”. *Psychology and Aging*, 10: 64-75.

Vermeulen B., Lauwers H., Spruytte N., Van Audenhove C., Magro C., Saunders J., and Jones K. (2015) *Experiences of family caregivers for persons with severe mental illness: an international exploration*, available at: http://www.caringformentalhealth.org/c4c_reports /c4c_global.pdf.

Wahlbeck K., Westman J., Nordentoft M., Gissler M., and Laursen T. M. (2011) “Outcomes of Nordic mental health systems: life expectancy of patients with mental disorders”. *The British Journal of Psychiatry*, 199: 453-58.

Walsch F. (2007) “Family Resilience. Strengths Forged through Adversity”. In Walsch F. [Ed.] *Normal Family Processess*, 339-427. New York: Guilford Press.

Werner P., Mittelman M.S., Goldstein D., and Heinik J. (2012) “Family stigma and caregiver burden in Alzheimer’s disease”. *Gerontologist*, 52(1): 89-97.

Wittmund B., Wilms H.U., Mory C., and Angermeyer M.C. (2002) “Depressive disorders in spouses of mentally ill patients”. *Social Psychiatry and Psychiatric Epidemiology*, 37(4): 177-82.

Wojciechowski P., Kulik M., Małowicka M., Mucha E., Górka A., Chudzicka A., and Ziobro M. (2015) *Schizofrenia. Rola opiekunów w kreowaniu współpracy*, available at:

http://www.janssen.com/sites/www_janssen_com_poland/files/pdf/RAPORT-Schizofrenia-Rola-opiekunow-w-kreowaniu wspolpracy.pdf.

WHO (2001) *The World Health Report*, available at: http://www.who.int/whr/2001/chapter2/en/index3.html.

Yang L.H., Kleinman A., Link B.G., Phelan J.C., Lee S., and Good B. (2007) "Culture and stigma: Adding moral experience to stigma theory". *Social Science and Medicine*, 64(7): 1524-35.

Healthcare, migrations and everyday bioethics: Weighing the difference

Carlo BOTRUGNO[*]
L’Altro Diritto RUEBES - University of Florence

ABSTRACT: This work uses the lens provided by the everyday bioethics perspective to assess the weight of the difference, which currently overwhelms migrants in both maintaining psychophysical wellbeing and accessing adequate healthcare services in host countries. I will start by outlining the main risks for migrants’ health during their transit, as well as the main obstacles usually preventing them from accessing adequate healthcare services in receiving countries. I will elaborate by trying to shed light on the association between people movement and the spread of infectious diseases, which arguably represents the core of current political debate and tensions over international migration flows. Thereafter, I will continue by looking at the interplay of detention, migration and healthcare, in which both illegal and legal migrants are often entrapped because of their intrinsic precarious conditions. I will then highlight the main challenges associated with socio-cultural misconceptions in health and healthcare that exacerbate health inequalities to the detriment of migrant people. In the conclusions, I will try to build on the everyday bioethics approach of Giovanni Berlinguer by speculating what its contribution may be to both bioethics and the attempt to enhance the protection of migrants’ health.

1. Introduction

In the Encyclopaedia of Bioethics, Warren Thomas Reich defines bioethics as the “systematic study of the moral dimensions – including moral vision, decisions, conduct, and policies – of the life sciences and health care, employing a variety of ethical methodologies in an interdisciplinary setting” (Reich, 1995: xxi). Metaphorically speaking, bioethics arose in the midst of the 20th century as a means of ‘putting out fires’, such as reacting to the atrocities of Nazi medical experimentation, or to the outrage provoked by the US Tuskegee Syphilis study (1932-1972). In the following decades, bioethics has evolved extraordinarily and contributed to enhancing patients’ dignity and other fundamental rights, such as the right to

---

[*] Corresponding author: Carlo BOTRUGNO | carlo.botrugno@gmail.com

be informed about one’s health conditions, as well as to choose the care or treatments one must undergo. Nonetheless, when considering the elements included in that definition – life sciences, health care, moral visions, decisions, conducts and policies – it is possible to observe that each of them assumes a different weight within contemporary bioethics debates. Indeed, bioethics scholars show a clear preference for discussion and research over cutting-edge topics and dilemmas arising from technological advancements in health sciences and healthcare. Nevertheless, as highlighted by the Italian physician and bioethicist Giovanni Berlinguer (1924-2015) these topics represent only a part of bioethics that he defined as ‘frontier bioethics’. Besides frontier bioethics, Berlinguer describes (claims for?) an ‘everyday bioethics‘, which includes matters that concern the majority of the population in contemporary societies, such as health access and equity, health inequalities and discrimination, public health and primary care services. Far from underestimating the relevance of societal challenges posed by cutting-edge discoveries and technological developments, Berlinguer advocates an alternative role for bioethics aimed at enhancing the impact of this discipline in the individuals’ everyday life (Berlinguer, 2003; 2000). Although it has been suggested that the approach of everyday bioethics lacks a proper theoretical basis (Biller-Andorno, 2003), it has nonetheless been welcomed especially in Italy, where the National Bioethics Committee (CNB) has referred to it in several circumstances. The CNB states that:

> Frontier bioethics focuses on the most problematic and controversial matters involving public policies and personal choices, especially for what concerns classic boundaries (i.e. birth and death); the troublesome character of these matters often depends from its being radically new, resulting from the continuous development of biomedical sciences, as well as from new technological advancements. Conversely, everyday bioethics originates from a dimension that is much closer to individuals’ common experience; rather than the exceptionality of extreme cases, it instead looks at situations of normalcy (CNB, 2010: 5)

Therefore, it is possible to assert that the approach of everyday bioethics is primarily concerned with health justice, which entails taking into account the moral visions and needs of the entire population, and not only parts of it (Lecaldano, 1999). If all individuals are equal in the eyes of the law – so to speak – yet they are not likewise equal in the face of disease and suffering. Indeed, when talking about health justice and healthcare organization, it is necessary to consider the weight of cultural, social, and economic factors such as employment, income, education, gender, and discrimination. Although these factors are external to healthcare organization, they are, to a significant extent, able to influence the effectiveness of health protection, especially when considering access to healthcare by the most vulnerable groups (Botrugno, 2014a). Over the last decades, the analysis of these factors has assumed a renewed relevance due to the work of the WHO Commission on Social Determinants of Health (WHO, 1998; 2003). Additionally, empirical research conducted in the last few years regarding the correlations between socio-economic conditions and health inequalities has shown that each of these factors has its own impact on individuals' health conditions and often negatively affects health protection, being largely responsible for a social gradient in health and healthcare access (e.g. Fox, 1989; Kunst & Mackenback, 1992; Costa & Faggiano, 1994; Kawachi, 1999; Subramanian *et al.*, 2002; Padovani, 2008; Marmot, 2017). This body of evidence has made it possible to show that migrant status in industrialized societies represents a cause of multi-dimensional vulnerability, the seriousness of which is such to undermine health protection more than any other factor (Costa *et al.*, 1998; Hayward & Heron, 1999; EU FRA, 2011; Reyneri, 2011; Tognetti Bordogna, 2013).

Migrant people are today estimated to number 244 million worldwide, corresponding to 3.3% of the global population (UN, 2016). While international migrations increase at a constant pace – being today 41% higher than in the year 2000 –, the utopian dream of a world without borders, envisaged the day after the collapse of the Berlin Wall, has rapidly made way for a strengthening of border control, and an exacerbation of political tensions and national ambitions imbued with xenophobia and racism. Therefore, the main objective of this work is to use the lens provided by everyday bioethics to assess the 'weight of the difference', which currently overwhelms migrants in both maintaining psychophysical wellbeing and accessing adequate healthcare services in host countries. Though mostly referring to the situation in the EU and the Mediterranean area, many of these considerations also apply to the overall migration phenomenon. I will start by outlining the main risks for migrants' health during their transit, as well as the main obstacles usually preventing them from accessing adequate healthcare services in receiving countries. I will elaborate by trying to shed light on the association between people movement and the spread of infectious diseases, which arguably represents the core of current political debate and tensions over international migration flows. Thereafter, I will continue by looking at the interplay of detention, migration and healthcare, in which both illegal and legal migrants are often entrapped because of their intrinsic precarious conditions. I will then highlight the main challenges associated with socio-cultural misconceptions in health and healthcare that exacerbate health inequalities to the detriment of migrant people. In the conclusions, I will try to build on the everyday bioethics approach of Giovanni Berlinguer by speculating what its contribution may be to both bioethics and the attempt to enhance the protection of migrants' health.

2. International migrations and health risks

To define what migration is, I mostly refer to the work developed by the French-Algerian anthropologist Abdelmalek Sayad (1933-1998), who applied to migration the perspective of social phenomena as 'total social facts', developed by Marcell Mauss (Sayad, 2006). Following Sayad, migration should be seen as an 'epistemological itinerary‘, since its analysis involves the whole spectrum of social sciences: law, economy, history, geography, demography, sociology, anthropology, linguistics, and socio-linguistics, etc. Nevertheless, despite the great appeal of Sayad's thought, the epistemological complexity that should characterize the analysis of migration issues has been largely disregarded within political discourses and official orientations adopted by the EU and Member States. Conversely, simplifications have been useful to both policy-makers and mass media to legitimize the distinction between 'economic migrants' and asylum seekers, which has become a central point of the 'flows' management strategy' pursued by the EU over the last few decades (Botrugno, 2014b). Indeed, since turning back asylum-seekers is explicitly forbidden by the 1951 UN Geneva Convention Relating to the Status of Refugees – see the so-called *non refoulement* principle at Art. 33 – the distinction between asylum-seekers and economic migrants[1] has enabled national authorities to overlook their obligations toward the protection

---

[1] As highlighted by the 2016 UN International Migrations Report, a migrant is an individual who is living in a country other than where he/she was born (UN, 2016). Therefore, in this work, the term 'migrant' is used to

of foreign individuals intercepted at land borders, or those rescued in international waters. By contrast, when it comes to weighing the incidence of push-and-pull factors, it should be acknowledged that the majority of these flows shall be framed into the category of ‘forced migrations’. A forced migration entails that individuals have little or no choice of leaving their origin countries. As a matter of fact, escaping from famine, serious unemployment, political, cultural, ethnic, or religious persecution, physical or psychological violence, or threat of violence means being forced to leave. On this note, it’s worth to recall a well-known classification of the health risks faced by migrants – pre-migration factors, migration factors, and stay factors (Bhugra & Gupta, 2010; Loue & Sajatovic, 2012) – which provides a significant insight into the epistemological complexity of contemporary migrations, seen as ‘a total social fact’.

Among the most common pre-migration threats to migrants’ health are the exposure to infectious diseases (e.g. HIV, cholera, diphtheria, ebola, hepatitis, malaria, gastroenteritis, measles, pertussis, tuberculosis, tetanus, pneumonia, and typhus), and the risk of developing diseases caused by malnutrition and scarce hygienic conditions (e.g. marasmus, kwashiorkor, anaemia, ariboflavinosis, beriberi, goitre, pellagra, rickets, scurvy, and xerophtalmia). Furthermore, it is necessary to consider parasitic diseases and neglected tropical diseases (NTDs). In particular, the persistence of NTDs has been recently reported in 149 low- and middle-income countries of tropical and subtropical regions, especially in Africa, Asia and Latin America (WHO, 2017a). NTDs include disorders such as dracunculiasis (also known as Guinea-worm disease), trachoma, lymphatic filariasis, schistosomiasis, soil-transmitted helminths, onchocerciasis, buruli ulcer, chagas, cysticercosis, dengue fever, echinococcosis, fascioliasis, human African trypanosomiasis (also known as African sleeping sickness), leishmaniasis, leprosy, rabies, and yaws[2]. Lastly, among pre-migration risk factors, some of the above-mentioned push factors should also be included (e.g. exposure to war, torture, terrorism, famine, and violence). Indeed, beyond acting as push factors for migration, they can also act as social determinants of health, leading to the emergence of diseases or other relevant conditions such as psychological distress or physical injuries.

---

encompass any kind of human movement, including economic migrants, refugees, asylum-seekers, and undocumented migrants.

[2] The first six of these have also been defined as “tool ready diseases”, since they can be controlled or eradicated through massive drug administration or other ordinary interventions (US-CDC, 2017).

When it comes to consider the repercussions of migration on an individual's health (i.e. migration factors), it is necessary to take into account not only those events and conditions that are strictly related to the journey, but also any other events that precede its beginning. This is especially necessary when considering the criminal gangs of people smugglers and traffickers[3] on which migrants rely in the attempt to reach EU soil. In particular, this is the case of migrants coming from the sub-Saharan African region, who are forced to pay considerable sums of money to smugglers, and deal with long and dangerous journeys before reaching the embark points at the Mediterranean coast. As reported by many NGOs operating in the Mediterranean Sea area, besides the psychological distress and physical suffering related to traveling in very precarious conditions, smugglers often leverage the migrants' condition of subjection to abuse them and rob their savings. Additionally, migrants are frequently subjected to violence, rapes, and torture. Not least, they may also be sold, executed, abandoned in the middle of the desert or in the open sea. According to data collected by initiative of the International Migration Organization's "Missing Migrants Project", 2961 migrants have been found dead in 2017 alone (IOM, 2017). Thus, it is clear that during migration routes, migrants' health and lives are threatened by a countless series of factors, including injuries, hypothermia, burns, gastrointestinal illnesses, cardiovascular events, pregnancy complications, diabetes, hypertension, and psychological distress.

As for stay factors, once migrants have survived the smugglers and the dangerous journeys, they then have to deal with a series of issues related to their adaptation and integration in receiving countries. As shown dramatically by recent clashes between border authorities of the EU Mediterranean countries and NGOs active in migrants' rescue operations, welcoming undocumented migrants and refugees to the EU soil is getting complicated. Countries such as Italy, Spain, Greece and Malta are reacting to the (assumed) excessive exposure to migration flows, and claim for a 'fair relocation' of migrants, which

---

[3] Although the distinction between smuggling and trafficking is very subtle, it may be useful to recall the UN Protocols on smuggling and trafficking of people, both adopted in 2000. The "Protocol Against the Smuggling of Migrants by Land, Sea and Air" defines smuggling as "the procurement, in order to obtain, directly or indirectly, a financial or other material benefit, of the illegal entry of a person into a State Party of which the person is not a national or a permanent resident" (UN, 2000a: Art. 3). Meanwhile, the "Protocol to Prevent, Suppress and Punish Trafficking in Persons, especially Women and Children" defines trafficking as "the recruitment, transportation, transfer, harbouring or receipt of persons, by means of the threat or use of force or other forms of coercion, of abduction, of fraud, of deception, of the abuse of power or of a position of vulnerability or of the giving or receiving of payments or benefits to achieve the consent of a person having control over another person, for the purpose of exploitation" (UN, 2000b: Art. 3).

involves sharing the ‘migration burden’ with the other EU Member States. Additionally, subsequent international tensions are heightened by some right-wing political parties that leverage the fear of an ‘invasion of strangers’ – in particular by Muslim people – to exacerbate nationalist and xenophobic attitudes among autochthones.

Upon arrival, illegal migrants face two main difficulties: getting a job and achieving legal status. These difficulties are tightly correlated since both the EU and Member States’ national policies in the field of immigration have mostly associated foreigners’ right to stay with the obtainment of a job. Therefore, getting a job and obtaining legal status may represent a problem not only for illegally entered migrants, but also for the so-called ‘overstayers’, which refers to those foreign national citizens who entered the EU through a temporary visa – for work, tourism, or study – and remained after the period they were allowed to stay Despite the common perception that migrants are invading the EU through illegal disembarkations, the majority of illegal immigrants in the EU are currently represented by overstayers (Cuttitta, 2007). Nonetheless, since it is very difficult to obtain a job without first holding a legal status, many migrants are forced to accept illegal, precarious, dangerous, and underpaid jobs on the black labour market (Reyneri, 2011).

The overall state of subjection lived by migrants in receiving countries has a direct incidence on their state of health, increasing exposure to psychosocial disorders, reproductive problems, infant mortality, nutritional disorders, noncommunicable diseases, and drug and alcohol abuse (WHO, 2017b). Furthermore, the condition of illegality in which many of these individuals are forced, prevents them from gaining adequate access to healthcare services, except for emergency treatments. Moreover, the persistent economic crisis that industrialized societies have experienced in the last decade has legitimized attempts of introducing ‘zero tolerance’ policies in what concerns undocumented migrants’ access to healthcare. For instance, in Italy in 2009, the approval of Law no. 94/2009 by the Italian Parliament has, for the first time, introduced the crime of ‘illegal stay’ into the Italian legal system. Additionally, this law detailed an obligation for healthcare professionals to report any illegal migrants they receive for care reasons. This quite controversial obligation has been largely disregarded and strongly contested by Italian healthcare professionals, as well as by many NGOs that have promoted ‘I do not report’ campaigns.

Nonetheless, the introduction of this obligation has turned into a significant deterrent for undocumented migrants who have avoided – more than ever before – to seek access to healthcare services.

An even worse situation has occurred in Spain with the introduction of Royal Decree no. 16/2012, that has excluded undocumented migrants from having access to healthcare services unless for emergency treatments. Even in this case, the introduction of such a provision has been openly contested for its inhuman effects by citizens, healthcare professionals, and NGO activists. Additionally, several Spanish Regions have *de facto* eluded its application and continued to provide healthcare to migrants regardless of their legal status. Nonetheless, the Decree's approval has achieved dramatic effects over time, with at least 873 000 health books withdrawn since 2012, and approximately 3340 migrants excluded from healthcare services since 2014 (Red Acoge, 2015; Reder, 2017).

3. People on the move and infectious diseases: a threat to public health?

The association between human movements and the risk of infectious disease arguably represents the core of current debate and political tensions over international migration flows. But are migrants' health conditions a threat to public health in receiving countries? Before answering this question, it should be made clear that a growing body of literature has recently highlighted the seemingly paradoxical 'healthy immigrant effect' (HIE). This expression has increasingly been used by scholars to describe the fact that migrants arriving to industrialized countries are on average healthier than native-born populations, although the firsts usually live in worse conditions, have lower socio-economic resources, and sub-optimal access to healthcare services (Kennedy *et al*., 2015; Domnich *et al*., 2012). More research is needed in order to fully understand the main features of the HIE, especially when considering that several explanations are possible, and many factors may be involved. Nonetheless, available evidence shows that the HIE results from 'multiple filters', among which is the combination of migration with employable age:

> it is well known that workers are generally healthier than other members of society (the healthy worker effect) and that employment is one of the most important reasons for immigration, it is possible to affirm that the healthy worker effect selects healthy immigrants. (Domnich *et al*., 2012: e7532)

A further filter invoked to explain the HIE is ‘cultural buffering’. This expression describes the protective effect played by lifestyles and behaviours typical of non-industrialized societies and cultures, many of which appear to be healthier than those adopted by native-born populations in receiving countries. However, it has been also reported that the HIE tends to dissolve during migrants’ stay in receiving countries. Indeed, after a first period of adaptation, in many cases most indicators of migrants’ health worsen until they reach levels comparable to those of native-born populations. This induced the literature to speak of an ‘exhausted migrant effect’ (e.g. Tognetti Bordogna, 2013; Constant *et al*. 2015). Besides the adoption of new unhealthy lifestyles, the good state of health enjoyed by migrants upon their arrival may be undermined by the difficulties encountered to stabilizing their presence within receiving countries – e.g. poor housing and working conditions, discrimination and marginalization (EU FRA, 2017), and last but not least, inadequate access to healthcare and prevention services (Mondo *et al*., 2017).

Going back to the central question – do migrants’ health conditions represent a threat to public health in receiving countries? – it should be considered that in recent times, the assumed association between migration flows and the spread of infectious diseases, especially HIV, has been used at a political level to legitimize right-wing orientations and politics directed to strengthen border control, and prevent undocumented migrants’ entry[4]. On one hand, it is undeniable that infectious diseases may represent a threat to public health, as shown by the spread of syndromes such as severe acute respiratory syndrome (SARS), Middle East respiratory syndrome (MERS), and more recently, West African Ebola (see also Blumberg *et al*., 2010). Nonetheless, it should be made clear that the relevance of these threats has always been controversial and deemed to be highly variable, depending on the specific features of the concerned diseases, as well as on the conditions that fostered their

---

[4] HIV infection risk has been a fundamental part of anti-immigrant rhetoric conducted by Donald Trump both before and after the 2016 US presidential election, especially against Mexican migrants. With regard to the EU, similar arguments have been repeatedly used by political parties such as the Polish *Prawo i Sprawiedliwość*, the Italian *Lega Nord*, and the UK’s Independence Party during the 2016 Brexit campaign.

spread. Additionally, both political claims and mass-media representations leave often unclear that infectious diseases do not arise from genetic or ethnic factors, but are rather provoked by extremely poor hygienic and living conditions. Therefore, infectious diseases are not at all a peculiarity of African, Asian or South-American countries. Over time, industrialized countries have significantly downscaled the incidence of infectious disease among the native population thanks to improved living conditions, access to clean water, adequate sanitation, more efficient health systems, vaccination programmes, and the availability of antibiotics. Indeed, a huge body of literature agrees in rejecting the link between migration flows and the importation of infectious diseases, an association which has been deemed epidemiologically unfounded (e.g. CNB, 2017; Castelli & Sulis, 2017; Pfortmueller *et al*., 2016; Arnold *et al*., 2015; ISS, 2015). In spite of the common perception that exaggerates the risk of infections upon migrants' arrival, available evidence shows that infectious diseases among migrants have a 'negligible impact' on the epidemiology of destination countries: "infectious diseases are not at all a health priority at hotspots and first arrival sites, where traumatic, obstetrical and psychological disorders are most prevalent" (Castelli & Sulis, 2017: 4). In this regard, the Italian Superior Health Institute (ISS) has reported that infectious diseases detected in groups of illegal migrants upon their disembarkation in Italy – which is one of the countries most exposed to illegal migration flows – are mostly limited to dermatological infections like scabies and other controllable diseases such as measles and varicella (ISS, 2015). Furthermore, the association between migration and the importation of infectious diseases has been explicitly rejected by the WHO:

> Communicable diseases are associated primarily with poverty. Migrants often come from communities affected by war, conflict or economic crisis and undertake long, exhausting journeys that increase their risks for diseases that include communicable diseases, particularly measles, and food- and waterborne diseases. [...] The risk for importation of exotic and rare infectious agents into Europe, such as Ebola, Marburg and Lassa viruses or Middle East respiratory syndrome (MERS), is extremely low. Experience has shown that, when importation occurs, it involves regular travellers, tourists or health care workers rather than refugees or migrants. (WHO, 2017b)

Notwithstanding these data, as reported within the UNAIDS report “Outcome Framework 2009-2011”, several countries correlate migrants’ admittance, stay and residence with HIV testing results. These politics are not only discriminatory to migrants and totally contrary to the most basic ethical principle of taking care for the sick, but they are also not justified by an effective risk of infection, in that a chance of physical contact with HIV-affected individuals is not enough to propagate infection, nor is the physical presence of nearby affected individuals. Paradoxically, these politics may achieve the opposite effect (thus endangering public health), because they induce infected individuals to hide their conditions in the attempt of eluding border controls. For the purposes of this work, it is also worth remembering that Recommendation no. 200 issued by the International Labour Organization (ILO) forbids considering HIV infection as a means of discrimination, and explicitly inhibits employers from requiring HIV testing or other forms of HIV screening (ILO, 2010: 25). Following the Recommendation, workers should not be required to disclose HIV-related information about themselves, and their access to employment should not be endangered by HIV testing. Concerning migrant people, the Recommendation explicitly states: “Migrant workers, or those seeking to migrate for employment, should not be excluded from migration by the countries of origin, of transit or of destination on the basis of their real or perceived HIV status” (ILO, 2010: 26).

As suggested by a huge body of literature in this field, the key to ensuring safety against the spread of infectious diseases is the implementation of adequate surveillance systems and specific screening programs aimed to detect and neutralize major threats to public health (e.g. Soto, 2009; IOM, 2010; WHO, 2013). Nonetheless, in this regard, it has been reported that only a few of EU Member States have adopted specific immunization programmes to the benefit of migrants and refugees (WHO, 2017c), which means that migrants still face significant obstacles in accessing vaccination services in destination countries.

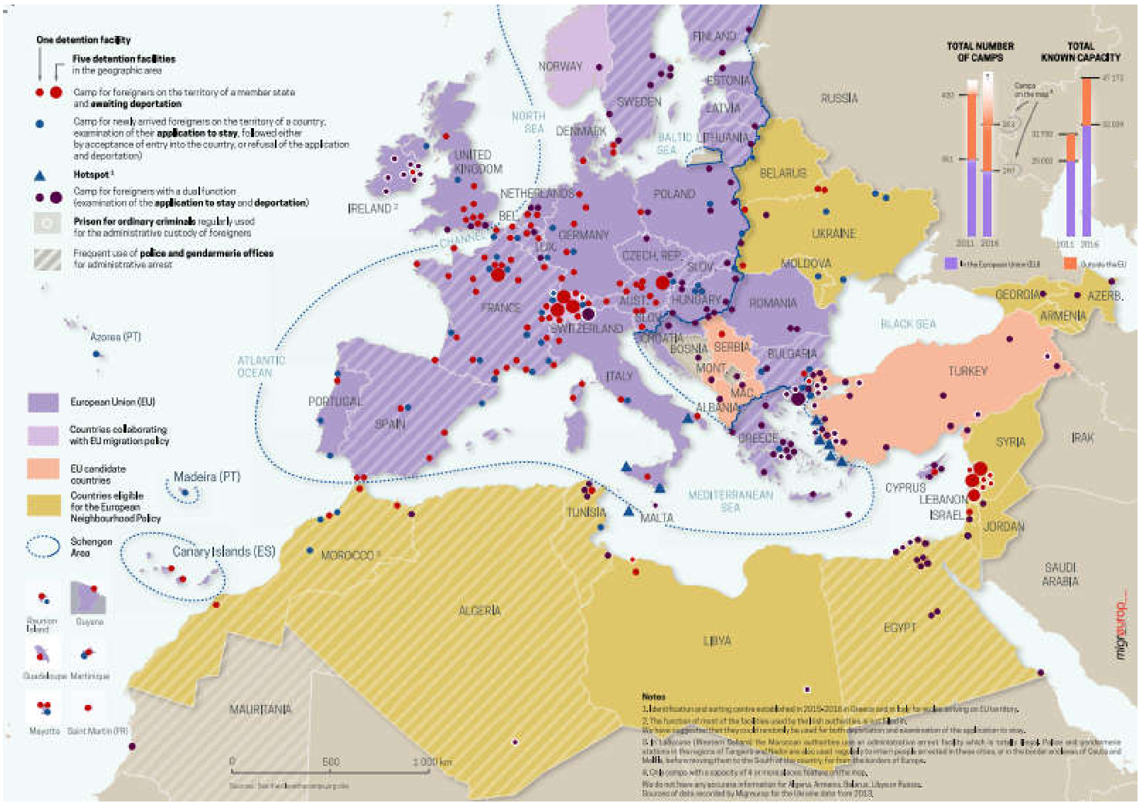
4. Migrants, detention and healthcare

Since the 1999 Council of Tampere, the EU institutions have been committed to elaborating and implementing a complex strategy of ‘migration flows’ management‘. This strategy has lead to the integration of the Schengen Convention into EU treaties, and it has been mostly concerned with the involvement of third countries' local authorities in strengthening border controls, as well as with the physical containment of illegal migrants and asylum-seekers intercepted at the borders (Botrugno, 2014b). Meanwhile, in the majority of EU countries, intolerance towards the presence of migrants has proliferated. This has led the EU Member States to adopt:

> [a] set of seemingly disparate developments concerning the constant reinforcement of border controls, tightening of conditions of entry, expanding capacities for detention and deportation, and the proliferation of criminal sanctions for migration offences, accompanied by an anxiety on the part of the press, public and political establishment regarding migrant criminality can now be seen to form a definitive shift in the European Union towards the so-called 'criminalisation of migration' (Parkin, 2013: 1)

As a main corollary of adopting policies that limited the legal entry of migrants, illegal migration routes have developed further, and criminal gangs leveraging migrants' desperation have flourished. As mentioned previously, over time this has contributed to a dramatic increase in the number of deaths both in the Mediterranean Sea and on the way to reach the embark points.

When intercepted at land borders, or rescued in the Mediterranean Sea, migrants are brought to 'identification centres' or 'temporary centres', and held there for a period of time that may vary (from 6 up to 18 months), depending on Member States' national policies. On paper, the stay of migrants in these centres should not go beyond the necessary time for their reception, identification, and eventual repatriation. However, in reality these centres represent today the main instrument of physical containment adopted by the EU over the last three decades, under the label of 'managing the flows'. Not least, the bilateral agreements signed by the EU with third countries' governments under the *aegis* of the European Neighbourhood Policy have made way for an 'externalization' of the borders. This means that third countries' national authorities have been urged by the EU to prevent illegal migrants' departure, with a view to reduce incoming flows. As also highlighted by reports from NGOs (Del Grande, 2007), many of the countries with which the EU has signed a partnership completely disregard fundamental rights, which explains why local authorities are often charged of inflicting, on migrants in transit, abuses and violence that do not differ from those inflicted on them by traffickers and smugglers.



Migreurope Detentions Camps Map 2016.
Available at http://www.migreurop.org/IMG/pdf/migreurop_carte_en_hd-compressed.pdf.

Migrants are usually detained in identification centres for much more than the maximum allowed time, and in conditions that have been often reported as comparable to those of concentration camps. In this regard, the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) has repeatedly highlighted that most of the EU detention centres are overcrowded and lacking the most basic hygienic conditions (CPT, 2017). Moreover, the centres often host rival ethnic groups in the same space, which increases episodes of fights and violence among detainees. Consequently, disease and trauma easily proliferate among the detainees, with a worrying escalation of self-harm episodes and suicides (Fekete, 2011; MSF, 2016; MEDU, 2017). Additionally, most of the centres lack adequate care professionals and services, and abuse of drugs has been reported as a means to control detainees and prevent agitations. For instance, a research conducted by the Italian Association MEDU in 2013 has shown that prolonged stays in detention centres are often associated with starting or increasing use of benzodiazepines (MEDU, 2013).

These drugs are often administered without the due psychiatric assessment and with higher dosages than recommended – up to seven times higher – after which, individuals fall into a state of confusion for a prolonged time. The use of psychiatric drugs has been also reported as a way of punishing detainees that try to escape, manifest dissent, or show attitudes that are considered as inadequate by professionals working for the centres (MEDU, 2013). For the purposes of this work, it is worth to recall the Principles of Medical Ethics adopted by the UN General Assembly in 1982, according to which, the restraining of prisoners or detainees is an open contravention to medical ethics, unless carried out in accordance "with purely medical criteria as being necessary for the protection of the physical or mental health or the safety of the prisoner or detainee himself, of his fellow prisoners or detainees, or of his guardians, and it presents no hazard to his physical or mental health" (UN, 1982: art. V).

Regarding the situation of the identification centres, the Italian National Bioethics Committee (CNB) has recently claimed the introduction of a torture crime in the Italian legal order, as a way to prevent "dramatic experiences like those suffered by migrants, and especially women, such as arbitrary detention, inhuman treatments, sexual harassment and rape, slavery for purpose of prostitution" (CNB, 2017: 4).

Undocumented migrants who survive the adversities of the trip and/or escape from the control of border authorities are forced to live in a condition of uncertainty and precariousness, which often leads them to resort to the black labour market, or to fall into the trap of criminality. As shown by Santoro (2006), when considering the situation in EU penitentiaries, it is possible to observe a clear disproportion between the incidence of foreign people in the general population, and the incidence of foreign people detained in penitentiaries. Unless resuscitating Lombrosian nightmares of ethnic- or morphological-inspired criminal instincts, this leads to the conclusion that denying migrants the opportunity to gain a legal status arguably represents the waiting room of criminalization processes. The analysis of Santoro also provides an interpretation through which framing the over-representation of detained migrants within the wider economic and political context of the EU. As he argues, the deliberate exclusion of migrants from citizenship and enjoyment of social rights has been used as a means to cover the “perception of the inevitable scarcity of resources at the disposal of the State for welfare purposes” (Santoro, 2006: 69). In other words, while migrants are largely denied civil and social rights, they are also massively exploited by the productive systems of the EU countries and used at a political level as a scapegoat for justifying the progressive loss of financial sovereignty by national governments. From a slightly different viewpoint, the over-representation of migrants in EU penitentiaries confers a renewed relevance to the work of Sayad, who coined the expression of the *double peine* of the migrant – signifying their being guilty and being a migrant – to describe the burden overwhelming migrants in contemporary societies, where each of their gestures, behaviours or attitudes seems to be reproachable and prosecutable.

5. How much does the difference weigh? Socio-cultural misconceptions and inequalities in health and healthcare

In “The Foundation of Bioethics”, T.H. Engelhardt coined the definition of the ‘stranger in a strange land’ to describe the asymmetrical position in which a non-professional stands when facing the bureaucratic-based organization of contemporary healthcare systems (Engelhardt, 1996: 295). Though Engelhardt was not specifically concerned about migrants, it would be impossible to find a better expression to explain the exceptionally asymmetrical position in which most migrants to industrialized societies stand when trying to get access to healthcare services in receiving countries. Beyond the lack of legal status – which, as seen above, is in itself a significant obstacle – many other factors may hinder an effective access to healthcare by migrant people. As easily imaginable, an initial main obstacle is the language barrier. Unfriendly care services expose migrants to linguistic difficulties and incomprehension, thus amplifying the perception of strangeness and unfamiliarity experienced in approaching the healthcare system. A huge body of literature – not only from bioethics and medical ethics, but also from sociology of health and medical anthropology – has contributed to shedding a light on the distance separating the technical perspective of healthcare professionals from the lay vision of patients. In particular, Clark & Mishler (1992) have described this distance as a conflict between two different voices:

> the 'voice of medicine', expressing a technical, biomedical frame of reference, and the 'voice of the lifeworld', reflecting the patient's personal, 'contextually-grounded experiences of events and problems', expressed in familiar terms. Usually, the voice of medicine dominates the discourse, but the conflict tends to recur throughout the encounter at various levels of intensity (Clark & Mishler, 1992: 346)

Following this interpretation, the efforts made by patients to tell their own stories shall not be seen as a mere complaint accompanying the experienced suffering, but an attempt to make sense of technical facts such as symptoms and medical prescriptions. If healthcare professionals do not strive to mediate the distance, it is highly probable that patients will have a negative experience, which may lead to a failure of the 'therapeutic alliance'. Therefore, it is clear that language barriers can have a terrible impact on interaction between migrants and healthcare professionals, thus increasing sensations of fear, discomfort, and inadequacy, which may deter migrants to seek access to healthcare.

To stay on the topic of language(s) and voice(s), a second factor to be considered here is what kind of meaning lies behind the patients' voice. Language is a conventionally established system of communication and significance, which depends on social and cultural practices, values, beliefs, and norms. But when considering the features of communication in medicine and healthcare from the patients' viewpoint, language turns into a system of reference that often hides more than it expresses. Considering both language barriers and the restriction of verbal expression induced by the asymmetry and reverence towards healthcare professionals, a significant part of patients' expression shifts to nonverbal communication, which is arguably the most socially and culturally grounded mode of expression known to date. Indeed, expressing feelings as pain, embarrassment, approval, disagreement, (dis)satisfaction, sadness, happiness, subjection, and engagement is highly dependent on the cultural variables that contribute to shape individual and collective identities. Correlatively, the multiple forms of expressing these feelings call on likewise different ways of conceptualising the body, as well as its relation with practices, values, beliefs, and norms. In this regard, bioethics is already facing severe challenges arising from socio-cultural misconceptions, especially when it comes to establishing what belongs to the moral spectrum of individuals and social groups, what the individual's hierarchy of values is, and how to balance dominant hierarchies with those of minorities[5]. Disregarding the incidence of socio-cultural factors in healthcare may lead to 'pathologizing diversity', which could thus be considered as a deviation from the standard biomedical parameters, social practices, and behaviours involved in the relationship between health, disease, and the body (Botrugno, 2014c).

To summarize, migrants in industrialized societies are often caught in a pathological circle of discrimination, criminalization, language barriers, poor living conditions, and socio-cultural misconceptions (McGuire & Martin, 2007; Fassin, 2001). In this circle, migrants are often reduced to invisible beings because they are to a large extent discriminated, which means that they end up having much less agency than autochthones, as well as much less ability of moving into the meanderings of the healthcare system. Moreover, they have less time and economic resources, which shall be coupled with the fear of being discriminated and blamed. This affects their agency and, again, condemns them to being invisible in the hosting societies. To understand the weight of these differences, and how invisible migrants may be to healthcare services, it is possible to look at inequalities in health and healthcare. A considerable body of evidence shows indeed that the migrant status represents a significant disadvantage to both maintaining a good state of health and accessing adequate healthcare services. The countless inequalities reported to the detriment of migrants include but are not limited to: a higher rate of complications in pregnancy and birth, and lower access to gynaecological public services than autochthones (Tognetti Bordogna, 2011); more difficulties in expressing individual needs and understanding physicians than autochthones (ISTAT, 2013); higher exposure to on-the-job injuries and job-related diseases than autochthones – up to two times higher – while migrants' employment levels remain lower (EU-OSHA, 2007; Reyneri, 2011); higher incidence of post-traumatic stress disorders among refugees – around ten times higher – than in the general population (Fazel *et al.*, 2005); and higher depression and anxiety disorders rates among refugees – around two times higher –

---

[5] For instance, consider the controversial cases in which a blood transfusion shall be performed on a Jehovah's Witnesses, or the refusal of Muslim patients to be treated by professionals who are not of the same sex.

than in general population (Lindert *et al*., 2009). In this regard, it is also worth considering that the European Parliament has adopted a clear position with the Resolution on "Reducing Health Inequalities" (EU Parliament, 2010), in which EU Member States are called on:

> to ensure that the most vulnerable groups, including undocumented migrants, are entitled to and are provided with equitable access to healthcare [and] to assess the feasibility of supporting healthcare for irregular migrants by providing a definition based on common principles for basic elements of healthcare as defined in their national legislation (EU Parliament, 2011: 5)

Moreover, a specific consideration is given to the health protection needs of immigrant women and the correlated necessity of developing "training initiatives enabling doctors and other professionals to adopt an intercultural approach based on recognition of, and respect for, diversity and the sensitivities of people from different geographical regions" (EU Parliament, 2011: 6).

6. Conclusions: What can everyday bioethics do for bioethics (and for migrants)?

The medical anthropologist Paul Farmer has used the expression 'materiality of the social' to qualify the perspective he claims as necessary to seize the embodiment of structural violence that generates a socially-informed distribution of diseases (Farmer, 2004). As Farmer argues, "the adverse outcomes associated with structural violence – death, injury, illness, subjugation, stigmatization, and even psychological terror – come to have their 'final common pathway' in the material" (Farmer, 2004: 308). The materiality of the social has much to share with the approach of everyday bioethics, especially when considering that the latter pursues social justice and aims to give value, protect, and respect diversity, as well as to consider differences in health and healthcare. Nonetheless, as argued by Wild (2012), what is missing in bioethics today is a wider debate:

> on moral responsibilities that explicitly addresses the different groups of migrants, whether differential treatment for citizens can ever be morally

> justified, and how these moral evaluations should find their way into public and institutional policies (Wild, 2012: 12)

An attempt to bridge this gap is currently represented by the work of Mocellin Raymundo (2011), who traces a noteworthy connection between bioethics and interculturality, finding that both converge on the common ground of respecting diversity and crossing disciplines. Indeed, as reminded by Raymundo, appreciating the difference(s) arguably represents one of the most important inspiring principles of bioethics, as also predicted by Van Rensselaer Potter (recalled by Raymundo, 2011: 495). On this basis, Raymundo claims for a Bioethics that is able to recognize and protect the plurality of epistemologies and cultural perspectives in healthcare, avoiding the dominance of any particular one – usually the western biomedical perspective – upon the others. Here, it is worth adding that this kind of orientation is compliant with the 2001 UNESCO “Declaration on Cultural Diversity”, according to which, defending cultural diversity shall be considered as:

> an ethical imperative, inseparable from respect for human dignity. It implies a commitment to human rights and fundamental freedoms, in particular the rights of persons belonging to minorities and those of indigenous peoples. No one may invoke cultural diversity to infringe upon human rights guaranteed by international law, nor to limit their scope (UNESCO, 2001: art. 4)

From a partially different viewpoint, everyday bioethics may also take inspiration from the well-known reflection developed by Juan Carlos Tealdi in the attempt to enhance a ‘bioethics of human rights’. In his work, Tealdi claims that there is a need to restore the moral universalism that inspired the emergence of bioethics at an international level after the end of World War II. According to Tealdi, the bioethics of human rights shall serve as a meta-theory through which to react to the extremism of ethical principles, as well as to the correlated moral imperialism that proceeds from neo-pragmatism and neoliberalism (Tealdi, 2008: 177). The bioethics of human rights is relevant to the everyday bioethics’ approach in so far as it pursues justice as an unavoidable obligation, which also entails recognizing the unconditioned value of human dignity (Tealdi, 2008: 178).

Undoubtedly, interculturality and human rights are fundamental pieces – among others – to complete the puzzle of everyday bioethics. In this regard, it is worth clarifying that the approach of everyday bioethics was not conceived by Giovanni Berlinguer as a new or alternative bioethics theory. It was rather proposed as a perspective through which conferring a renewed value to some elements that have always belonged to bioethics, although *de facto* set aside by the prevalence of individual-based theories, approaches, and questions. Metaphorically speaking, therefore, it is possible to argue that enhancing everyday bioethics may be seen as an attempt to enhance equity in bioethics debate. In practical terms, this would entail working towards a set of tools through which to help individuals reacting to the hierarchies of values, interests, and practices resulting from established relations of power in healthcare (Carapinheiro, 1993). By disregarding the application of the newly introduced obligation to report illegal migrants, the above-mentioned Spanish and Italian healthcare professionals have reacted to inhuman and unfair rules, which they felt as not grounded in the common – or maybe, the universal, so to recall Tealdi – moral vision that defends everybody's right to access healthcare. Additionally, by acting in this way, those professionals have *de facto* opened the black box of legal order(s), showing the (material) gaps, conflicts, and negotiations that separate the 'law in the books' from the 'law in action'. Therefore, let's consider everyday bioethics as a 'bioethics in action'.

Enhancing everyday bioethics also requires further research and further education based on this perspective. Applied to migrants, this entails educating healthcare professionals on how to receive foreign patients and how to establish good (intercultural) care relationships. It may also involve making it known to population in receiving societies that migration flows are not a 'disease' of the contemporary era, nor does the migrants' arrival represent a crisis or a threat to our stability. Rather, migration flows are the final outcome of combining poverty, war, persecution, and social exclusion, to which extent industrialized countries have enormous responsibilities (Buxo i Rey, 2004). Additionally, receiving societies should be aware that migrants are usually healthier than native-born populations in industrialized countries, and that their health problems are mostly due to malnutrition, poor education, and poor living conditions. Furthermore, migrants represent a significant resource for the economic development of receiving countries, as also explicitly recognized by EU policy-makers (European Commission, 2005).

To summarize, from an everyday bioethics' perspective, there are several reasons why we should not hesitate in taking care of migrants' health:

- it's a matter of public health: an effective prevention requires the implementation of surveillance systems and immunization programmes to neutralize potential threats of spreading diseases;
- it's a matter of economy: primary care services and prevention activities are much less expensive and much more efficacious than treating acute episodes, dealing with emergencies, or managing chronic diseases;
- it's a matter of justice: migration flows shall be seen as a global movement for social justice, and healthcare access is a fundamental right to be protected regardless of citizenship or legal status;
- it's a matter of professional deontology: healthcare professionals have an ethical obligation to care for the sick, which implies not to 'close one's eyes' in the face of human suffering, but rather to develop a proactive attitude to meet the needs of the most vulnerable and underserved populations.

Therefore, in order to ensure that migrants have full access to healthcare, it is indispensable to adopt policies directed to compensate health inequalities and eliminate discrimination in healthcare, which may be achieved through:

- promoting of migrant-friendly care services, not only in English but also in migrants' native languages;
- developing a systemic approach to migrants' health protection to be shared among the EU Member States;
- educating healthcare professionals in order to enable the recognition and protection of cultural diversity and the development of linguistic competency, and to contrast 'policies of deterrence' and anti-immigrant rhetoric.

In conclusion, the everyday bioethics' approach may contribute to raising awareness and enhancing bioethics as an active discipline through which to contrast inequalities, defend equity, and protect fundamental rights of all populations, especially those of the most vulnerable.

References

Arnold F., Katona C., Cohen J., Jones L., and McCoy D. (2015) “Responding to the needs of refugees”. *Bmj*, 351: h6731.

Berlinguer G. (2000) *Bioetica quotidiana*. Firenze: Giunti.

——— (2003) *Everyday Bioethics: Reflections on Bioethical Choices*, New York: Baywood Publisher.

Bhugra D., and Gupta S. [Eds.] (2010) *Migration and Mental Health*. Cambridge: University Press.

Biller-Andorno N. (2003) “Everyday bioethics: reflections on bioethical choices in daily life – Book Review”. Bull World Health Organ, 81(4): 306.

Blumberg H.M., Migliori G., Ponomarenko O., and Heldal E. (2010) “Tuberculosis on the move”. *The Lancet*, 375: 2127-29.

Bollini P., and Siem H. (1995) “No Real Progress Towards Equity: Health of Migrants and Ethnic Minorities on the Eve of the Year 2000”. *Society Science & Medicine*, 41: 819-28.

Botrugno C. (2014a) “Diritto alla salute, diseguaglianze e materialità del sociale: una ricognizione per leggere le molteplici correlazioni tra diritto e società nell’area del benessere”. In Bonato R., and Nobile M., *Il benessere: un percorso multidisciplinare*, 33-44. Milan: Ledizioni.

——— (2014b) “Immigrazione e Unione Europea: un excursus storico ragionato”. *Sociologia del diritto*, 1: 143-65.

——— (2014c) “Il diritto alla salute dinnanzi alla sfida della complessità: dalla crisi del riduzionismo biomedico alla global health”. *Italian Journal of Legal Philosophy*, 2: 495-512.

Buxó i Rey M. (2004) “Bioética Intercultural para la Salud Global”. *Revista de Bioética y Derecho*, 1: 12-5, available at: http://revistes.ub.edu/index.php/RBD/article/view/7934/9835.

Carapinheiro G. (1993) *Saberes e Poderes no Hospital. Uma Sociologia dos Serviços Hospitalares*. Oporto: Afrontamento.

Castelli F., and Sulis G. (2017) “Migration and infectious diseases”. *Clinical Microbiology and Infection*, 23(5): 283-89.

CDPC [Center for Disease Prevention and Control] US Department of Health & Human Services (2017) available at: https://www.cdc.gov/globalhealth/ntd/index.html.

Clark J.A., and Mishler E.G. (1992) “Attending to patients’ stories: referencing the clinical”. *Sociology of Health and Illness*, 14: 344-72.

CNB [Comitato Nazionale per la Bioetica] (2010) *Le condizioni di vita della donna nella terza e quarta età: aspetti bioetici nella assistenza socio-sanitaria*, available at: http://bioetica. governo.it/media/170708/p93_2010_donne_terza_quarta_eta_it.pdf.

Constant A.F., García-Muñoz T., Neuman S., e Neuman T. (2017) “A “Healthy Immigrant Effect” or a “Sick Immigrant Effect”? Selection and Policies Matter”. *Eur J Health Econ*, 19(1): 103-21.

Costa G., and Faggiano F. [Eds.] (1994) *L’equità nella salute in Italia. Rapporto sulle diseguaglianze sociali in sanità*. Milano: Franco Angeli.

Costa G., Cardano M., and Demaria M. (1998) *Torino, storie di salute in una grande città*. Turin: Municipality Statistic Office, Turin Socio-economic Observatory.

CPT [European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment] (2017) *Immigration Detention Factsheet*, available at: https://rm.coe.int/16806fbf12.

Cuttitta P. (2007) “Le rotte che cambiano i confini”. *Segno*, 33(289): 49-54.

Del Grande G. (2007) *Fuga da Tripoli. Rapporto sulle condizioni dei migranti di transito in Libia*, available at: http://briguglio.asgi.it/immigrazione-e-asilo/2008/gennaio/rapp-fortresse-eu-libia.pdf.

Domnich A., Panatto D., Gasparini R., and Amicizia D. (2012) “The “healthy immigrant” effect: does it exist in Europe today?”. *The Italian Journal of Public Health*, 9(3), e7532: 1-7.

Engelhardt H.T. (1996) *The Foundations of Bioethics*. New York: Oxford University Press.

EU FRA [European Union Fundamental Rights Agency] (2011) *Migrants in an irregular situation employed in domestic work: Fundamental rights challenges for the European Union and its Member States*, available at: http://fra.europa.eu/en/publication/2012/migrants-irregular-situation-employed-domestic-work-fundamental-rights-challenges.

——— (2017) *EU-MIDIS II: European Union minorities and discrimination survey*, available at: http://fra.europa.eu/en/project/2015/eu-midis-ii-european-union-minorities-and-discrimination-survey.

European Commission (2005) *The Green Paper on an EU approach to Managing Economic Migration*, available at: europa.eu/rapid/press-release_SPEECH-05-364_en.pdf.

European Union Parliament (2011) *Reducing health inequalities in the EU*, Resolution 8 March 2011 [2010/2089(INI)], available at: http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//NONSGML+TA+P7-TA-2011-0081+0+DOC+PDF+V0//EN.

EU-OSHA [European Agency for Safety and Health at Work] (2007) *Annual report 2007: bringing safety and health closer to European workers*, available at: https://osha.europa.eu/en/publications/annual_report/2007full/view.

Farmer P. (2004) "An anthropology of structural violence". *Current Anthropology*, 45(3): 305-25.

Fazel M., Wheeler J., and Danesh J. (2005) "Prevalence of serious mental disorder in 7000 refugees resettled in western countries: a systematic review". *The Lancet*, 9-15, 365(9467): 1309-14.

Fassin D. (2001) "Une double peine. La condition sociale des immigrés malades du sida". *L'Homme*, 160: 137-62.

Fekete L. (2011) "Accelerated removals: the human cost of EU deportation policies". *Race and Class*, 52(4): 89-97.

Fox J. (1989) *Health inequalities in European countries*. Aldershot: Gower Press.

Hayward M.D., and Heron M. (1999) "Racial inequality in active life among older Americans". *Demography*, 36: 77-91.

ILO [International Labour Organization] (2010) *Recommendation no. 200 concerning HIV and AIDS and the World of Work*, available at: http://www.ilo.org/aids/WCMS_142706/lang--en/index.htm.

IOM [International Organization for Migration] (2010) *Increasing Public Health Safety Alongside The New Eastern European Border: An Overview of Findings from the Situational Analysis*, available at: http://www.iom.int/jahia/webdav/shared/shared/mainsite/activities/health/PHBLM-SAR-Public-Report-2010.pdf.

——— (2013) *International Migration, Health and Human Rights*, available at: https://publications.iom.int/system/files/pdf/iom_unhchr_en_web.pdf.

——— (2017) *Missing Migrants Project Report*, available at: https://missingmigrants.iom.int/region/mediterranean.

ISS [Istituto Superiore Sanità] (2015) *Salute pubblica ed emergenza immigrazione*, available at: http://www.epicentro.iss.it/argomenti/migranti/ReportSpeim.asp.

Kawachi I. (1999) "Social capital and community effects on population and individual health". *Annals of the New York Academy of Sciences*, 896: 120-30.

Kennedy S., Kidd M.P., McDonald J.T., and Biddle N. (2015) "The Healthy Immigrant Effect: Patterns and Evidence from Four Countries". *Journal of International Migration and Integration*, 16(2): 317-32.

Kunst A.E., and Mackenback J.P. (1992) *An International comparison of socio-economic inequalities in mortality*. Department of Public Health and Social Medicine, Erasmus University Rotterdam.

Lecaldano E. (1999) *La Bioetica. Scelte morali*. Roma/Bari: Laterza.

Lindert J., Ehrenstein O.S., Priebe S., Mielck A., and Brähler E. (2009) "Depression and anxiety in labor migrants and refugees - A systematic review and meta-analysis". *Social Science and Medicine*, 69: 246-57.

Loue S., and Sajatovic M. (2012) *Encyclopedia of Immigrant health*. New York: Springer.

Marmot M. (2017) "Social justice, epidemiology and health inequalities". *Eur J Epidemiol*, 32(7): 537-46.

Martinez O., Wu E., Sandfort T., Dodge B., Carballo-Dieguez A., Pinto R., Rhodes S.D., Moya E., and Chavez-Baray S., (2015) "Evaluating the Impact of Immigration Policies on Health Status Among Undocumented Immigrants: A Systematic Review". *J Immigr Minor Health*, 17(3): 947-70.

McGuire S., and Martin K. (2007) "Fractured migrant families: paradoxes of hope and devastation". *Family and Community Health*, 30: 178-88.

MEDU [Medici per i Diritti Umani] (2013) *Arcipelago CIE. Indagine sui centri di identificazione ed espulsione italiani*, available at: http://www.mediciperidirittiumani.org/pdf/ARC IPELAGOCIEsintesi.pdf.

——— (2017) *Una malattia chiamata tortura. Rotte migratorie dall'africa sub-sahariana all'Europa*, available at: http://www.mediciperidirittiumani.org/una-malattia-chiamata-tortura-rotte-migratorie-dallafrica-sub-sahariana-alleuropa/.

Mondo L., Silvestrini G., Rusciani R., Monastero V., and La Rosa A. (2017) “Immigrazione e salute: Come l’esperienza migratoria influenza il capitale di salute e la mortalità”. In Costa G., Stroscia M., Zengarini N., Demaria M. [Eds.] *40 anni di salute a Torino. Spunti per leggere i bisogni e i risultati delle politiche*, available at: http://www.disuguaglianzedisalute.it/wp-content/uploads/2017/03/FactsheetImmigrazione_WEB.compressed-1.pdf.

MSF [Médecins Sans Frontières] (2016) *Traumi Ignorati. Richiedenti asilo in Italia: un’indagine sul disagio mentale e l’accesso ai servizi sanitari territoriali*, available at: http://archivio. medicisenzafrontiere.it/pdf/Rapp_Traumi_Ignorati_140716B.pdf.

Padovani G. (2008) *Il diritto negato. La salute e le cure sono uguali per tutti?*. Roma: Il Pensiero Scientifico.

Parkin J. (2013) “The Criminalisation of Migration in Europe. A State-of-the-Art of the Academic Literature and Research”, *CEPS Paper in Liberty and Security in Europe*, no. 61, available at: https://www.ceps.eu/system/files/Criminalisation%20of%20Migration%20in%20Europe%20J%20Parkin%20FIDUCIA%20final.pdf.

Pfortmueller C.A., Schwetlick M., Mueller T., Lehmann B., and Exadaktylos A.K. (2016) “Adult Asylum Seekers from the Middle East Including Syria in Central Europe: What Are Their Health Care Problems?”. *PLoS One*, 11(2): e0148196.

Santoro E. (2006) “Dalla cittadinanza inclusiva alla cittadinanza escludente: il ruolo del carcere nel governo delle migrazioni”. *Diritto e questioni pubbliche*, 6: 39-79.

Raymundo M.M. (2011) “Uma aproximação entre bioética e interculturalidade em saúde a partir da diversidade”. *Revista HCPA*, 31(4): 494-99.

Razum O., Zeeb H., and Rohrmann S. (2000) “The Healthy Migrant Effect - Not Merely a Fallacy of Inaccurate Denominator Figures”. *International Journal of Epidemiology*, 29: 191-2.

Red Acoge (2015) *Los efectos de la exclusión sanitaria en las personas inmigrantes más vulnerables*, available at: http://redacoge.org/mm/file/2015/Jurídico/Informe%20Sanidad%20RED_ACOGE.pdf.

REDER [Red de Denuncia y Resistencia] (2017) *La salud en los márgenes del sistema*, available at: https://www.reder162012.org.

Reich W.T. [Ed.] (1995) *Encyclopedia of Bioethics. Introduction*. New York: Macmillan.

Reyneri E. (2011) *Sociologia del mercato del lavoro. Le forme dell’occupazione*. Bologna: Il Mulino.

Sayad A. (2006) *L'immigration ou les paradoxes de l'altérité. L'illusion du provisoire*. Paris: Raisons d'Agir.

Soto S.M. (2009) "Human migration and infectious diseases". *Clinical Microbiology and Infection*, 15, Suppl. 1: 26-8.

Subramanian S.V., Belli P., and Kawachi I. (2002) "The macroeconomic determinants of health". *Annual Review of Public Health*, 23: 287-302.

Tealdi J.C. [Ed.] (2008) *Diccionario Latinoamericano de Bioética*, available at: http://unesdoc. unesco.org/images/0016/001618/161848s.pdf.

Tognetti Bordogna M. (2013) "Nuove diseguaglianze in salute: il caso degli immigrati". *Cambio*, 3(5): 59-72.

UN [United Nations] (1982) *Principles of Medical Ethics*, Resolution no. 37/194 of 18 December 1982, available at: http://www.un.org/documents/ga/res/37/a37r194.htm.

——— (2000a) *Protocol against the Smuggling of Migrants by Land, Sea and Air, supplementing the United Nations Convention against Transnational Organized Crime*, available at: https://www.unodc.org/documents/southeastasiaandpacific/2011/04/somindonesia/convention_smug_eng.pdf.

——— (2000b) *Protocol to Prevent, Suppress and Punish Trafficking in Persons, especially Women and Children, supplementing the United Nations Convention against Transnational Organized Crime*, available at: https://www.osce.org/odihr/19223?download=true.

——— (2010) *UNAIDS Outcome Framework 2009-2011*, available at: http://www.unaids.org/sites/default/files/sub_landing/files/20100728_HR_Poster_en.pdf.

——— (2016) *International Migrations Report*, available at: http://www.un.org/en/development/desa/population/migration/publications/migrationreport/docs/MigrationReport2015.pdf.

UNESCO (2001) *Declaration on Cultural Diversity,* Cultural Diversity Series No. 1, available at: http://unesdoc.unesco.org/images/0012/001271/127162e.pdf.

WHO (1998) *A Conceptual Framework for Action on the Social Determinants of Health*, available at: http://www.who.int/social_determinants/resources/csdh_framework_action_05_07.pdf.

——— (2013) *Migración internacional, salud y derechos humanos*, available at: http://www.ohchr.org/Documents/Issues/Migration/WHO_IOM_UNOHCHRPublication_sp.pdf.

——— (2017a) *Neglected Tropical Diseases*, post available at: http://www.who.int/neglected_diseases/diseases/en/.

——— (2017b) *Migrations and health: key issues*, post available at: http://www.euro.who.int/en/health-topics/health-determinants/migration-and-health/migrant-health-in-the-european-region/migration-and-health-key-issues.

——— (2017c) "A review of evidence on equitable delivery, access and utilization of immunization services for migrants and refugees in the WHO European Region", *Health Evidence Network Synthesis Report 53*, available at: http://www.euro.who.int/en/publications/abstracts/review-of-evidence-on-equitable-delivery,-access-and-utilization-of-immunization-services-for-migrants-and-refugees-in-the-who-european-region-a-2017.

WHO Commission on Social Determinants of Health (2003) *Social determinants of health The Solid Facts*, available at: http://www.euro.who.int/__data/assets/pdf_file/0005/98438/e81384.pdf.

Wild V. (2012) "Migration and Health: Discovering New Territory for Bioethics". *The American Journal of Bioethics*, 12(9): 11-3.

Healing or fleeing?
Reflecting on international protection and health challenges from three refugee pathways

Inês Vieira[*]
Interdisciplinary Centre of Social Sciences, CICS.NOVA - NOVA FCSH

ABSTRACT: The situation of contemporary refugees can be reflected as paradigmatic of the international efforts and challenges to provide universal access to human rights, namely the right to health. Yet, refugees' experiences might denote meanings of health services that do not correspond to places where health care is provided. After acknowledging the protection principles of international asylum systems, three critical events are considered, as narrated by refugees while reflecting on their pathways from Ethiopia to Italy, passing through Libya, both before and after the completion of the asylum request procedure. These events, contextualized in health services' settings, allow us to reflect on: health services as safer spaces and least regulated than detention facilities, and health care as a relatively important issue in contexts where freedom and survival are threatened; and health services as spaces of restricted healthcare and assistance in situations of limited freedom, such as in the EU refugee context of limited rights of mobility. This paper follows a human/health ecology approach, proposing a critical and intersected reading of protection and health issues, and suggests that efforts to recognize refugees' right to health demands changes in the overall asylum system.

1. Introduction: background of international protection and health challenges for refugees

Within the 'transnational turn' in diverse policy fields over the last decades, mobility and protection issues have been considerably pondered in the international agenda. Yet, it is possible to observe a distance between the legal framework for the protection of persons of concern at the international scale, and the practical aspects of that protection. Moving from the background of international protection regimes for refugees and other forced migrant

---

[*] Corresponding author: Inês VIEIRA | ines.vieira@fcsh.unl.pt

groups, this paper aims to contribute to present debates while grasping the sense conferred to ‘protection’, mainly at the European scale, and its distance from the health challenges faced by these groups.

In the aftermath of the Second World War, in a context of high pressure in the international agenda of issues relating to refugees and displaced persons, the international regime for refugee protection was established. This regime is rooted in the United Nations (UN) Geneva Convention of 1951 (UN, 2010; grounded in Article 14 of the Universal Declaration of Human Rights, 1948), generalized in its temporal and geographical extent through the New York Protocol of 1967. The Convention defined the refugee status as applicable to situations of “well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion” (Article 1, point 2), provided the person is out of the country of origin or habitual residence and cannot be protected by that country. The Geneva Convention followed the creation of UN’s High Commissioner for Refugees (UNHCR), a key institution with the aim of finding permanent and long-lasting solutions for refugees, namely through integration in an asylum country or resettlement in a second host country. The mandate of UNHCR covers the majority of refugee situations in the world, exception made to Palestinian refugees, which are assisted by the UN Relief and Works Agency for Palestine Refugees in the Near East (UNRWA).

Within European Union (EU) legislation, persons seeking asylum who do not qualify as refugees can be eligible for subsidiary protection, as stated in Directive 2004/83/EC[1] (EU, 2004) and Directive 2011/95/EU (EU, 2011). According to these acts, a person can be eligible for subsidiary protection status if he/she is a third-country national or stateless person facing a real risk of suffering serious harm if returning to the country of origin or habitual residence, among which: (a) death penalty or execution; or (b) torture or inhuman or degrading treatment or punishment of an applicant in the country of origin; or (c) serious and individual threat to a civilian's life or person by reasons of indiscriminate violence in situations of international or internal armed conflict (EU, 2004, articles 2 and 15).

---

[1] No longer in force, validity ended on 21/12/2013.

Since the 1990s there has been a particular effort to create a Common European Asylum System (CEAS)[2], aiming to improve the current legislative framework towards harmonization of common minimum standards for asylum and cooperation between Member States (MS). Within this system, besides the aforementioned protection regimes, special Directives have been created regarding Temporary Protection (EU, 2001) and Family Reunification (EU, 2003). This system also includes the (now under revision) Dublin Regulation (European Union, 2013a), which determines the State responsible for examining the asylum application and clarifies the rules governing relations between states (so far on the premises that, for the facilitation of asylum administrative procedures, only one asylum request should be presented and, upon its acceptance, the protected person should remain in that country); and the EURODAC Regulation (EU, 2013b), that rules the EU database of asylum seekers’ fingerprints.

Also within the EU, from 2015 to 2017, a relocation scheme was developed to facilitate the transfer of asylum seekers in clear need of international protection from one MS (Italy or Greece) to another one (EU, 2015)[3]. Additionally, under the UN Convention on Human Rights (UN, 1948) and legislation of individual states, special protection can be granted based on humanitarian needs that may go beyond the scopes of refugee and subsidiary protection schemes.

Which definition of protection can be underlying all these international devices? According to the Inter-Agency Standing Committee (IASC), which is the primary mechanism for inter-agency coordination of humanitarian assistance involving UN and non-UN partners, protection can be defined as “all activities aimed at ensuring full respect for the rights of the individual in accordance with the letter and spirit of the relevant bodies of law (i.e. human rights law, international humanitarian law and refugee law)” (European Commission, 2016: 5). Despite being criticized for its ubiquity and difficult operability, this wide concept allows capturing different dimensions of protection, not only regarding material needs but also at the level of personal safety and dignity. Regarding protection in humanitarian situations, the

---

[2] European Commission, Migration and Home Affairs – Common European Asylum System, available at: https://ec.europa.eu/home-affairs/what-we-do/policies/asylum_en.

[3] No longer in force, validity ended on 26/09/2017. Further information on this program can be found in European Asylum Support Office - Questions and answers on relocation, available at: https://www.easo.europa.eu/operational-support/hotspot-relocation/relocation/questions-and-answers-relocation.

European Commission fosters “material assistance, such as food, water, shelter and medical assistance, as well as physical integrity, psychological wellbeing and dignity”, particularly when these needs are “a consequence of violence, deliberate deprivation and restrictions of access” (European Commission, 2016: 5).

Within the asylum law, refugee, subsidiary and humanitarian protection can thus be considered paradigmatic of the international efforts to provide universal access to basic human rights, including the right to health care. Yet, these frameworks do not directly assure practical provision of health care. Even in the EU context alone, there is a considerable variability on the types of health services and assistance available for refugees and other vulnerable groups. Besides the considerable inequalities between migrants and non-migrants in EU countries, asylum seekers and undocumented migrants are the groups that face more restrictions in their statutory rights to health care (Mladovsky, 2011).

Furthermore, within the specific case of the ‘forced migration continuum’ – considered as “the movement of migrants who transit through and then outside their region of origin” – many protection gaps and challenges can be identified against the intention to provide safety, security and reduce vulnerability for people who are forced to move (Zetter, 2014: 13).

With an ecological and holistic approach to health care and services (Honari, 2005), if we ponder the specific challenges for forced migrants, it is important to acknowledge the need of an intersectional view of health within economic, political and psycho-social factors. These challenges can range from: (a) the epidemiological level, which goes beyond genetic predisposition when considering the effect of different patterns of exclusion and segregation in the exposition to diverse diseases and reproductive health issues, and adding to it a lower access to information on prevention and healing options; to (b) the consequences of migrants’ pathways, often associated to stress and traumatic processes, and to their needed adaptation, namely to new food patterns and deep changes in life style; and (c) the lower access to health services, mainly by undocumented migrants, further confirming this group as one of the most vulnerable in the international scene (Fernandes *et al.*, 2007). Related to the difficulties in accessing health services, barriers to refugees’ and asylum seekers’ registration within public health structures, lack of language support, and a scarce consideration of these groups’ particular needs (namely regarding mental health and chronic illnesses) have been repeatedly reported (Feldman, 2006).

If we ponder these health issues in constrained situations – namely in prisons or detention centers and, in a different level, within the overall limited right to mobility for refugees in Europe –, how can we consider the nexus between the background concept of protection and the empirical realities of health care?

In this paper, after presenting the methodological approach, critical events narrated by three refugees will be presented, about health care and services in their pathways from Ethiopia to Italy, passing through Libya, both before and after the completion of the asylum request procedure. These events will allow us to explore some of the complex meanings and challenges that health care and services might assume for refugees, particularly regarding (1) health services as safer spaces and less regulated than detention facilities, and health care as a relatively important issue in contexts where freedom and survival are threatened; and (2) health services as spaces of restricted health care and assistance in situations of limited freedom, such as in the EU refugee context of limited rights of mobility.

2. Methodological approach

This paper brings into discussion critical events narrated in three out of 32 interviews developed with Ethiopian and Eritrean refugees and migrants in Bologna, in 2012 (this PhD project[4] further included 22 interviews with Cape Verdean migrants in Lisbon, Portugal, 2013-2015). The aim of this work was to explore the reflexivity of migrants and refugees from countries with environmental risk, observing their representations of environmental factors in the countries of origin, interrelated with other drivers of mobility (mainly economic and political), and the framing within their experiences of mobility towards Southern Europe.

The chosen method for most of this research was the interview, which can capture different senses that social actors attribute to their practices and experiences, as well as retrace past processes and occurrences (Quivy & Campenhoudt, 2008). The interview guide was built before holding the interviews, following a phase of theoretical reading and review of empirical studies (Vieira, 2010). The guide included six sections: (1) identification of the interviewee; (2) former pathways of mobility; (3) social networking; (4) work on the land and strategies of adaptation in the context of origin; (5) factors in the context of origin that

---

[4] This research was supported by a FCT grant (SFRH/BD/68730/2010).

influenced migration; (6) memories and present life in Italy and Portugal. The guide was written in Portuguese and Italian and, when needed (particularly with recently arrived refugees in Italy), was translated into English.

Sampling was initiated through contact with migrant associations and through participant observation in significant spaces for Ethiopian and Eritrean groups in Bologna, Italy, and for Cape Verdean groups in Lisbon, Portugal. Interviews were conducted using a research process of contextualization (framing the content and process in which the interviews were gathered, so as to better understand the connections between text and context) and interaction (acknowledging the social interactions in the research process, deepening the listening and translation skills of the interviewer, and assuming the 'inter-view' bilateral dimension within the methodological approach) followed by verification (observing and categorizing the gathered information, so as to observe its recurrences, yet trying to avoid the risk of over-standardizing life experiences) that suggested saturation of the information gathered (Ferrarotti, 2011). Interviews had a medium length of one hour and were held in places chosen by each interviewee: associations, shops, cafes and bars, gardens and other public spaces, work and residential places.

All interviews were preceded by an introductory presentation of the research project and subject to a written consent declaration as a safeguard to interviewees' anonymity. Whenever authorized, interviews were audio recorded and transcribed. Interviews were subject to content analysis with a thematic focus, proceeding to an analytical synthesis of the gathered texts through a regrouping of content into structural categories of analysis (Bardin, 2004).

Besides this primary source of data, for the specific aim of this paper it was necessary to consult secondary sources to update the political framing of refugees and the right to healthcare. Secondary sources include documentation on rights and policies for migrants' health – particularly in the case of international protection in the EU.

Regarding the theoretical framework, this research derived from a PhD program on Human Ecology at the *Faculdade de Ciências Sociais e Humanas da Universidade Nova de Lisboa*. On the one hand, this approach to Human Ecology is sustained in the urban ecological Chicago School (Park *et al*., 1992; Wirth, 1938), which fosters an interpretation of the city as having an innovative character as human habitat, thus generating new social dynamics, and an environmental effect considered determinant on society. On the other hand, it also embeds the perspective of socially focused environmental sciences (Catton & Dunlap, 1978; Hawley, 1950) that proposes to look not only at the adaptation of human beings to environmental factors, but also at the ways in which humans impact the environment.

Two concepts are considered central in the PhD thesis underlying this work – mobilities and environment, which are allusive to the social production of movement and nature, in a context of modern abstraction of space and time (Cresswell, 2006), and interpreted on a constructivist reading of territory and environmental issues. Such concepts are considered against a background of growing affirmation of the environment as a global social problem (Yearley, 2009) and of rising assertions about a paradigm of mobilities, including but not limited to international migrations (Sheller & Urry, 2006; Urry, 2007).

Considering that neither the overall debate on mobilities and international migrations, nor environmental issues are at the focus of this paper, we propose to specify the discussion around issues of limited mobility (including detainment, detention and asylum), care and international protection, in a health ecology perspective (Honari, 2005) and considering health and migration challenges as observed from the EU arrival contexts.

A final observation regards the usage of the term 'refugee' in this paper. The concept of refugee is rather specified in international protection jurisdiction and can be distinguished from other types of international protection and from concepts of forced migrations, asylum seekers, resettlement and relocation, internally displaced persons, and other categories of displacees and persons of concern (Castles *et al.*, 2014: 221-223). Bearing in mind that the cases to be presented in the next section regard the contexts of origin, transit and arrival – both prior and after the recognition of international protection –, the term 'refugee' will be used to refer to all the considered situations, as a rather descriptive category instead of a juridical one, thus contributing to grasp repeated experiences in this type of pathways (in line with the broad field of forced migration and refugee experiences).

3. Refugees' contexts and critical events regarding health care and services

In this section, brief syntheses of the biographies, pathways and critical events (regarding health care and services) of three refugees will be presented. The three refugees escaped from

Ethiopia, between 2006 and 2007, and applied for international protection in Italy, where they arrived between 2008 and 2011. The reference to critical events regards episodes in the interviewees' biographical narratives that had a markedly negative impact on their lives; these events can be considered as part of the mobility drivers, as they provoked or contributed to the decision of rapidly changing location. These critical events were related to incidents within health services in the contexts of origin, transit and arrival: (3.1) escaping from a hospital after an aggression in an Ethiopian prison; (3.2) escaping from a hospital while imprisoned for being undocumented in Libya; and (3.3) refused chronic disease follow-up in Italy, after irregularities in the asylum process (attempt to live in other countries).

3.1 Escaping from a hospital after an aggression in an Ethiopian prison

A man from Addis Ababa, the capital city of Ethiopia, described the first critical event that happened in his country of origin. He was 23 years old when he arrived in Italy, in 2009. He didn't know any person in Italy before arriving; all the fleeing people that he knew went to Kenya. He had been arrested in 2006, in Ethiopia, for political reasons (explained further below in the text). He fled from Ethiopia and spent six months in Khartoum, Sudan, and two years in Tripoli, Libya. Only after six traumatizing attempts to cross the Mediterranean Sea, by paying approximately $1000 (around 700€) for each attempt, he was able to reach Italy and ask for political asylum, which was approved. Once in Italy, after six months waiting for his administrative process to be concluded, and thereafter lacking official financial support or family support networks in the new country, he had trouble at work, specially receiving the due payments (he worked in the same transport and handling companies of his co-nationals) to arrange accommodation, which resulted in some months of homelessness. After living in Italy for a while, he suffered a physical and verbal aggression motivated by racism, about which he won the judicial procedure against his offenders. He considered his integration in this country difficult for all the experiences so far, and aimed to reach another country for final resettlement.

To provide the context for the critical event (escaping from a hospital after an aggression in an Ethiopian prison), the interviewee participated in a political demonstration in Ethiopia against the 2006 electoral process, in which he aimed to defend the rights of Eritrean descendants in Ethiopia. His father is Eritrean, living in Ethiopia for nearly 40 years; all other family members are Ethiopians. Ethiopian authorities considered him one of the organizers of the demonstration, in a context of limited political freedom and widespread political imprisonment[5]. He was considered an Eritrean due to his father's origin (an argument that other Eritrean descendant interviewees referred as being enough to be "returned" to Eritrea or at least to have limited rights while living in Ethiopia) and detained in the Ethiopian city of Gondar for four months. While in jail, he was aggressed and tortured by the Ethiopian authorities. After one of the beatings he needed hospital assistance to amputate one finger. Once in the hospital, while recovering after the surgery, he escaped and took the route out of Ethiopia.

3.2. Escaping from a hospital while imprisoned for being undocumented in Libya

A woman from Addis Ababa was the narrator of this second critical event, passed in Libya, one of the transit countries during her flee. She was 22 years old when she arrived in Italy, in 2011. She was the first person in her family having migrated. After the killing of her father due to political issues and ethnic persecution, the interviewee was also persecuted and therefore not safe in her country of origin. She decided to ask for political asylum in a European country, which was granted after her request in Italy. Since she arrived in Italy, her main integration issue was the lack of work opportunities; whenever possible, she worked as a cook in Ethiopian and Eritrean restaurants and bars in different Italian cities.

She began her flee back in 2007, passing Sudan in a short time but having been stuck in Libya for three years. In Libya, due to the long and unforeseen stay (which surpassed all the financial support that her family back in Ethiopia could give to her) and the additional money needed to cross the Mediterranean Sea, she needed to work and the only job offer she found

---

[5] The Ethiopian context of limited political freedom has been identified in diverse editions of the yearly world reports by Human Rights Watch Organization (https://www.hrw.org/publications). For the specific case of political imprisonment, recently the Ethiopian Prime Minister affirmed the intention to release all political prisoners, in an effort to promote national reconciliation (see, for example: "Etiopía anuncia que liberará a todos sus presos políticos", El País, with the agency from Addis Ababa, 03/01/2018, available at: https://elpais.com/internacional/2018/01/03/actualidad/1514988296_790123.html.

was in cleaning and house care. Due to the public exposition characterizing this work activity, Libyan authorities identified her undocumented situation and she was detained.

During imprisonment, she needed medical assistance, although it was not possible to clearly ascertain the main reason for this need, since throughout the interview she was accompanied by another refugee who translated her silence on this issue by "being sick" and "having been attacked". Other interviewed Ethiopians and Eritreans mentioned that permanence in Libya was generally difficult for them, mostly due to their situation as undocumented migrants. Particularly in the case of working while undocumented, local authorities were seen as a threat, with some reports on corrupt practices (namely through collaboration with smugglers), as well as physical and sexual attacks, particularly towards women. Besides, all the interviewees needed to approach smugglers so as to cross the Sahara desert and the Mediterranean Sea, to then cross from the Libyan to the Italian coast. Smugglers were described as being violent and focused on the financial gains from migrants, disregarding migrants' situation and commonly abandoning them in difficult contexts. Additionally, in a context of growing Islamic extremism in the region (even though extremism was not associated by the interviewees to the majority population in the country), Ethiopians and Eritreans were associated with the Orthodox Christian religion (many had visible religious scarifications and tattoos) and consequently attacked. In this context, when the interviewee understood that she was somehow less observed by the Libyan authorities in the hospital, with limited security considering her medical condition, she escaped and soon left the country towards Italy.

3.3. Refused chronic disease follow-up in Italy after irregularities in the asylum process

A man from Addis Ababa narrated this third critical event, occurred in Italy, his arrival country in the EU. He was 23 years old when he arrived there, in 2008. Other members of his family and friends had fled to the United Arab Emirates and the United States of America. He was an Ethiopian descendant from Eritreans, a situation that granted fewer rights while living in Ethiopia and that could end up in an order to live in Eritrea, as it was referred in the first story (3.1). Additionally, considering his family's memory of many armed conflicts in Ethiopia and in Eritrea, he was one of the only three children chosen, in his family of eight siblings, to be officially declared to the Ethiopian state, in an effort to avoid that all siblings would eventually be called to military conscription. After shorter travels between Ethiopia and Eritrea, he took the route to Sudan, Libya and the Mediterranean Sea, which took him two years to complete. His longer stay was in Sudan, where he was repeatedly identified by authorities, put in jail or sent back to the Eritrean frontier. His most traumatizing memory was related to the long stays in the Sudanese part of the Sahara desert. Upon arrival, Italy conferred him humanitarian protection.

After years of unemployment or bad working and living conditions in Italy, he escaped towards France and the United Kingdom, trying to find a better life. In both countries, and in more than one flight attempt (2009 and 2012), he was found by authorities and sent back to Italy – considering that this attempt to live in a country different from the one which granted him international protection was forbidden according to the asylum regulation.

Soon after having returned from the second flight attempt, he was hospitalized in Italy, in need of a surgery. He was waiting for the surgery for a long time already, having been followed in the Italian hospital for a chronic kidney problem. Nevertheless, the surgery did not proceed; irregularities were found in his administrative process, due to his attempts to live outside of Italy, and this blocked the official medical follow-up of his chronic condition.

4. Possibilities and challenges of protection and health suggested in the refugees' pathways

The three life and mobility pathways presented in the previous section can provide us with different clues for further exploring the places and challenges of protection and health that refugees can face in their countries of origin, transit and arrival.

A first, general observation regards the political trigger factors underlying the decision to leave the country of origin. Situations of political imprisonment, political and ethnic persecution, but also the minor rights granted as Eritrean descendants, and the fear of being conscribed in military activity in a context of repeated national and international conflict and war, have been considered sound arguments for the international protection of these refugees. This type of political background is important to acknowledge while recalling the dignity and safety dimensions of the concept of protection (European Commission, 2016: 5).

All the mobilities took a long time to complete, from two to four years. Indeed, these could have ended as cases of ‘protracted refugee situations’, a term applied by UNHCR to refugee populations of 25.000 persons or more, who spend five or more years in exile. In these cases, refugees tend to remain in poor countries, which can have a limited capacity of protection and material assistance, and where there are few possibilities for work or education. Resettlement to another country would be the hope for these cases, but chances are few: projections in 2014 concluded it would take up to 80 years to resettle all the refugees in protracted exile, provided no new refugees would arrive; this can explain the spontaneous movements to seek asylum through a direct application in different potential host countries (Castles *et al.*, 2014: 229-230).

Another remark regards the traumatic experiences that the three refugees endured on their ways towards the EU. Physical aggression and risk have been observed in different settings and situations in the three pathways: in detainment structures, in the relation with smugglers and authorities, during long stays in the Sahara desert and in the attempts to cross the Mediterranean Sea. Presently, these issues can already be known to the public: they have been broadly mediatized in EU countries, associated with the political crisis that followed an unprecedented number of asylum seekers in Europe since 2015 (Vieira, 2016). Instead of echoing the risk of sensationalism through these stories, our proposal is to question how these traumatic experiences can be further considered in protection frameworks and in the health dimension of these pathways.

Focusing on the detention experiences, the first two critical events were contextualized in prisons in the country of origin and in a transit country. Different levels of aggression have been alluded by different agents within these settings, including torture and sexual attack. In both cases, refugees needed and were permitted the access to health services – hospitals – where they could be assisted; and, in both cases, these were the places through which they could escape from political- and undocumented-related confinement.

Following these cases, we can ponder health services as safer spaces and least regulated than detention structures, thus allowing to escape from detention. In such contexts where survival and freedom were threatened, health care has been seen as an only relatively important issue. In this situation, instead of having completed their treatments, refugees opted for escaping and proceeding their pathways up to the recognition of their political situation and their need of international protection.

These cases can be seen from the standpoint of international protection frameworks, namely in what regards the Common European Asylum System. On the one hand, prospects would be different if migrants would not need to follow a strategy of spontaneous multi-country asylum seeking, as referred before, if a resettlement program would actually guarantee that refugees in different arrival places could be resettled in a safe host country in a reduced amount of time. This would avoid, at least up to a certain level, traumatizing experiences of people in more vulnerable and undocumented situations, as those previously referred, who do not seek asylum in countries considered more insecure, which are a needed part of their pathways but not the final destination. On the other hand, one should also reflect on the violence reported in these detention settings and their overall context, namely regarding political imprisonment[6] and inhumane detention practices. Of particular remark is to ponder if countries of origin and transit can be considered ‘safe countries’, where asylum seekers denied international protection in the EU can be returned to, live safely and with dignity. If these basic protection conditions are not guaranteed by the principles of asylum procedure and return, the possibility of health and care seems threatened by definition.

The third critical event must be considered at a different level than the previous cases. In this case, after asylum acceptance in Italy, the country of arrival, there has been a clinical monitoring of a chronic situation. The medical follow-up was stopped when irregularities have been found in the asylum process, related to the refugee’s attempt to live in other countries. In this example we are not referring to detention situations, but rather to the limited rights of mobility of refugees.

Within the Common European Asylum System (and particularly the Dublin regime), so as to facilitate the administrative management of asylum requests, each process can only be processed in one country, possibly the country where the asylum seeker entered the EU (or a third country where he/she was sent to with a resettlement program). Once the asylum is accepted, the refugee is compelled to live in that country. This turns out to be a problem, for example, for the refugees to whom the country of arrival (or resettlement) was not their destination, or those who find it difficult to live in the host country for economic and social

---

[6] See note 3, on the announcement of the presumed end of political imprisonment in Ethiopia.

reasons (e.g. labor, income and cost of living, housing, language issues, discrimination and racism, lack of family support, among other factors).

In this third case, health services were turned into places of restricted health care and assistance, in a situation of limited rights of mobility. Observing it critically, this EU approach to refugees' international protection risks threatening other social rights – namely the right to health care – due to the focus on their administrative procedures. Furthermore, it can represent a heavier burden in individual states' health systems, considering that chronic conditions like the one in this example could later derive into acute problems demanding other types and costs of care; besides the 'waste' of previous investment in the medical follow-up of this patient, who will probably need to repeat previous steps and procedures.

5. Final remarks

In this paper, contexts (of origin, transit and arrival) and critical events regarding the use of health services by three Ethiopian refugees have been presented. These cases have been reflected against the protection principles of international asylum systems, in an effort to understand some of the possibilities and challenges faced by refugees when seeking protection and health care. Instead of reflecting directly on health care, services and systems, a critical and intersected reading of protection and health issues has been followed, along with the (re)construction of overall political frameworks that condition these experiences of asylum.

The three cases presented in this paper can also be reflected upon considering the continuous exposure to risk (including, but going beyond the risk of lacking health care) within the particularly vulnerable situations of (1) persecuted/oppressed people in the countries of origin, (2) undocumented migrants in transit countries, and (3) refugees in countries of arrival. These correspond to three repeatedly observed stages of a pathway that can be generalized to other refugee-like situations (as observed in other interviews with refugees in Italy coming from Ethiopia and Eritrea, as well as in other studies, namely in pathways from Africa to Europe. Yet, such a reflection cannot occur without acknowledging the risk to generalize 'a refugee experience'– an essentialized anthropological category, a kind of culture, identity, social world or community sharing a common condition or nature, besides sharing a common legal status (Malkki, 1995: 511). With no intention of contributing to such an essentialized construction of 'the refugee', we consider these three cases as pertinent to observe how the vulnerability associated to them can be related to the aggressiveness of social and political regimes, but also to important restrictions and barriers in the international asylum regime.

On the other hand, these critical events, and the inscription of these refugees' experiences in different phases of their paths and biographical narratives, can allow to grasp the agency of persons in refugee-like situations, thus contrasting the risk of portraying refugees as merely victims and not agents on their pathways of mobility. Besides, they can also contribute to deepen the comprehension of certain refugee-related labels while going beyond their political use – for example, surpassing the use of the 'transit migration' label for the externalization of EU migration control, a political site where it can be used as a justification for increasing border control (Düvell, 2012).

With these critical events, contextualized in health services' settings, one can grasp a meaning attributed to health services that does not correspond to 'places where health care is provided'. Instead, these places can be faced as similar to 'facilitating factors' for the continuity of these persons' spatial mobility (considering their lesser control and confinement when compared to prisons, as it was seen in the first two cases), and as 'blocking factors' for the effective integration of refugees in their countries of resettlement (in the context of limited rights of mobility for refugees in Europe and possible consequences of unauthorized mobility in health care provision, exemplified in the third case). This mismatch – between 'escape' or 'disintegration' meanings of health services for refugees, and these services' mission of providing health care – can be alluded to in the form of the question on whether 'healing or fleeing?', a kind of a metaphor for this paradoxical situation.

In the aftermath of this discussion, further attention can be put on the importance of attending to both the specificities of each national context/host country, and to the spaces and gaps in the common/international structures of refugee protection. Efforts to recognize refugees' right to health (among other social rights) must be accompanied by effective practices at each local level, but also by the challenging introduction of changes in the overall asylum system, so as to improve the global framework of refugees' protection and rights.

With the progressive shift towards a safer framing of the international asylum regime, the departing question on whether ‘healing or fleeing?’ would more possibly cease.

References

Bardin L. (2004) *Análise de conteúdo*. Lisbon: Edições 70.

Castles S., Haas H., and Miller M. (2014) *The age of migration. International population movements in the modern world*. Hampshire and New York: Palgrave Macmillan.

Catton W., and Dunlap R. (1978) “Environmental sociology: a new paradigm”. *The American Sociologist*, 13: 41-9.

Cresswell T. (2006) *On the move: Mobility in the modern western world*. London: Routledge.

Düvell F. (2012) “Transit migration: A blurred and politicised concept”. *Population, Space and Place*, 18: 415-27.

European Commission (2016) Humanitarian Protection. Improving protection outcomes to reduce risks for people in humanitarian crises. DG ECHO Thematic Policy Document n° 8, available at: http://ec.europa.eu/echo/sites/echo-site/files/staff_working_document_humanitarian_protection_052016.pdf.

EU [European Union] (2001) Council Directive 2001/55/EC of 20 July 2001 on minimum standards for giving temporary protection in the event of a mass influx of displaced persons and on measures promoting a balance of efforts between Member States in receiving such persons and bearing the consequences thereof. OJ L 212, 7.8.2001.

——— (2003) Council Directive 2003/86/EC of 22 September 2003 on the Right to Family Reunification. OJ L 251, 3.10.2003.

——— (2004) Council Directive 2004/83/EC of 29 April 2004 on minimum standards for the qualification and status of third country nationals or stateless persons as refugees or as persons who otherwise need international protection and the content of the protection granted. OJ L 304/12 of 30.04.1998.

——— (2011) Directive 2011/95/EU ofthe European Parliament and ofthe Council of 13 December 2011 on standards for the qualification of third-country nationals or stateless persons as beneficiaries of international protection, for a uniform status for refugees or for persons eligible for subsidiary protection, and for the content of the protection granted. OJ L 337, 20.12.2011.

——— (2013a) Regulation (EU) No 604/2013 of the European Parliament and of the Council of 26 June 2013 establishing the criteria and mechanisms for determining the Member State responsible for examining an application for international protection lodged in one of the Member States by a third-country national or a stateless person. OJ L 180, 29.6.2013.

——— (2013b) Regulation (EU) No 603/2013 of the European Parliament and of the Council of 26 June 2013 on the establishment of 'Eurodac' for the comparison of fingerprints for the effective application of Regulation (EU) No 604/2013 establishing the criteria and mechanisms for determining the Member State responsible for examining an application for international protection lodged in one of the Member States by a third-country national or a stateless person and on requests for the comparison with Eurodac data by Member States’ law enforcement authorities and Europol for law enforcement purposes, and amending Regulation (EU) No 1077/2011 establishing a European Agency for the operational management of large-scale IT systems in the area of freedom, security and justice. OJ L 180, 29.6.2013.

——— (2015) Council Decision (EU) 2015/1601 of 22 September 2015 establishing provisional measures in the area of international protection for the benefit of Italy and Greece. OJ L 248, 24.9.2015.

Feldman R. (2006) “Primary healthcare for refugees and asylum seekers: A review of the literature and a framework for services”. *Public Health*, 120: 809-16.

Fernandes A., Malheiros J.,and Miguel J.P. [Eds] (2007) *Health and Migration in the European Union. Challenges for health in the age of migration*. Lisbon: European Council.

Ferrarotti F. (2011) *L’empatia creatrice. Potere, autorità e formazione umana*. Rome: Armando Editore.

Hawley A. (1950) *Human ecology: a theory of community structure*. New York: Ronald Press Co.

Honari M. (2005) "Health Ecology: an introduction". In Honari M., and Boleyn T. [Eds.] *Health Ecology: Health, culture and human-environment interaction*, 1-34. London and New York: Routledge.

Malkki L. (1995) "Refugees and Exile: From 'Refugee Studies' to the National Order of Things". *Annual Review of Anthropology*, 24: 495-523.

Mladovsky P. (2011) "Migrant health policies in Europe". In Rechel B. *et al.* (Eds.) *Migration and health in the European Union*. Berkshire and New York: McGraw Hill/Open University Press.

Park R., Burgess E., and McKenzie R. (1992) *The city: Suggestions for investigation of human behavior in the urban environment*. Chicago: The University of Chicago Press.

Quivy R., and Campenhoudt L. (2008) *Manual de Investigação em Ciências Sociais*. Lisbon: Gradiva.

Sheller M., and Urry J. (2006) "The new mobilities paradigm". *Environment and Planning A*, 38: 207-26.

UN [United Nations] (1948) *Universal Declaration of Human Rights*. Paris: United Nations General Assembly.

UNHCR [United Nations High Commissioner for Refugees] (2010) *Convention and Protocol relating to the Status of Refugees*. Geneva: The UN Refugee Agency.

Urry J. (2007) *Mobilities*. Cambridge and Malden, MA: Polity.

Vieira I. (2010) *Migrações e ambiente. Imigrantes ambientais no contexto europeu*, Master Thesis (Project Work) on Human Ecology and Contemporary Social Problems, Lisbon: FCSH/NOVA.

——— (2016) The Construction of the Mediterranean Refugee Problem from the Italian Digital Press (2013-2015): Emergencies in a Territory of Mobility". *Networking Knowledge*, 9(4), available at: https://ojs.meccsa.org.uk/index.php/netknow/article/view/448.

Wirth L. (1938) "Urbanism as a way of life". In Le Gates R., and Stout F. [Eds.] (1996) *The city reader*. London and New York: Routledge.

Yearley S. (2009) *Cultures of environmentalism. Empirical studies in environmental sociology*. Hampshire and New York: Palgrave Macmillan.

Zetter R. (2014) *Protecting Forced Migrants. A State of the Art Report of Concepts, Challenges and Ways Forward*. Bern-Wabern, Federal Commission on Migration FCM.

Contemporary health care systems, local worlds and limited options: On agency and choice within Mozambican infertile couples' therapeutic navigations

Inês FARIA*
CSG-SOCIUS/ISEG - University of Lisbon

ABSTRACT: In this article I explore the intersections between Mozambican infertile couples' reproductive intentions and their local and transnational therapeutic itineraries in the quest for conception. Based on ethnographic fieldwork in Maputo, Mozambique, and carried out in and out of clinical settings, my aim is to shed light into the constraints and agencies within such therapeutic itineraries, as well as into local stakes on reproduction and infertility, particularly on how these manifest in everyday lives of women and couples. To do so I propose the concept of therapeutic navigation which pins down the social and therapeutic ways in which people manoeuvre and attune their treatment choices to socially and structurally determined fields of opportunity in order to profit the most from temporary life conjunctures and move towards a therapeutic objective – in this case, overcoming infertility and having a child.

1. Introduction[1]

In Mozambique, parenthood and reproduction are socially embedded processes. As reported elsewhere (Inhorn & van Balen, 2003), there are great expectations regarding fertility and a couple's capacity to reproduce once in a stable relationship (Faria, 2016). In this context, reproductive difficulties pose a crisis situation for couples (van Balen & Bos,

---

* Corresponding author: Inês FARIA | inesdffaria@gmail.com

[1] The Portuguese national funding agency for science and technology (FCT) supported the empirical research – under the research project PTDC/AFR/110176/2009 – and the writing and revision of this article – under the Postdoctoral fellowship UID/SOC/04521/2013. The final part of the research and the data analysis were supported by the AISSR, University of Amsterdam – under a doctoral writing fellowship. I thank all the participants in my research without whom it would have neither a subject nor a purpose. I thank as well all the people – supervisors, teachers, family, friends and colleagues - who supported my PhD research and that directly or indirectly contributed to its development.

2010), not only because they represent the inability to fulfil a personal desire, but also because of the complex relationships – with birth and in-law families, as well as in everyday life social circles – that are entangled in reproductive intentions.

In the southern region of Mozambique – where Maputo is located, the city where the research underlying this article was conducted – the predominant kinship system is patrilineal, and high reproductive expectations are often felt strongly by couples, though by women in particular (Mariano, 2014). Despite the fact that Maputo is a transforming urban context, and taking exceptions into account (Faria, 2016), women living in the city may suffer social consequences if they find themselves in an involuntarily childless relationship. These consequences may include pressure to reproduce coming from in-law families, marital tensions, and marginalization and stigmatization regarding familial and social circles (Gerrits, 1997; Inhorn & van Balen, 2003; Mariano, 2014; Faria, 2016). In this context, once a lack of fertility is suspected, women, or couples, immediately seek ways to circumvent it.

In this article, my aim is to explore the intersection between Mozambican infertile couples' reproductive intentions (Browner & Sargent, 2011) and their local and transnational therapeutic navigations in the quest for conception (Inhorn & Patrizio, 2015; Inhorn, 2014). As I will show, these treatment seeking and uptake processes reveal structural constraints (Schütz, 1972), local stakes (Kleinman, 2006) and grounded agencies. The latter are largely shaped by contextualized pragmatics and choices manifest in the everyday interactions between patients and particular healing instances (Kleinman, 1978; Granjo, 2009; Mariano, 2014).

Drawing on the development of previous studies on infertility, as well as on parenthood, motherhood and reproduction in sub-Saharan Africa, it is possible to observe an increasing focus on agency (van Dijk *et al.*, 2007), generally analyzed as part of a broader picture and often emphasizing suffering and structural violence rather than individual or collective action or navigation (Chapman, 2010; Mariano, 2014). Taking into account the importance of these perspectives in the depiction of structural inequalities (Farmer, 2004) and the prevailing trend of stratified reproduction (Ginsburg & Rapp, 1995), I came to understand how important it is, especially within a geographical site where few social studies on infertility have been conducted (Mariano, 2014; 2004; Arnaldo, 2004), to account for biographical agency and the social and medical aspects intersecting fertility treatments. To do so, I propose the concept of therapeutic navigation (Faria, 2016), which, inspired by Vigh's notion of social navigation (Vigh, 2009), pins down the ways (involving socialities and therapeutics) in which people manoeuvre and attune their treatment choices to socially and structurally determined fields of opportunity in order to profit the most from temporary life conjunctures and move towards a therapeutic objective – in this case, overcoming infertility and having a child (Faria, 2016).

Among my respondents, agencies and pragmatism were contextualized by a slowly changing transnational social matrix: a macro-social context – field of possibilities – that affected the disposition of their grounds of action – grounds of navigation – towards their parenthood project. In this sense, by moving through uncertain and transforming social environments, my respondents were acting inside structurally shaped fields of possibility (Schütz, 1972; Velho, 2003) that constrained but did not prevent them from acting. These fields of possibility were the 'spaces' in which people dwelled in order to implement their biographical project (Schütz, 1972; Velho, 2003) of having a child, and the differences between them were largely determined by people's different backgrounds and social class.

My respondents were always acting in pursuit of the realization of a reproductive intention, and akin to the slowly changing transnational and local arenas that they inhabited, their projects also transformed. They were attuned to momentary circumstances (Velho, 2009; Vigh, 2003) inevitably connected to complex healing contexts that can be looked at through the lens of the 'medicoscape'. The concept of medicoscape emphasizes the interrelations between individuals, organizations, practices and artefacts within particular national and transnational contexts of agency framed by different policies, powers and healing regimes (Dilger *et al*., 2012; Hörbst & Wolf, 2014: 184). In this sense, while relating to broader global and local contemporary economic and social states of affairs, as well as to national contexts and to the fluidity that these matrixes encompass, it is possible to assert that Mozambican infertile couples' therapeutic navigations can be analysed as agency processes, where different localized vectors, entangled with different medicoscapes, intersect. The latter include therapeutics as well as local stakes regarding reproduction and healing that interact with fertility treatments and are unveiled in patients' therapeutic choices and navigations.

The research underlying this article covered mainly biomedical infertility treatment seeking and uptake. Nevertheless, through patients' accounts, both traditional and biomedical healing instances came to be included, both in the research and in this article, namely traditional healing, biomedical healing at home (in Maputo) in the public and private sector, and biomedical healing abroad in South Africa's private sector fertility clinics close to the Mozambican border (Faria, 2016). The medicoscapes that Mozambican couples travelled through were thus transnational ones, including Mozambique (Maputo) and South Africa – two countries with different health care systems and unequal access to health care resources (WHO, 2014a; 2014b).

Despite the fact that both Mozambique and South Africa struggle to provide medical coverage for their populations, Mozambique has significantly fewer resources and depends much more on foreign cooperation programs in many health care provision areas (Faria, 2016; MISAU, 2012). In Maputo, the private health care sector is not as developed as in South Africa. Despite some recent growth, fed mainly by international partnerships, the private health care sector in Mozambique is yet to provide high-tech medical procedures, including assisted reproduction technologies (ARTs) (Gerrits & Shaw, 2010; Mariano, 2014; Faria, 2016; 2015). In Maputo, at the time of my research, there was only one clinic providing selected assisted reproduction treatments (in-vitro fertilization – IVF, but not intracytoplasmic sperm injection – ICSI) to infertile couples, treatments which were unavailable in the public hospital. The private health care sector in South Africa is, by contrast, well developed and clinics in the country not only provide high-tech medical and surgical procedures – including state-of-the-art ARTs – but they also target medical travellers (Scheper-Hughes, 2011).

As I will show, my respondents' therapeutic navigations marked a point of intersection of many different aspects. Patients' therapeutic itineraries departed from a country with deficient biomedical treatment provision in general – and in terms of infertility treatment in particular – and with a poorly resourced and rundown public health care sector. In this context, for those who could afford it, they could access the growing private health care sector in the region, which included in its service provision state-of-the-art ARTs in South African clinics. Aside from public health providers in Maputo and private health providers in Maputo and South African cities close to the border, traditional healing was also part of the medicoscapes framing my respondents' therapeutic navigations. While relating to each of these healing universes, their agency was influenced by their own ideas about kinship, parenthood and reproduction, and furthermore by their economic power, which enabled or restrained their access to certain modalities of infertility care.

My respondents' therapeutic navigations included different healing regimes and kinds of medical interactions (between patients and institutions, or simply between patients and practitioners or healers), and materialized in dissimilar medicoscapes. While unfolding in such complex personal and contextual matrixes, Mozambican couples' quests for fertility were characterized by certain freedoms framed by particular life configurations – in particular, the limitations and possibilities to choose treatments and the activeness of patients in their interactions with chosen healing instances.

Below, I introduce my research methods. The third section then comprises a description of the sites where my respondents looked for infertility care – the public hospital, the private clinic in Maputo, and private clinics in South Africa. Following the descriptions of the medical sites, I present two short examples of therapeutic navigations for infertility treatment. Finally, in the last section, there is a discussion of therapeutic navigations and the dynamics of constraints versus freedom of choice in the particular medicoscapes and moral worlds (Kleinman, 2006) through and in which Mozambican infertile women and men moved and dwelled.

2. Methods

This article is based on a socio-anthropological study about Mozambican infertile women's and couples' infertility treatment seeking and uptake processes in Mozambique and South Africa. The research underlying the article was based in Maputo, Mozambique, and was conducted over a period of 9 months in 2013. It included periods of ethnographic fieldwork in one private fertility clinic in the city – the only one providing ARTs in the country at that moment – and one public hospital. A total of two Mozambican practitioners and 25 female infertility treatment patients (previous or current) were interviewed. The interviews were audio recorded upon permission and were transcribed verbatim during and after the fieldwork period. Adding to this, periods of participant observation in clinical sites were also carried out and registered. Despite the limited number of respondents, the sample was consistent enough to function as a basis for socio-anthropological reflections on various aspects of medical interactions from the perspective of patients attending public sector fertility consultations, as well as those resorting to ARTs in the private sector, both in Maputo and through reproductive travel to South Africa. All data were analysed using a qualitative analysis software and in comparison with the reviewed literature.

The 25 interviewed women had undergone fertility treatments between their early 20s and mid-40s. Women attending the public hospital and private clinic in Maputo were recruited at the clinical sites themselves. Women who had engaged in reproductive travel in South Africa were recruited through snowball sampling as well as in the private clinic in Maputo, where I met women who had previously engaged in reproductive travel. Aside from the clinical sites in Maputo, the research covered three clinics in South African cities close to the Mozambican border – Pretoria, Nelspruit and Johannesburg – which Mozambican couples attended.

The research focused on the phases of treatment in which women or couples were attending biomedical facilities. Traditional healers were therefore not part of the study's focus or sample, though resort to traditional healing was accounted for in the research and is included in this article, as the cases below will show, since it was a common therapeutic option for women or couples before, during or in between biomedical treatments, independent of their socio-economic background.

3. Medicoscapes on the ground: On public and private infertility health care provision in Mozambique and in private South African clinics

In this section, I will present contextualized ethnographic descriptions of (some of) the biomedical sites that my respondents attended throughout their quests to overcome infertility. Descriptions include the public hospital and the private clinic where I did fieldwork in Maputo, as well as accounts of South African clinics. The characterization of the clinical sites in Maputo is based on participant observation, and the characterization of South African clinics is partly based on observation (made in visits) but mostly on patients' descriptions of clinical sites and of their experiences within such spaces.

3.1. Maputo: The public hospital infertility consultation

The first time I visited a public health facility in Maputo, I had scheduled a meeting close to the maternity ward operation room of the city’s main hospital. I entered the big modernist building, that looked like a late 1950s or early 1960s construction, and went up a couple of flights of stairs to the 4th floor, where the maternity ward was located. Once I got there, I saw a busy health care assistant cleaning up a massive quantity of water off the worn out blue linoleum floor of the ward. As I observed her and the overall space, I could not help noticing the missing pieces of the soaked old floor, and the stains of humidity expanding along the ceilings and walls. The ward was full and occasionally a hospital bed passed by with a patient lying on it. Doctors were also running around the corridors. Although I had an idea of how different public and private health facilities could be, it was only then, while waiting for my meeting, that I faced empirically the overwhelming dimension of the resource gap between the two sectors.

In the hospital where I did my fieldwork, the working and consultation rooms were fair. The building was old, hot and had a visible lack of maintenance, but however frail the general infrastructures might have been, everything in the surroundings of the infertility consultation room looked well maintained and organized. Infertility consultations always took place in the same rooms, separated from the waiting patients by a closed wooden door; this door was occasionally opened, a woman would be called inside, and the door would be closed again behind her. Once inside, there were three open consultation cubicles facing a longitudinal pathway where patients and doctors circulated. There was one doctor sitting behind a desk in each one of these open rooms and a chair for the patient on the opposite side of the desk. To get to the frequently used scanning machine, patients had to cross other consultation cubicles. The director of the gynaecology service and infertility consultation – Dr. Macamo – was always running around supervising and attending to patients. I never saw him sit long at any of the desks; rather, he moved around asking and answering questions.

In these busy rooms, practitioners had many patients to attend to, which, as happens in many big hospitals, meant that the consultations and recommendations for treatment were quick, with little time for extensive questions. Adding to the fast pace of the consultations, the language spoken was Portuguese, which some patients did not speak fluently. This kind of organization for the infertility consultations was likely to influence patients’ perceptions of both the hospital and the treatment. They commonly perceived biomedicine as a modern[2] institution, but frequently took treatments as a series of steps to be accomplished and paperwork to be processed. In this rational medicalized context, patients frequently sought support from one another. Through networking with peers – other infertile women – and by sharing their experiences for mutual support, my respondents informally improved their knowledge about medical diagnoses and treatments to a certain extent. When in doubt, women related more closely to nurses and other medical staff than to doctors. They would pose more questions about treatment procedures and steps to these members of the medical staff than to doctors themselves. Occasionally – if the health professional could – these side interactions with medical staff would be in dialect (Ronga or Shangana), and they normally took place on the other side of the abovementioned wooden door, when nurses or staff came outside to call another patient in or to forward documents to another hospital department. The women waiting outside would then ask, sometimes simultaneously, their questions about the next (bureaucratic or therapeutic) step of their treatment.

In the public sector, patients were diagnosed by gynaecological exam, scan and pre-scheduled diagnosis, or, if necessary, corrective laparoscopy. Blood testing and other exams were prescribed and, according to my respondents, outsourced. As Dr. Macamo told me, although the conditions to treat female hormonal causes of infertility existed in the hospital, it was difficult to deal with cases of masculine or mechanical (mainly tubal) infertility, for which IVF was likely to be the most appropriate option in therapeutic terms. For cases of suspected hormonal infertility – among which the most common were ovarian cysts or uterine fibroids, which was the case for some of the women I encountered – hormonal medication would be prescribed as an attempt to reduce obstructions (such as cysts or fibroids) in the women's reproductive system.

For mechanical causes, hormonal medication is unlikely to work, thus women in the public sector were left with the only option of corrective laparoscopic surgery and had no access to ARTs. For male infertility, the process was complicated. Although diagnostic means for sperm examination were available[3], when facing a situation of male factor

---

[2] This perception of modernity regards the progressive post-colonial socialist ideology advocated by FRELIMO. For more information on notions of modernity in Mozambique, see (Arnfred, 2011; Cavallo, 2013; Faria, 2016).

[3] In the public sector, diagnostic sperm examination normally took place in exam laboratories located outside of the hospitals.

infertility, doctors frequently did not have enough resources to treat it with medication (as medication stocks in the hospital's pharmacy were often poor), or to circumvent it with other suitable technical procedures (such as ARTs). According to Dr. Macamo, in (rare) cases of couples where the sperm quality could be enhanced with medication (e.g. mild oligospermia), and where the female reproductive system was in order, intra-cervical insemination with the husband's sperm was possible, but intra-uterine fertilization was not. More complicated cases would be discussed by the medical team in the quest for the best available option. In the public hospital, treatments and consultations were cheaper than in the private sector, and came to 1 MZN (0.01 EUR) per appointment.

Among my respondents using the public sector biomedical infertility services, therapeutic impairments went beyond the material and physical aspects of healing. Adding to the hospital's scarcity of therapeutic resources to treat non-hormonal or male infertility causes, men were frequently absent from the infertility consultations and marital instability among infertile couples was common. In such situations, in order to continue their (frequently socially demanded) quests for parenthood, interaction with biomedicine required (but also enabled) women to challenge the same matrix of values that likely triggered their treatment seeking to begin with (Faria, 2016). By contrast, for middle class and cosmopolitan women using private sector infertility care, including ARTs, male participation in treatment was not as challenging. In these cases, as described below, adding to the patients' social and couple disposition to uptake treatment together, there were more and better resources for diagnosis and treatment procedures than in the public hospital.

3.2. Maputo: Infertility consultations in the private clinic

In Maputo, private sector infertility consultations took place in a clinic where different areas of medical expertise were provided. As I approached the old building in a busy corner of the city's downtown area, the clinic would almost go unnoticed if it was not for the sign above the main entrance, located in a gallery where street sellers and others offered their services. Once inside the automatic glass door, I followed the stairs up to the first floor where the gynaecology rooms were located. There, in a very simple waiting room that at the time was lacking air conditioning (something that all of the other clinics I visited had), some women were already waiting their turn, watching television while nurses passed back and forth and the receptionist's phone rang non-stop. After a while the doctor arrived, the faces of the waiting patients lit up, and consultations began. The average time of each consultation was higher than in the public hospital, and despite the long waiting times, these were still shorter than in the public sector[4]. Although the equipment did not look as new as in other private health facilities I visited, both in Maputo and South Africa, my overall impression of this clinic was that it worked swiftly and did not lack any essential materials or staff to provide patients with the diagnosis and healing procedures they needed. However, due to the scarcity of health professionals, in the case of an emergency in the public hospital, the doctor could eventually have to interrupt consultations and attend to such occurrences, after which consultations would be resumed if possible.

The women in the waiting room would be called one by one into the consultation rooms by a nurse, and the doctor took his time with each one of them – there was enough time for doubts and questions in each consultation, and to explain the medication prescribed and what it was for (something that did not happen as often in the public hospital or even in the South African fertility clinics). In the private clinic in Maputo, the consultation style and conditions as well as the patients' behaviour echoed Lupton's (1997) idea of the patient-client: empowered patients who can make their own choices about important steps in their treatment. After their consultations, patients were forwarded to the reception desk to pay for the appointment and schedule further consultations, exams or ART procedures. The costs of treatment in the clinic were 1,500 MZN (21 EUR) per consultation and 60,000 MZN (828 EUR) per IVF cycle, with exams and medications added to these costs. Among the patients in the private clinic that I had contact with, husbands were generally cooperative and the couples acted as a team in the pursuit and uptake of treatment.

This clinic had its own laboratory for assisted reproduction techniques and provided all ART treatments with the exception of ICSI (Mausse *et al.*, 2014), which during the time of my fieldwork was only being provided in South African clinics. Although more economical than the treatments in South African fertility clinics, the prices in this clinic were still

---

[4] The average waiting time for an appointment at this clinic was slightly unpredictable as the doctor also had to attend to emergencies in the public sector and thus her presence in the clinic could be delayed or suddenly interrupted. Nevertheless, once the doctor started consultations, the average waiting time was about 30 minutes to one hour.

considerably more expensive than in the public hospital. The doctors working in the private infertility clinic in Maputo had been eager to establish the space and to offer an almost full range of ART treatments, and step by step it seemed as if they were succeeding. However, they faced a number of difficulties, including, according to Dr. Macamo, the local instability of resource access, financial flows and compromised sponsorships. Furthermore, the difficulties in forming international partnerships made the process of establishing a state-of-the-art ART clinic time-consuming.

Despite being the best possible option available in the city of Maputo and in Mozambique at large, and despite providing patient-oriented treatment, the private clinic in Maputo was at the time of my study yet to attain the technological level of many of its South African peers. Nevertheless, many women and couples preferred to pursue treatment in their own country and considered reproductive travel only as a last option. Others, by contrast, opted for reproductive travel as a first option, and would consider treatment at home in Mozambique only in case all else failed.

3.3. South Africa: Sites of reproductive travel

For couples undertaking reproductive travel to South African fertility clinics, therapeutic itineraries were geographically longer and economically more demanding, but offered all of the available state-of-the-art procedures to circumvent infertility and achieve a pregnancy. Yet even for these travelling patients, where all of the resources and diagnostic and treatment means were available, the chances of success were still small (Vayena *et al.*, 2002)[5]. Dr. Macamo, while talking about travelling patients, mentioned how success rates in state-of-the-art clinics are still only around 30%.

The South African private fertility clinics I visited looked different from both the public hospital and the private clinic in Maputo. They had comfortable and air conditioned waiting rooms, more than one consultation room in use and, as speciality clinics, these sites frequently had fertility information pamphlets lying around in the common spaces. Despite being private sector institutions, however, the way in which my respondents described the

---

[5] Assisted reproduction success rates vary widely according to a woman's age and fertility problems. However, even for women of reproductive age and/or with apparently simple fertility problems, for whom IVF would most likely be successful, treatment outcomes are never predictable and average success rates are never high.

workings of the fertility clinics resembled much more the functioning of a public hospital, with short meetings (less than 10 minutes) between patients and doctors, and with nurses taking care of most of the social part of the treatment.

Several of my informants mentioned how these sites were quite business-oriented and how doctors even attended to two different couples at a time, in quick consultations where the latter interacted mostly with nurses. Teresa was a mother of IVF twins, together with her husband Mohammed. They had sought treatment in a fertility clinic in Johannesburg, where they had reached a successful pregnancy. While explaining to me her experience, she told me about the organization of the fertility clinic's consultation and medical staff:

> *You know what the doctors do? They have two offices, you are in one of those, and it's the nurse that tells you everything. The doctor is all 'Oh yes, oh we can do this, we can do…' whatever he says. And I only saw the nurse looking at him. Then there is another door, and he goes and checks on the other patient waiting in the other room. So, he [the doctor] is walking from office to office. He stays with you five or six minutes, 10 tops!*

Unlike in the private clinic in Maputo, where consultations were slightly longer and the doctor was the one doing most of the talking with the patients, in the infertility clinics in South Africa that my informants attended, the situation was often as Teresa depicted. According to their accounts, medical interactions in these sites were short, rational and cold. Doctors attending couples in two different consultation rooms simultaneously was something that only happened (according to my respondents) in one clinic, but certainly all of them mentioned the general lack of contact with the doctors and the business-like structure of the clinics. In these sites, the treatment cost for a simple IVF cycle was 35,000 R (2,136 EUR). This was without exams and consultation, which ranged from 700 R (43 EUR) to 2,800 R (171 EUR) for the former, and 1,000 R (62,31 EUR) for the latter. Adding to institutional and other cost-related obstacles, for patients undergoing reproductive travel there was yet another difficulty: consultations were held in English, a language that several of my informants, especially the less well-travelled women, were not fluent in.

In spite of the generally cold and impersonal functioning of the fertility clinics in South Africa, they were equipped with state-of-the-art facilities and experts and were the clinical sites where the most ART options were available. These ranged from basic insemination with the husband’s sperm to surgical procedures, all sorts of IVF (including ICSI), use of donor gametes and surrogacy. Therefore, despite repeatedly mentioning how cold and profit-oriented these sites were, many women/couples relied on them as their best possible option for conception with biomedical help. Like the couples attending the private clinic in Maputo, most of my respondents undertaking reproductive travel sought treatment as a couple and, with few exceptions, men were supportive of their wives.

As seen in the descriptions above, the health care provision contexts involved in this research, and in Mozambican women’s and couples’ therapeutic navigations, were different in terms of both resources and the medical interactions they engendered. These contexts form part of broader medicoscapes that include international health care agendas and local priorities, particular legal frameworks and policies, and modes of operation (Faria, 2016; WHO, 2014a; 2014b; MISAU, 2012), all of which affect local contexts of health care provision. Infertility care is particularly affected, as it is not considered a priority for the region under study, either at the national or international level (ICPD, 2014).

Below, I will explore two particular therapeutic trajectories framed by these conjunctures, and which reveal the possible agencies and therapeutic choices within them: the case of Candida, a woman who resorted to traditional and biomedical healing in the public hospital, and Camila and Felisberto, a couple that was attending the private clinic in Maputo when we met and were considering attempting ARTs in South Africa in case the treatment at home was unsuccessful.

4. Choosing and constrained freedoms: Navigating unequal medicoscapes

Mozambican women’s and couples’ therapeutic navigations in the quest to overcome infertility normally started with homemade concoctions, often recommended to women by their mothers or sisters. After these first steps, they then resorted to traditional healing and/or biomedical treatments. Treatment choices were constrained by economic as well as conjuncture factors. The latter were normally related to expectations of treatment efficacy and costs, but also involved negotiations over the local stakes regarding reproduction and infertility (Kleinman, 2006), where choice also responded to a desire for secrecy about reproductive impairments, normally on the part of women, for whom infertility, independent of its origin (i.e. male or female caused infertility), could bring about tensions or social hardships.

4.1. Navigating choices to overcome infertility: between traditional healing and biomedicine

Candida and I met at the public hospital. She was 36 years old. Despite having a teenage daughter she wanted to have a child with her current husband. This man was not her daughter's father, from whom she had separated years before, and they wanted to consummate the relationship by starting a family. Facing the absence of a wanted pregnancy, she had decided to look for help. Her therapeutic pathway had begun more than 6 years before we met. Having started by looking for a traditional cure to her reproductive impairments, Candida navigated multiple forms of healing all in the quest for a child. During our conversation she explained:

> *Yes, yes. Traditionally we make tries, we go there [to the healer] and we take, take [medicines], but nothing (...) I tried different times (...) we take some liquids of roots that we boil and drink, and also a washing preparation. I took it but I am tired (...). Until now I only did traditional [treatments]. I had tried to start here [at the public hospital] already in 2008, but there were doctor transfers, and with all the confusion I ended up not knowing where to buy my medicines, because I needed a prescription. So I stopped coming to the hospital then. (...) When I was going to the traditional healer, I did not come here. Because I thought I would be intoxicated with a medicine from here, another from there (...) It would be a mess and I would end up not knowing which medicine was not working, so I take my time in each. If it is traditional [it] is that part, if it is the hospital [it] is another.*

As seen in the above quote, Candida's choice was affected by being worn out with the preparation and taking of traditional medication. However, even after deciding to pursue biomedical care for infertility, Candida was faced with the change of medical teams that left her disoriented and contributed to her dropping out of her first treatment (Gerrits, 1997; Gerrits & Shaw, 2010). Nevertheless, she had eventually returned to the public hospital and had stayed in treatment, at least at the point when we met. She explained how her decision to stick to biomedicine was not only influenced by being tired of traditional remedies, but also by issues of cost and trust.

> *Here you pay nothing. While in the traditional healer [curandeiro] you pay and spend a lot of money for nothing. One consultation is 750 MZN [10.30 EUR], without counting the medicines he tells you to buy. Here I don't pay anything besides 1 MZN [0.01 EUR] for the consultation ticket. (...) I leave home at 5 [am] and at 6 I am here, and the appointments start at 7:30.*

Candida's case shows how, among other factors, there were everyday life pragmatics connected to infertility treatment choice. In her case, besides being tired of traditional remedies, biomedicine was also chosen for economic reasons. The fact that a medical appointment was a lot cheaper than any other kind of healer made it an appealing solution for infertility, particularly in a situation where she was funding treatment alone. Furthermore, it shows how trust in the treatment provider and the methods' success is also an issue when it comes to therapeutic choice (Rodrigues, 2016).

My respondents' switch to biomedical health care was often due to experiences with ineffective traditional treatments, to the degree of social exposure that the traditional medicine involved, to issues of (dis)trust in the healers (Faria, 2016; Pfeiffer, 2002), and finally to treatment costs. As with most women in the public hospital, Candida funded the consultations herself. In the public sector, it was common for women to uptake treatment alone as far as possible. This was because men did not usually contribute to treatment unless they were willing to pursue it together with their wives, which was not common among the women I met in the public hospital. In this context, and despite being economically dependent on their husbands, the low cost of the public sector consultations made it accessible for women without incurring catastrophic expenditures. Public hospital infertility consultations required a symbolic contribution, and despite the long waiting times, it was considered a fruitful attempt to circumvent infertility. Even in cases where women like Candida needed to travel in the chapa (collective transport vans) for one hour or more to get to the hospital, they did not seem greatly bothered by the transportation times and fees, while seeing it in the light of possible treatment success – an expectation that most of my respondents maintained, mainly through word-of-mouth accounts of the positive outcomes of modern biomedical treatments. Nevertheless, it was common for women, or couples, to hop between biomedical and traditional healing. Candida's case shows that movement as well. If by the time I met them in the hospital or clinics my respondents had chosen biomedicine, this was the case for the time being, and in future life configurations they could decide to change therapeutic options once again.

For my respondents, and at the time and place we met, biomedicine was considered rather convenient as a treatment option. In this sense, despite being further away from most of my respondents' homes than local traditional healers (Granjo, 2009; MISAU, 2012; Mariano, 2014), they saw biomedical infertility treatment as a more reliable therapeutic option in terms of medication, cost-effectiveness, reliability and anonymity.

Among public sector users, the options were fewer than for private sector users, and despite being able to choose, they had restricted fields of possibility in which to do so. Nevertheless, they still navigated their options for conception by attuning their projects to their fields of possibility (Schütz, 1972; Velho, 2003).

4.2. Navigating choices to overcome infertility: Transnational biomedical arenas and technology

Camila was attending the private infertility clinic in Maputo. When we met she had been together with her husband, Felisberto, for 10 years, but it was only after five years of being together that, upon deciding to get married and build a family, their lives were hampered by infertility. They were a well-off couple living in Maputo, with enough resources to attend the private infertility clinic in the city and to consider a potential future visit to a South African fertility clinic in case their current treatment failed.

It was the fact that she did not get pregnant that triggered Camila and Felisberto's quest for both traditional and biomedical healing options, and various sorts of herbal and pharmaceutical medicines. At different biomedical appointments, doctors told Camila that she was fine and that her infertility was likely to be hormonal. Felisberto, an attentive husband who cooperated in every step of the different treatments, was also healthy and medical doctors could not find any problems with his reproductive system. The couple kept looking for a solution during the following five years of marriage, and by the time we met they were still in treatment. Despite the absence of a definitive diagnosis, they kept pursuing their family-making project. However, by the time we met, Camila had visible proof that something was not normal with her reproductive system. As she told me herself, she was constantly bleeding: “I don’t have any pain, and it is not a lot of bleeding, but still, when I take traditional remedies and clinic medication it doesn’t stop. (…) How will I ever get pregnant with this bleeding?”[6].

After different attempts by Camila and Felisberto to fulfil their desire for a pregnancy through different healing modalities, they decided to opt for treatment in the private sector, which they could afford. Since it was available in their own country, they decided to give it a try in the private clinic in Maputo and to leave the option of reproductive travel open in the event of an unsuccessful treatment at home. Camila explained:

> *The hypothesis, the last one I had was here. After, if I see it doesn’t work, I will look [for treatment] somewhere else. My hypothesis is also that maybe later we can look for an artificial treatment [ARTs]. People always say that in South Africa they have it, so it was that what we wanted. The last, really last [option] is that one, after this, it will be there.*

Camila’s expectations were high, as this would be her last home-based attempt to circumvent her infertility. The bleeding worried her, but still she relied on biomedicine and assisted reproduction as the best accessible means to attain her objective. Like many other women, after uncertain therapeutic itineraries aimed at achieving pregnancy, Camila longed for a positive result, or at least for a hope-giving diagnosis, where somebody would tell her exactly what had to be fixed in order to make her and Felisberto parents at last.

Being a parent was perceived differently by people from different social backgrounds. For some of my better-off informants like Camila and Felisberto, parenthood was a strong desire, while for others, especially women from more traditional backgrounds, reproduction, although equally desired, was also a social requirement. Nevertheless, expectations about diagnosis and a positive outcome of infertility treatment were equally high. However

---

[6] Idioms of physical affliction normally include reference to bleeding, blockage or pain. Although attending biomedical health facilities, women’s descriptions were much more focused on bodily sensations than on biomedical diagnosis, and if they spoke about the latter, they normally related it to the sensation that had led them to the doctor.

elevated, these expectations were frequently disrupted throughout winding healing pathways, materializing in dissonant medicoscapes and involving uncertain clinical turns. In many cases, there were limitations to the treatments available, and each couple's situation was specific. Even when they had the possibility to go abroad, state-of-the-art ARTs could be unable to solve the problem. For Camila and Felisberto, this was yet to be confirmed.

Camila and Felisberto's case shows that beyond the possibility to choose to use ARTs, there was yet another possibility: opting whether to engage in reproductive travel or to pursue ART treatment at home. For women like Candida, both of these options were very unlikely and the public hospital would probably be the final stop in their biomedical therapeutic navigations. Having local, transnational or hybrid[7] therapeutic itineraries, women's hopes and expectations were managed according to each clinical site and the respective treatment opportunities[8]. Moreover, the combination and/or changing of clinics was used as a rupture point along an unsuccessful therapeutic pathway, in order to start a 'fresh' one and thus reset previously disrupted hopes. By changing or coordinating clinical options, women restored (at least partly) their ideas of possible conception. Although aspiring for the same result, lower class women did not have access to ARTs, and therefore their scope of possibility was narrower than for middle class and cosmopolitan women attending private clinics at home and abroad. For all of these women with an identical objective of having a child, the means to attain this objective were conditioned by their socio-economic status (Ginsburg & Rapp, 1995; Velho, 2003; Vigh, 2009).

5. Discussion

Within Maputo, and between Mozambique and South Africa, public and private sector infertility services were very different. The public hospital in Maputo tried to help as many women as possible at a very low cost, making infertility treatments easily available to women or couples with limited resources. The treatment options at this site were, however, very

---

[7] By hybrid therapeutic itineraries, I mean the simultaneous combination of infertility care and treatment in South Africa and further consultation in infertility clinics at home.

[8] From basic hormonal therapy to the full availability of ARTs, including intracytoplasmic sperm injection and surrogacy. Donor gametes were not normally sought after, as for most of my respondents, especially men, genetic relatedness was very important in their parenthood project.

limited, and no ARTs, not even IVF, were available. In this way, when women accessed biomedical infertility care in the public hospital, their choices were restricted to corrective, hormonal and basic infertility treatments. By contrast, private sector infertility services offered a range of ART options; in Maputo, this included basic IUI and IVF, and in South Africa all possible ART options were available, including ICSI and surrogacy.

The two cases provided above shed light on Mozambican women's and couples' therapeutic navigations through unequal healing landscapes, and their underlying motivations and expectations. The examples also depict the choices that women or couples made according to the amount (and use) of social connections and economic capital that they could draw upon in their quest for a child. Women's and couples' therapeutic navigations towards reproduction entailed overcoming various personal and conjuncture obstacles. If the economic capacity of a couple did not determine the ways in which they perceived infertility, it did determine to a great extent the kind of solutions that they had access to.

While analysing the therapeutic itineraries of people from various socio-economic backgrounds to overcome couple infertility, I realized that the main class-based difference – which did not include exceptions, incongruities or changes – was that of therapeutic choice. This resonates with other authors' accounts of inequalities in access to infertility treatments (Inhorn & van Balen, 2003; Inhorn & Patrizio, 2015) and aligns with Ginsburg and Rapp's (1995) notion of stratified reproduction. For my respondents, treatment choice and navigated medicoscapes (Hörbst & Wolf, 2014) were to a great extent class-based: wealthier women or couples could resort to traditional healing, to the private fertility clinic in Maputo that provided some ARTs, and/or to reproductive travel to South African private fertility clinics offering all ARTs. Poorer women could only resort to traditional healing and to the public health care sector in Maputo, which provided mainly corrective treatments and no ARTs.

These differences affected women's and couples' therapeutic navigations and thus determined the broader field of possibility that they could access to implement their parenthood projects (Schütz, 1972; Velho, 2003) through infertility treatments. Despite the low success rates of ARTs, seeking a pregnancy without them further reduced the possibility of success. Notwithstanding the existing economic inequalities affecting access to treatment (especially regarding access to private sector ARTs), within the therapeutic fields of possibility that my respondents could access, they used various temporary therapeutic options. This meant that women or couples could resort to healing pluralism, in the sense that they used traditional or biomedical treatments at different stages of their therapeutic navigations (Kleinman, 1978). Furthermore, when attending the private sector, they could choose different clinical sites both in and beyond Mozambique.

If social class determined to a great extent the therapeutic terrains through which my respondents navigated, it did not fully affect their treatment choices in each specific field of possibility. Depending on their economic capacities in terms of accessing more or less high-tech infertility treatments, women or couples used all of the resources and options within their reach in their therapeutic navigations. The conditions that enabled some Mozambican women with the funding capacity to attend private clinics for infertility care were not available to everyone. In this context, economic capital as well as social connections – such as transnational informal social networks, supportive family networks or other infertile women who provided advice – were important tools in shaping women's or couples' treatment seeking trajectories (Faria, 2016).

With their therapeutic trajectories departing from within an overall fluid society, where many things transform quickly and where people's everyday lives intersect with various local and global ideas, practices and institutions, my respondents' stories encompassed both challenges and mutations; challenges coming from hampered parenthood projects, and mutations coming from the non-linear paths that were their quests for parenthood. In fact, change and flexibility were a constant in my respondents' navigations towards conception. From ideas regarding gender to notions about womanhood, parenthood, healing and family making, my respondents were constantly attuning their parenthood projects to the possibilities of the context in which they were trying to realize it. In this way, while attempting to overcome an affliction, their strategic navigations in a transforming urban matrix were flexible, yet also represented vectors of broader contextual transformation (Faria, 2016; 2015). In this sense, Mozambican women's and couples' therapeutic quests to overcome infertility departed from particular moral worlds (Kleinman, 2006), where local values and practices are often (re)examined according to particular situations – in this case, living in an infertile relationship. Taking into account the familial, marital and social dimensions involved in reproductive intentions and parenthood expectations, my respondents were looking for a way to have a child, while simultaneously challenging and negotiating local socialities and values in the process.

Freedom within contemporary health care systems is constrained, not only due to personal financial and informational asymmetries, but also because of national health care provision contexts. These create structural constraints in terms of access to treatments – in this case, infertility treatments and ARTs. However, even within constrained fields of possibility (Schütz, 1972), people navigate their best options at any given moment, and thus often change their therapeutic choices and pathways according to what seems to be more a suitable treatment in a given situation. This is done through a process of reasoning that involves various factors, including family relations, religious background, treatment experiences and word-of-mouth stories of success. So even regarding major structural and national inequalities, there are always contextualized pragmatics and choices taking place within therapeutic navigations, and these stem from the intersection between intimate and non-intimate life conjunctures for patients and their experiences of interaction with medical systems.

Mozambican infertile women's and couples' therapeutic navigations shed light on the strategies used and the obstacles faced in fulfilling a reproductive intention, and on how people try to overcome these obstacles by taking advantage of constrained freedoms.

References

Arnaldo C. (2004) "Regional Fertility Trends in Mozambique". *Journal of Population Research*, 21(2): 177-97.

Arnfred S. (2011) *Sexuality & Gender Politics in Mozambique: Rethinking Gender in Africa*. London: Boydell & Brewer.

Browner C., and Sargent J. (2011) *Reproduction, Globalization and the State: new theoretical and ethnographic perspectives*. Durham: Duke University Press.

Cavallo G. (2013) *Curar o passado: mulheres, espíritos e "caminhos fechados" nas igrejas Zione em Maputo, Moçambique*. PhD Thesis defended at Institute of Social Sciences, University of Lisbon, available at: http://repositorio.ul.pt/handle/10451/9897.

Chapman R. (2010) *Family Secrets: Risking Reproduction in Central Mozambique*. Nashville: Vanderbilt University Press.

Dilger H., Kane A., and Langwick S. [Eds.] (2012) *Transnational Medicine, Mobile Experts: Globalization, Health and Power In And Beyond Africa*. Bloomington: Indiana University Press.

Faria I. (2015) “Kinship Reimagined: assisted reproduction and parenthood in Mozambique”. In Koroloke C., Myong L., Adrian S. and Tjørnøj-Thomsen T. [Eds.] *Critical Kinship Studies*. London: Rowan & Littlefield International.

——— (2016)*Therapeutic Navigations: national and transnational quests for fertility among Mozambican women and men*. PhD Thesis defended at Amsterdam Institute for Social Science Research, University of Amsterdam, available at: https://pure.uva.nl/ws/files/2810028/176848_11_Appendices.pdf.

Farmer P. (2004) ”An Anthropology of Structural Violence”. *Current Anthropology*, 45(3): 305-25.

Gerrits T. (1997) ”Social and cultural aspects of infertility in Mozambique”. *Patient Education and Counselling*, 31: 39-48.

Gerrits T., and Shaw M. (2010) “Biomedical Infertility Care in Sub-Saharan Africa: a social science review of current practices, experiences and view points”. *Facts, Views and Vision in ObGyn*, 2(3): 194-207.

Ginsburg F., and Rapp R. (1995) *Conceiving the New World Order: the global politics of reproduction*. Berkeley: California University Press.

Granjo P. (2009) “Saúde e Doença em Moçambique”. *Saúde Soc*, 18(4): 567-81.

Hörbst V., and Wolf A. (2014) “ARV and ARTs: Medicoscapes and the Unequal Place-making for Biomedical Treatments in sub-Saharan Africa”. *Medical Anthropology Quarterly*, 28(2): 182-202.

Lupton D. (1997) “Consumerism, Reflexivity and the Medical Encounter”. *Social Science and Medicine*, 45(3): 373-81.

Inhorn M., and van Balen F. (2002) *Infertility Around the Globe: new thinking on Childlessness, gender and reproductive technologies*. Berkeley: California University Press.

Inhorn M., and Patrizio P. (2012) “Global Landscape of Cross-border Reproductive Care: twenty key findings for the new millennium”. *Current Opinion in Obstetrics and Gynaecology*, 24: 158-63.

——— (2015) “Infertility Around the Globe: new thinking on gender, reproductive technologies and global movements in the 21st century”. *Human Reproduction Update*, 21(4): 411-26.

Kleinman A. (1978) “Concepts and a Model for the Comparison of Medical Systems as Cultural Systems”. *Social Science and Medicine*, 12: 85-93.

——— (2006) *What Really Matters: living a moral life amidst uncertainty and danger*. New York: Oxford University Press.

Mariano E. (2004) “Involuntary childlessness among the Shangana (Mozambique)”. *Journal of Reproductive and Infant Psychology*, 22: 261-9.

——— (2014) *Understanding experiences of reproductive inability in various medical systems in Southern Mozambique*. PhD thesis defendet at KU Leuven, available at: https://lirias.kuleuven.be/handle/123456789/436311.

Mausse F., Mabota F., and Bugalho A. (2014) ”Assessment of Male Infertility Causes in Mozambique: a case study of working class patients by IVF at Médicos Associados Clínica Cruz Azul Laboratory, Maputo”. *International Science and Technology Journal Namibia*, 3(1): 100-6.

MISAU [Ministério da Saúde, Moçambique] (2012) *Revisão do Sector Saúde, Health Ministry of Mozambique Report*, available at: https://www.hfgproject.org/relatorio-da-revisao-sector-de-saude-mozambique-health-systems-assessment-portuguese/.

Pfeiffer J. (2002) “African Independent Churches in Mozambique: Healing the Afflictions of Inequality”. *Medical Anthropological Quarterly*, 16(2): 176-99.

Rodrigues C.F. (2016) “Medicines and Therapeutic Pluralism in Maputo: exploring modalities of trust and the (un)certainties of everyday life users”. *Health, Risk and Society*, 18(7-8): 385-406.

Scheper-Hughes N. (2011) “Mr. Tati's Holiday and João's Safari. Seeing the World through Transplant”. *Body & Society*, 17(2-3): 55-92.

Schütz A. (1972) *The Phenomenology of the Social World*. Evanston: Northwestern University Press.

UNFPA [United Nations Population Fund] (2014) *Framework of Actions for the follow-up to the Programme of Action of the International Conference of Population and Development beyond 2014*, available at: http://www.unfpa.org/publications/framework-actions-follow-programme-action-international-conference-population-and.

Van Balen F., and Bos H. (2009) "The Social Consequences of Being Childless in poor-resource areas". *Facts, Views and Vision in ObGyn*, 91(2): 106-21.

Van Dijk R., Bruijn M., and Gewald J. (2007) "Social and Historical Trajectories of Agency in Africa: An introduction". In Bruijn M., Van Dijk D., and Gewald J. [Eds.] *Strength Beyond Structure: Social and historical trajectories of agency in Africa*. Leiden and Boston: Brill.

Vayena E., Peterson H., Adamson D., and Nygren K. (2009) "Assisted Reproductive Technologies in Developing Countries: are we caring yet?". *Fertility and Sterility*, 92(2): 413-16.

Velho G. (2003) *Projecto e Metamorfose: antropologia das sociedades complexas*. São Paulo: Jorge Zahar.

Vigh H. (2009) "Motion Squared: a second look at the concept of social navigation". *Anthropological Theory*, 9(4): 419-38.

WHO (2014a) *WHO Country Profile Mozambique*, available at: http://www.afro.who.int/en/mozambique/who-country-office-south-africa.html.

——— (2014b) *WHO Country Profile South Africa*, available at: http://www.afro.who.int/en/south-africa/who-country-office-south-africa.html.

Gender based violence between reproduction and social change. Research and action in four Italian municipalities

Lia LOMBARDI[*]
University of Milan

ABSTRACT: This article intends to discuss the issue of violence against women under two perspectives: by analysing the forms of domination and subjugation that reproduce the violent dynamics of men against women; highlighting the social change, analysed through the narratives of the interviewees involved in a quanti-qualitative research and also through the test of a governance model to contrast gender violence. The research was carried out from 2010 to 2013 in four municipalities of Milan province to investigate the socio-cultural factors of violence against women. It consists in: a survey of 300 interviews with women aged 20-59, three focus groups with 20 women involved in the previous survey, 10 in-depth interviews with sex-offenders prisoners (men) who were attending an Intensified Program of the Offence Elaboration. Research and actions taken on the four Municipalities, provide tools for understanding the social construction of gender violence phenomenon; the next step is to learn how to break the circle of violence. With reference to this last point, I bring the example of a governance model deployed by one of the municipal administration involved in the research project.

1. Introduction. Definitions and concepts of gender based violence

Gender violence and violence against women[1], in its various forms, has consequences and high costs in terms of the victims' physical and mental health. It severely affects both the

---

[*] Corresponding author: Lia LOMBARDI | rosalia.lombardi@unimi.it - l.lombardi@ismu.org

[1] 'Gender violence' and 'violence against women' are terms often used interchangeably because most of the gender-based violence is exercised by men against women and girls. However, it is important to keep the concept of 'gender-based violence', as this highlights the fact that violence against women is an expression of power inequalities that persist between men and women (EIGE website, http://eige.europa.eu/gender-based-violence/what-is-gender-based-violence).

management of daily life and relationships; besides, welfare costs and public health are not so negligible, as several European sources show (EIGE, 2014[2]).

Thus, what do violence against women and/or gender-based violence mean? According to the 3rd article of the Council of Europe's Convention on Preventing and Combating Violence Against Women and Domestic Violence, also known as the Istanbul Convention[3], "[G]ender-based violence against women shall mean violence that is directed against a woman because she is a woman or that affects women disproportionately (...)". The same Convention states that violence against women should be understood as a violation of human rights and a form of discrimination to the detriment of women. This includes all actions resulting in physical, sexual, psychological, and economic harms, or suffering caused to women, including the threat itself of those actions, coercion or arbitrary deprivation of liberty, both in public and in private contexts (Council of Europe, 2011: art. 3a).

Violence against women encompasses crimes that disproportionately impact on women, such as sexual assault, rape and 'domestic violence'. It is a violation of women's fundamental rights with respect to dignity and equality. The impact of violence against women stretches beyond those women who are themselves victims, since it affects families, friends and society as a whole. It calls for a critical look at how society and the state respond to this abuse. Measures to fight and prevent violence against women are therefore required at both European Union (EU) and national levels.

We can distinguish between direct and indirect forms of gender-based violence: direct violence against women includes physical (including violence in close relationships), sexual (including rape, sexual assault and harassment in all public and private spheres of life), psychological (including threats, humiliation, mocking and controlling behaviours), and economic violence, which means preventing the victim from accessing their financial resources, property, healthcare, education, or the labour market, and denying them participation in economic decision-making (EU Council, 2014).

Trafficking in human beings, slavery, sexual exploitation; harmful practices such as child and forced marriages, female genital mutilation; emerging forms of violations, such as online

---

[2] According to the European Institute for Gender Equality's report, gender-based violence costs the EU about 258 billion Euros per year while the actions to prevent it take only 1% of that figure (EIGE, 2014).

[3] The Italian government issues Decree-Law 93 in 2013 directed to implement the Istanbul Convention, which became Law 15 October 2013, n. 119.

harassment, stalking and bullying are also considered forms of direct gender-based violence (EU Council, 2014).

Intimate partner violence (IPV) is one of the most widespread forms of direct violence against women, and includes a range of sexual, psychological and physical coercive acts used against adult and adolescent women by a current or former intimate partner. According to the EU-wide Survey on Violence against Women conducted by the EU Agency for Fundamental Rights (FRA), 22% of women have experienced some form of physical and/or sexual violence by a current or previous partner (EU FRA, 2014).

According to the UN Special Rapporteur on violence against women, institutional or structural violence is “any form of structural inequality or institutional discrimination that maintains a woman in a subordinate position, whether physical or ideological, to other people within her family, household or community” (UN OHCHR, 2011: 8).

We can understand indirect violence as a type of structural violence, characterised by norms, attitudes and stereotypes around gender in general, and violence against women in particular. Indirect violence operates within a larger societal context; institutions, and individuals within and outside these institutions, are all engaged in the production and reproduction of attitudes that normalise violence against women (UN CEDAW, 1992).

Inequalities – and the forms of violence connected to them – are intersectional. They are the result of an interplay between multiple power structures that produce and reproduce hierarchical distinctions, for example regarding race, (dis)abilities, age, social classes, and gender. This means that while all women face discrimination based on gender, some women experience multiple forms of discrimination, of which gender is only one component (Zanfrini, 2016; 2005; Lombardi, 2016a; 2016b; 2016c; 2005).

2. The social and cultural roots

This section is dedicated to a reflection on some key elements of the socio-cultural construction of violence against women. In this space, we will try to discuss some issues that different theories interpret as the soil in which violence against women is produced and reproduced. We are going to talk about gender inequality and socialisation processes, which in turn build and reproduce inequalities and discrimination (Lombardi, 2016c). It is interesting to start by quoting the preamble of the aforementioned Istanbul Convention, which recognizes gender inequality and its structural connotation:

> Condemning all forms of violence against women and domestic violence;
> Recognising that the realisation of de jure and de facto equality between women and men is a key element in the prevention of violence against women;
> Recognising that violence against women is a manifestation of historically unequal power relations between women and men, which have led to domination over, and discrimination against, women by men and to the prevention of the full advancement of women;
> Recognising the structural nature of violence against women as gender-based violence, and that violence against women is one of the crucial social mechanisms by which women are forced into a subordinate position compared with men. (Council of Europe, 2011: 1)

This statement may suggest an institutionalization of the recognition of gender inequality and therefore the legitimacy to combat it, thus becoming a key factor for the elimination of violence against women. Several studies show continuity between domination and exploitation and violent actions against women (Romito, 2005; 2000; Reale, 2000; Filosof, 2000; Gillioz *et al.*, 2000). According to Romito (2000), indeed:

> The expectations society and partners have of women and their complete availability (material, sexual and emotional) are the conditions in which mistreatments appear as they are: the means for maintaining supremacy (Romito, 2000: 12)

Rape, in particular, is clearly linked to the relationship that identifies masculinity with power, domination and rudeness as Giddens writes: “mostly it is not the result of uncontrollable sexual desire, but the result of the link between sexuality and the sense of power and superiority”. In fact, the author still informs: “the sexual act itself is less important than the degradation imposed on women” (Giddens, 2000: 182).

According to many authors, gender violence is an issue that historically concerns the social construction of identities and gender relationships, and is rooted in patriarchal social relationships based on a system of male dominance and female subordination (Eisenstein, 1979; Romito, 2000; Giddens, 2000; Ruspini, 2003; Andersen & Taylor, 2013; 2004). This means that we can speak of sexism, which is the set of institutionalised practices and beliefs through which women are socially controlled, on the basis of the meaning given to the differences between genders (Andersen & Taylor, 2013). The concept of patriarchy is linked to the concept of sexism. The patriarchal system is spread all over the world and, in those kinds of societies, husbands have authority over wives in the private sphere, but the public and the institutional spheres too are not free from this disparity (Romito, 2000), because the decision-making positions and power are held by men. In short, "gender stratification is an institutional system based on specific belief systems that enshrine the superiority of men over women" (Andersen & Taylor, 2004: 236). The concept of gendered institution can be observed in the fact that every institutional environment is structured by gender. For example, children and young people learn about gender roles at school, which is a gender-oriented institution itself, as it is based on specific models of distinction, both institutional and individual. Gender is a part of the structure of society, as are race and social classes, and as such it is a privilege that builds an inequality system in which women are always disadvantaged. Actually, we are talking about stratification, which is the hierarchical distribution of resources by gender: gender stratification affects all societies, albeit in different forms and to different extents (Chafetz, 1984; Lombardi, 2016c).

3. The dimension of violence against women

The dimensions of violence in the world are considerable: it is estimated that 35% of women worldwide have experienced either physical and/or sexual intimate partner violence or sexual violence by a non-partner at some point in their lives. However, some national studies show that up to 70% of women have experienced physical and/or sexual violence from an intimate partner in their lifetime.

According to UN's Women Report, women who have been physically or sexually abused by their partners are more than twice as likely to have an abortion, almost twice as likely to experience depression, and in some regions, 1.5 times more likely to get HIV, as compared to women who have not experienced partner abuse. It is estimated that of all the women who were murdered worldwide in 2012, almost half were killed by intimate partners or family members, compared to less than six per cent of men killed in the same year. Psychological violence is even more difficult to estimate: in EU Member States, about 43% of women have suffered some form of psychological violence by their intimate partner. There is also some concern regarding sexual cyber-bullying: 10% of women (aged 15 years) are victims and the risk is especially high for the age group 18-29 years (UN Women, 2015).

According to a survey of the European Union Fundamental Rights Agency (EU FRA, 2014) based on 42,000 interviews carried out in the 28 EU countries, 7% of women aged 18-74 (13 million) suffered physical violence in the twelve months before the interview. Among them, 2% were victims of sexual violence (3,7 million), and 5% were victims of a rape since the age of 15. Moreover, 18% of women have experienced stalking since the age of 15, and 5% of them have experienced it in the twelve months preceding the survey, which means about 9 million women.

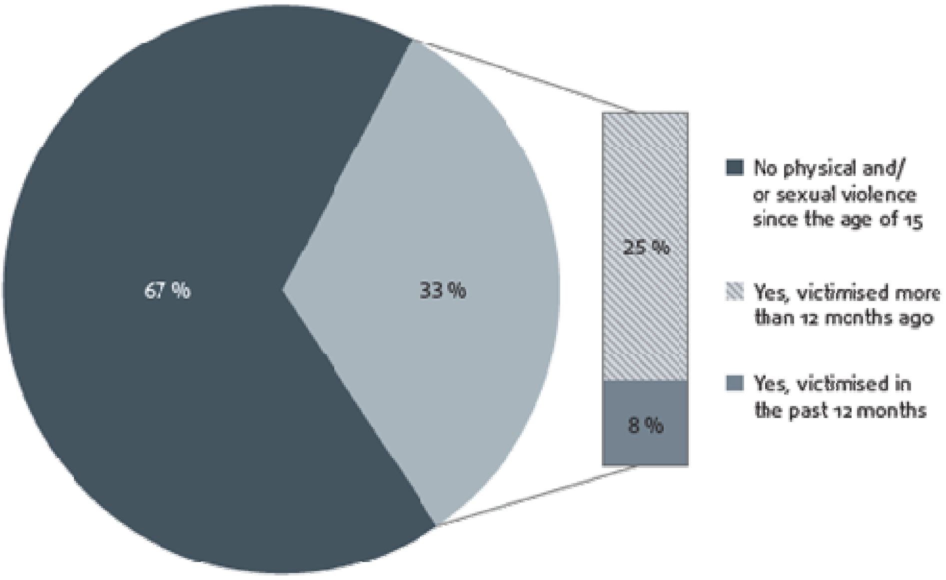


Fig. 1: Women experiencing physical and/or sexual violence since the age of 15 and in the 12 months before the interview, EU-28 (%). Based on all respondents (N = 42,002). Source: EU FRA (2014)

Some 12% of women indicate that they have experienced some form of sexual abuse or incident by an adult before the age of 15 (about 21 million women). The results show that 30% of women who have experienced sexual victimisation by a former or current partner also experienced sexual violence in childhood (EU FRA, 2014). Moreover, half of all women in the EU (53%) avoid certain situations or places, at least sometimes, for fear of being physically or sexually assaulted. In comparison, existing surveys on crime victimisation and fear of crime show that far fewer men restrict their movement.

3.1. The Italian context

With regard to the Italian context, in 2015, the National Statistics Institute (ISTAT) published the second report on “Women’s Safety” in Italy. The report highlights that 6,788,000 women (31.5%, aged 16-70 years) have suffered some form of physical or sexual violence in their lives: 20.2% were victims of physical violence, 21% were victims of sexual violence, 5.4% suffered severe forms of sexual violence (rape and attempted rape). The numbers related to stalking, too, are very important: 3,466,000 women have been victims in their lifetime (16.1%), 44% of them have suffered violence by former partners, and 56% by others.

The most serious acts of violence are committed by partners or former-partners (62.7% of the rapes) while the perpetrators of sexual harassment are mostly unknown (76.8%). Violence against minors is also high and requires a lot of attention and surveillance: 10.6% suffer sexual abuse before the age of 16. The so-called ‘witnessing violence’ is connected to the previous data, and there is an increase of 5% of children who are witness to violence committed against their mothers (65.2% in 2014).

Separated or divorced women are more at risk of physical or sexual violence than other women (51.4% vs. 31.5%). The situation of women with health problems or disabilities is equally critical: they are twice at risk of being subjected to rapes or attempted rapes compared to other women (10% versus 4.7%) (ISTAT, 2015).

3.2. Violence against migrant women in Italy

According to the ISTAT's report (2015), foreign women living in Italy run the same risk of being subjected to physical or sexual violence as Italian women (31.3% vs. 31.5%). However, physical violence is more frequent among immigrant women (25.7% compared to 19.6% of Italian women), while sexual violence is more frequent among Italian women than female immigrants (21.5% versus 16.2 %) (Table 1).

The most severe forms, such as rapes and attempted rapes, are prevalent among immigrants (7.7% vs. 5.1%). This means that Italian women are more affected by forms of less serious sexual violence, such as harassment, especially by strangers. Foreign women are more likely to suffer violence (physical or sexual) inflicted by partners or former partners (20.4% vs. 12.9% of Italian women) than by unknown men (18.2% vs. 25.3% of Italian women). Foreign women who suffered violence by a former partner are 27.9%, but for 46.6% of them the relationship had been broken off before arriving in Italy.

Forms of violence	**Current Partner**[4]		**Former partner**[5]		**Current or Former partner**[6]		**Non-partner**[7]		**Total**[8]	
	IT	FGS	IT	FGS	IT	FGS	IT	FGS	IT	FGS
Physical or sexual violence	4.9	7.8	17.9	27.9	12.9	20.4	25.3	18.2	31.5	31.3
Physical violence	3.9	6.4	15.4	25.8	11	18.2	12.3	12.6	19.6	25.7
Sexual violence[9]	1.8	3.6	7.8	12.2	5.5	9.1	18.3	9.7	21.5	16.2
Rape or attempted rape	0.4	1.1	3.6	6.4	2.2	4.2	3.3	4.6	5.1	7.7
Rape	0.3	0.9	2.9	6	1.8	3.8	1.1	2	0.09	5.3
Attempted rape	0.2	0.5	1.5	3.2	1	2.1	2.5	2.9	0.13	4.6

Table 1: Women aged 16-70 who suffered physical or sexual violence by men along their life. Distributed by authors, form of violence and nationality (IT=Italians; FGS=Foreigners). Source: ISTAT (2015).

---

[4] Out of 100 women with a current partner.

[5] Out of 100 women with a former partner.

[6] Out of 100 women with a current or former partner.

[7] Out of 100 women aged 16-70 years.

[8] *Ibidem*.

[9] Included rape and attempted rape.

4. Field analysis: a quantitative/qualitative study of women abuse in the metropolitan area of Milan

This section focuses on two studies carried out as part of two research projects funded by Lombardia Region[10]. The quantitative analysis, based on the Urban Project (Adami *et al.*, 2002) has been followed up by a qualitative study with three focus groups. The latter aimed to further investigate some of the issues emerging from the interviews and the social, cultural and psychological aspects of gender abuse. The quantitative analysis aimed to: (i) investigate the perception of security in the place of residence; (ii) investigate the awareness of gender abuse in its different forms; (iii) quantify the number of victimisation occurrences; (iv) measure the awareness of risk and protective factors.

Three hundred telephone interviews have been carried out with women aged between 20 and 59 and residing in the targeted municipality. The average age of the interviewees is 41.8 years old. Among them, 42% have a secondary school qualification; 74% are married, and 59% live with their partner and children. Fifty-five percent of the interviewees are in paid work, with 35% being in clerical employment. Only 47% of all interviewees consider themselves economically self-sufficient; 33% consider themselves partially self-sufficient, and 20% are economically entirely dependent from their partner or family of origin.

4.1. The quantitative study: some results

About 95% of the interviewees say that they have heard about sexual, physical and psychological abuse: 92% believe that sexual abuse affects all women, and only 3% think it only targets the most attractive women. The media are considered to be the main source of awareness for different forms of sexual abuse, with 95% of the interviewees mentioning the role played in this respect by television, 65% by the press, and 30% by the radio. Among them, 62% declare that drug and alcohol abuse are possible causes leading men to violence; 46% believe that male violence is rooted in the predominance of men over women; 44% think it is a consequence of low levels of education, and 34% believe that having already

---

[10] These are two regional projects, entitled: "Piccoli progetti per grandi idee" (2010-2011), and "Progettare la parità in Lombardia" (2012-2013). They have been carried out in partnership with seven public institutions (four councils and three schools) and several actors in the tertiary sector (ten associations and foundations).

been subjected to violence can trigger more. Drug and alcohol abuse and low levels of education are mainly mentioned by younger women (aged between 20 and 39 yo), while for older women (aged between 40 and 49 yo) predominance of the male over the female gender is the main cause of gender abuse. Women aged between 50 and 59 yo are more likely to justify violence by, for example, attributing it to provoking behaviours from women and by considering it to be part and parcel of male nature: 14% of them argue that those women who are victims of sexual abuse must “have done something to trigger it”. This different distribution between age groups could be attributed to social and cultural changes in gender relationships and stereotypes. Fifty-nine percent of the interviewees consider violence against women to be serious even when it takes place within the family or circle of friends, despite women aged between 50 and 59 being less likely to firmly condemn it. Importantly, 96% of all interviewees believe that under no circumstance can violence against women be justified.

Among the interviewees, 91% believe that a great proportion of abuse and violence against women takes place within the family and/or in a domestic environment. It is the kind of violence that Ignazia Bartholini calls ‘proximity violence’, “because it is the ‘foundation’ and ‘proprium’ of interpersonal behaviour; violence as a means to identity recognition, violence as a form of relationships of proximity” (Bartholini, 2013: 12). Moreover, 66% of the participants in the study consider that a man slapping his partner is a very serious act, while 29% considers this to be a rather serious act; 69% of the interviewees deem that a man forcing his partner to have sexual intercourse with him constitutes a very serious and non-justifiable act; 27% believe this to be serious because it reveals a lack of respect for the woman. Another important theme explored is the reason why women who are subject to their partner’s abuse do not leave. Contrary to what is commonly assumed, almost half of the interviewees (45%) argue that fear is the main reason why women who are victims of abuse do not leave their violent partners; 22% would not leave them because of the children, and 16% for economic reasons. Mention of fear is recurrent in the focus groups carried out with women, as we will see in the next sections.

The decision to stay with their partners despite the violence experienced cannot be labelled as ‘passive reaction’, inability, or ‘inadequacy’: it is often dictated by several factors and is accompanied by a strategy of ‘resistance’ and by actions that aim to change things, such as requests for help addressed to family members, friends or social and healthcare professionals (Romito, 2000; 2005; Creazzo, 2000). Only 9% of the interviewees (27 women) admit they have been subjected to violence/abuse during their lives. This percentage increases to 15% among women aged 20 to 29. Among those women who admit they have been subjected to violence and abuse in the two years preceding the interviews (15 women) only 25% (4 women) say they have reported the abuse to the police.

As far as risk factors are concerned, the majority of the interviewees (53%) identify a violent man as someone who is by nature prone to aggressiveness or who has psychological problems. Compared to protective factors, 72% of the interviewees mention social and healthcare services and charities as organisations that can offer help to women who have been victims of abuse; 70% mention the police as being able to help. Seventy-two percent of the interviewees mention harsher punishment, and 45% the protection and support for women as the most effective measures to fight the phenomenon. This indicates a normative/punitive approach rather than a constructive/reflective one, which reveals a cultural shift in gender socialisation and relationships.

4.2. The qualitative analysis: focus groups

The issues 'on the table' during the focus groups are those that had emerged in the quantitative study. The following issues have been investigated: a) the causes of insecurity for women; b) the reproduction of violence against women; c) the value system: images of violence and acts that are considered to be the most serious; d) the context in which violence takes place; e) change. Three focus groups have taken place with 14 women in total, living in the three targeted municipalities and chosen on a voluntary basis during the telephone interviews. With the exception of a 27-year old woman, all other participants were aged between 40 and 50; women taking part in the second focus groups were mainly employed in the educational sector (the majority being teachers); women taking part in the third focus group were on the contrary employed in different fields: they worked in research, were self-employed or civil servants; five women taking part in the three focus groups claim to have experienced physical and/or psychological violence.

Focus groups have taken place at different times and in different places, and this has defined the different composition of women participating in each group. Focus group 1 has taken place in the mornings, and therefore only unemployed or retired women have taken part. In this meeting, economic problems have been often discussed, thus highlighting the burden of being dependant on the partner, who is the main breadwinner. The other two focus groups have taken place in the evenings with all participants being in employment: the sense of independence and the freedom of judgement among these women have been significant.

4.3. The women's insecurity

The participants' observations on the causes for women's insecurity have raised some key issues. First of all, educational and female gender socialisation models have been mentioned:

> *I believe this insecurity stems from, on the one hand, the fact that we are brought up to be mothers, that is caregivers, which is what we, according to the Italian cultural model, should be…* (F1-f)

The cultural model which makes women feel insecure and inadequate is often debated and participants mention another upbringing and gender socialisation model: parity of and between genders:

> *there are several reasons why women feel fragile, because we have never been on a par with those we deal with. At work for example or when you are already a mother you must be a mother and nothing else, instead this is not true and you feel different, not on a par with your partner. Then in all things, you must give more to be on a par. I believe that on the contrary we are able to do much more than men...* (F2-c)

Participants are aware that change must come from different areas, and that social factors – family, school, religion and norms – must contribute to promoting equality, respect and sharing between genders. Not listening, pretending nothing has happened, not noticing the other's uneasiness are seen both as a form of insecurity and as real violence:

> *Then, years of depression, in bed, I used to cry, I could not be bothered: I used to get up in the morning and take my daughter to school, then went back*

> *home, went to bed, slept and cried. I used to get up at four to pick up my daughter from school. No one had ever noticed anything, neither my friends nor my husband. When I dared going to the doctor's and ask for some tranquillizers my husband said I wanted to lead the good life. He insulted me, Therefore I quietly fell back into line...* (F1-f)

This is accompanied by the silence of others: brothers and sisters, parents, and society in general. When women's anxiety and problems are neglected, or even stigmatised, how can one build awareness, self-confidence and the strength to change one's own life and what surrounds it? Loneliness and isolation are therefore also mentioned as factors that generate and reproduce fragility in women. Many have however also mentioned the role played by the media in generating insecurity (Misiti & Palomba 2002):

> *Going out on your own, being attacked, things that are often a little fuelled by the media. Insecurity is perceived. It's not that things do not happen, but perhaps perception plays a role in magnifying reality. There is a side to insecurity which stems from women being more fragile and another that is, so to speak, created* (F2-n)

About this, Franca Bimbi (2015) reflects on the representations of femicide in the Italian press, highlighting the emphasis on romantic and passionate loves that would lead to the murderous *raptus*. “In this case” – the author writes –, “the press acts as a social circle that reproduces the defensive stereotypes of reputation, in native cultures of masculinity” (Bimbi, 2015: 38).

Women's lack of confidence is also seen as a psychological factor which may have been triggered by a perhaps excessively protective family environment or by the upbringing received:

> *Lack of confidence is without a doubt a psychological reason which may stem from family-related factors, or depend on your upbringing: I think of my mother, who was a little too strict, that is was excessively concerned when I went out, how I behaved etc. Surely my family environment has had an impact* (F2-mc)

'Insecurity' is a multidimensional element which impacts on several aspects of women's social and personal life. Several participants in the focus groups declare they have no fear, and thus that they will not pass any on to their children. They are however aware that:

> *the lack of confidence that women carry within is much more subtle… in the home, in the family, at work, we have it inside. Unless we shake it off because we want to do so, society certainly does not help us. It suits men [that women feel fragile]. I can see this in the young mothers I deal with now...* (F2-s, a teacher)

Then there is fear, both perceived and induced, that kind of fear that:

> *generates lack of confidence, creates problems at work, in the relationships with others. This is what I dread all the time. I do not enjoy what I do, I lack confidence. I always feel "I cannot do this"* (F3-f)

An objective and a subjective dimension, the latter linked to the lack of confidence, emerge from both the quantitative analysis discussed earlier and from the focus groups. If, on the one hand, quantitative data show the objective and 'external' perception of people (e.g. the insecurity in the place of residence), on the other, the observations emerging from the qualitative study highlight a subjective dimension: this starts from within and uncovers new worlds and factors which contribute to the social construction of the lack of confidence of the female gender.

4.4. The social reproduction of gender violence

We have asked our participants in the focus groups what they think produces and perpetuates violence against women, and why this happens. Once again, answers and observations have been diverse, but always very articulated and complex.

According to some women, the problem is rooted in the system of values related to maternity and family, in the 'lack of appreciation' for women's reproductive role and their role within the family (Balbo, 1978; Bimbi, 2003). Therefore, *maternage* and family care become the centre of women's inequality and discrimination (Chafetz, 1984). Women's unequal position and the fact that they are discriminated easily leads to violence against them on the part of those who hold (or believe they are entitled to hold) power and control.

According to other participants, it is women's sense of guilt which often allows men to perpetrate and reproduce power and violence against women:

> *the sense of guilt... in my case plays a big role... such as... if I think I have done something not quite right, if I am then told off, if attention is drawn to it or if I see something I do not thoroughly agree with, I don't point it out, I keep quiet because I believe I made a mistake earlier and thus the sense of guilt prevails. I do not know whether this is a kind of violence I have made up, because I am the one who experiences a certain thing, here I am, instead of saying ok, I made a mistake earlier, but now he is the one making a mistake… Why am I locked inside this vicious circle?* (F1-e)

The participants also mention merely biological reasons for gender violence, which are hotly debated, leading to more complex and shared interpretations. Here are some extracts from this debate:

> *Since the origins of humankind it seems to me that violence has been a non-negligible factor, also from a biological point of view. Hence men are aggressive, and use and show aggressive behaviour. Hence it is normal for testosterone to manifest itself in violent acts... We must face violence every day and we must learn to dominate it, or at least to live with it.* (F3-P)
>
> *But is it testosterone which differentiates men from women? Why do we always talk about violence against women and rarely about violence against men? Is it just testosterone which determines this kind of violence, of aggressiveness?* (F3-f)
>
> *Well, it may be a cultural thing, for example men are more interested in power than women. Why? You can exercise violence against men, when you*

> *are in a powerful position, therefore it is not testosterone but who knows what, maybe blackmail* (F3-m)

> *However they are linked, male violence is linked to testosterone and to violent impulse because from a biochemical point of view they are two very similar phenomena... it is also linked to sexuality... sexuality is linked to the presence of sexual hormones and these hormones facilitate certain collateral behaviours, they are linked to one another. Therefore, male sexuality is a little different from female sexuality because there is a gender component [gender is mistaken for sex here] and therefore there are different dynamics at play here.* (F3-p)

Soon after this ‘bio-genetic’ interpretation of male violence, the same participant highlights aspects of change which are more linked to social and cultural phenomena: without initially realising it, she interprets the tight relationship between biological and socio-cultural phenomena as follows:

> *So this is the behaviour, but in future I think that there will be a big revolution... Now I think that already in our society several of these mechanisms are no longer valid because in many ways gender [sex] is no longer as determining as it was in the past (...) This cultural change will then have an impact on hormonal mechanisms* (F3-p)

Two additional and important issues are raised in order to provide an explanation for violence against women, the first of which is power and its handling by men:

> *Violence reminds me of war and what is war if not a way to conquer, to gain more power? When violence is exercised against a person this happens because I am more powerful than you, I can do this because I am stronger, I have control over you. I think it is a cultural characteristic more typical of men than of women, the will to affirm one’s own power* (F3-m)

The second is the lack of means on women’s part:

> *When I am subjected to an act of violence I react, if I do not react it is because I do not have the economic means to do so and I do not have the help/attention [she means from others], because if a woman upsets the order which is deemed by society to be what it should be, then she has the void around her* (F1-r)

> *we do not have the means, we are not trained as men would be and then we have the whole society around us making us feel guilty. Society does not want anything to change* (F1-f)

We thus come to the shared observation that behaviours, models and attitudes which refer to one gender rather than the other are mainly social constructions and induced upbringing models:

> *I have a son who has always played with dolls, he used to identify with certain TV characters… who when he saw his friends used to hide his toys, despite the fact I have never discouraged him, on the contrary I used to play with him so that he would have someone with whom to share. Despite all this, when he was with others he had to show he could play football and be tough. I do not think he is homosexual, I do not know, I have not yet found out. He still plays on his own because I think he cannot share his passion for cuddly toys with his fellow male mates. He is very creative. Hence he has few friends because when he invites them he must give up what he likes and adapt to what as a norm is required of a boy* (F2-na)

4.5. The value system: images of violence

Images of violence have always been very clear among the participants. Violence has been defined as destructive since it leaves women on their own, covers them with shame, and makes them feel different from those women who do not experience it:

> *The thing is this, that being a victim of violence is almost your fault… even psychologically you feel inferior because you have been subjected to an act of psychological violence and it is this which makes you feel inferior and stupid for having been subject to it. Therefore it is a sort of chicken and egg problem* (F2-1).

Another recurring image of violence against women is the lack of respect, the little consideration, first of all on an intellectual level. As already highlighted above, the images of violence against women – as a form of power and predominance – are often emphasised by the participants:

> *Violence presupposes a lack of respect for people...Violence can be physical but also more subtle, such as affirming one's own power and predominance on that person* (F3-m)

In inviting the participants to think about the feelings that a woman who has been victim of abuse and or violence can have, the most recurring images that emerge are: terror, hate, fear, resentment, disgust and contempt. The most effective image has been provided by a woman regarding her father:

> *I do not hate him, I have felt nothing, absolutely nothing and I think this is the worst thing. My father died not long ago, if I had lost a pet I would have felt worse. A total void. I have feared that lack of feelings. Hate is a feeling, affection is a feeling, love is a feeling. Feeling nothing is nothing. It is the worst possible thing… No feeling, and you see, having no feelings is difficult. Why this void?* (F3-f)

In recognising and defining the most serious forms of violence against women, participants have found themselves in disagreement, possibly as a consequence of their experiences and representations. As a result, according to some of them, physical violence (such as beating) is the most serious form of violence, while for others it is sexual violence:

> *I think that you can forget physical violence and that it is not as traumatic as sexual violence, because the latter is not only sexual, through that kind of violence a man destroys you* (F3-f)

If Giddens (2000) sees sexual violence as an act of degradation imposed on women, Susan Brownmiller (1975) goes further and interprets this kind of violence as a male system aimed at intimidating, which keeps all women in a state of fear and forces them to think about and adopt ‘protective’ measures in the various areas of their everyday lives (such as not staying out until late, getting dressed in a certain way, going certain places, etc.)

Other participants see psychological violence as the most serious form of abuse:

> *On the contrary, I think that psychological violence is much more powerful, because it makes you feel inferior, powerless, therefore you cannot fight it back in any way because you… if you could afford to be a person with the same rights as a man, you could defend yourself, or maybe he would not dare. On the contrary, when you are subjugated, psychologically too, you cannot escape from that prison, this one [the man] takes advantage in all possible ways, he makes you feel shit, excuse my language.* (F1-f).

We have collected some interesting observations on this issue, which lead us to consider more complex and multidimensional aspects of violence. For example, one participant highlights that there is a difference between an isolated attack or sporadic abuse and repeated violent acts:

> *I think we must distinguish between events. One thing is an isolated act of violence, another thing is repeated violence, maybe inside the home, either sexual or of another kind. What life can someone who lives in constant fear have, they are not a free person* (F3-m)

The ambivalence of a violent relationship is also taken into consideration:

> *I believe that if two people beat each other, but they are in a relationship, they do not experience violence in such a serious way, then this is also one of the reasons why women do no report abuse to the police...* (F3-p)

4.6. The context in which violence takes place

All participants have shown an awareness that in the majority of cases violence against women takes place inside the home but, much to their amazement, have indicated ‘external’ places as those that ‘instigate fear’. They have skilfully denied this apparent contradiction, blaming the media and some cultural stereotypes for portraying violence as taking place ‘outside’ and have also contextualised events:

> *I think that women can have fear depending on their personal situation: she who has an unsafe family context I imagine will experience fear at home, if she has a difficult situation in the workplace she will experience anguish even on her way to work.* (F3-m)

4.7. Change: what can be done?

At the end of each focus group we have invited all participants to suggest possible changes and actions that can promote a culture of parity and respect between genders. Suggestions have been many and varied but all pointing to some key issues: starting from women’s lack of economic independence, participants suggest forming women’s groups aimed at promoting employment and activity exchange: such actions will also help them become economically independent.

All participants highlight the need for adequate services (social, legal, healthcare services and shelters) with professionals adequately trained to welcome women who have been victims of violence. The participants report shortage/lack of such services in the areas where they live:

> *Create, in my opinion, services (women’s help-desks, hotlines, etc.) accessible to women who experience difficulty and especially who are alone, so that they are not left on their own, so that information can be exchanged. Because the fact itself of being able to communicate, to talk about their own problems, helps them to no longer feeling alone.* (F3-p)

Information is equally important: women must be informed of what protection is in place and what rights and points of reference are available to them. It is the kind of knowledge that helps people to do things, to change. Education is widely mentioned since it promotes cultural change. Schools are often referred to as a privileged environment in which to kick off change, in which to meet younger generations and their parents. Culture, together with education, is therefore deemed to be of significant relevance:

> *To me this is fundamental: to enable women to choose – to educate them from an early age – to recognise what is right for one or the other. While for my grandmother rules were strict and life pre-ordered, this was less the case for my mum and from this point of view we feel freer, since we have more choice (...) Nowadays women are more aware, they know what is right for them.* (F2-mc)

Another hotly debated issue is ‘women solidarity’ that is collective moments of mutual self-help and of action in the fight against violence, aimed at building self-awareness and at promoting virtuous behaviours and attitudes:

> *I think that women need to go out more often, turn the TV off, go out and meet other women and do things together: talk about their problems and try to find a strategy for change, even within their family. In other words, develop awareness.* (F1-f)

We think it is important to consider one last suggestion which, although only mentioned by two participants, we believe to be one of the main routes to be pursued in the fight against gender violence. It is about taking men into consideration too – be they rapists, abusers or not – in this path towards change. It is about prevention and cure, as a participant stresses:

> *To cure perhaps not just women but also these men, to make sure they stop. I don’t know... ideally putting these people in rehabilitation centres, not in prison. Unfortunately, society does not spend enough on this.* (F3-m)

> *We also need to find a way to meet with men, although these are men who are not easy to approach.* (F2-na)

5. ‘Talking to him’: reflecting on victims and offenders

These suggestions by the focus group participants prompted a new project[11]. In addition to awareness and training actions for social and educational workers, we also carried out a qualitative survey aimed at ten sex-offenders and abusers who were attending a ‘crime re-elaboration’ program in prison[12]. The purpose of this survey was to highlight an ‘inclusive’ methodological approach (‘between authors and victims’) by overcoming a conflicting approach. This perspective is represented by a slogan posted on the walls of some public buildings and which reads “Violence against women is a men’s problem” (Bozzoli *et al.*, 2013). Recurring issues in the analysis of sex-offender interviews were: violence decoding; family context; the relationship with women; change; and reference values. The ten interviews with perpetrators of violence (sex-offenders) and of mistreatments against women placed us, as researchers, in a context of observation and analysis which was very different from what we had expected. For example: a) the different territorial (north/south) and geographical origins (Italian/foreign) of the men interviewed did not appear to have a decisive influence on their criminal acts; b) with the only exception of two cases, no stereotypes and discrimination against women emerged.

On the other hand, as showed by current literature on this topic, social conditions of origin, having suffered or experienced family violence, infant abuse, and abandonment represent factors that significantly affect the different forms of violence against women. Another issue raised by almost all respondents is the use of physical strength, money, criminality or semi-criminality to gain power and respect. The participants use this kind of behaviour in their relationships with women, reproducing dynamics of gender inequality and discrimination and building relationships based on the possession and control of women.

---

[11] “Between offenders and victims. Breaking down stereotypes, banishing violence”, a project funded by the regional programme “Progettare la parità in Lombardia”, 2012.

[12] The ten interviews were conducted in cooperation with CIPM (Centro Italiano per la Mediazione) and a team of criminologists, psychologists and social workers working at the “Talk with him” project.

6. Conclusions

To conclude, a comparison between the work done by social workers during the writing workshop[13] and the interviews with sex-offenders shows some intertwined dynamics between victims and sex-offenders, as a social worker points out: “there is no victim without an abuser and vice versa”. This is a ‘hard’ statement, despite its alleged realistic analysis, perhaps expressing a prejudice on the part of social workers (Adami & Basaglia, 2002) who daily face painful and contradictory stories of women who are victims of violence and abuse. There is also evidence that violent dynamics, submission, silence and fear, and women’s expectation that the situation will change are accompanied by the expression of strength, control, aggression and terror exercised by men (Grimaldi, 2013). These trends – reinforced by gender inequalities and discrimination – reproduce rather than break the vicious circle.

The writing workshop has been carried out starting with three key words: aggressor, victim, violence. Once again, participants tell us about several violent acts, such as parents’ violence against their children, and children witnessing violence between their parents. Participants speak of a violence which is entirely internal to family relationships, something that Bartholini, as mentioned before, calls ‘proximity violence’ because it is a means of recognizing identity and a form of closeness relationship (Bartholini, 2013).

These stories are characterized by expressions of terror, helplessness, resignation. Once again, however, social workers emphasize the cycle of violence: abused and raped children, living in conflictual and/or degraded environments tend to reproduce the same relational mechanisms (Romito, 2005; Giulini & Xella, 2011). Women, on their part, tend to run into ‘strong’ and ‘dominant’ men who, in turn, are likely to seek ‘fragile’, ‘subordinate’ and ‘condescending’women: the latter accept violent acts with resignation or as part of a ‘normal’ male-female relationship. A vicious circle made of language, symbols, and specific communication categories produces and reproduces violent roles and dynamics in which, as Bourdieu argues: “[s]ymbolic violence is established through the adherence that the dominated grants to the dominant” (Bourdieu, 1998: 45).

As a matter of fact, vulnerability is considered to be one of the main risk factors. It is defined as the probability of someone being hurt by the dangerous behaviour of someone else (Nardacchione, 2009). According to Nardacchione, if the elimination of all the risks is an

---

[13] An action which is part of the same project mentioned in note 11.

abstract concept, in reality it seeks to achieve an acceptable level of risk: for women this means learning how to implement forecasting, prevention, protection and defence, all of which are activities aimed at reducing damage (*ibidem*).

The actions aimed at damage reduction are useful but not conclusive, and do not produce change. The research projects and activities carried out in the local municipalities, which we discussed in this paper, help us comprehend the social construction of gender violence and where and how violent behaviours generate and develop.

The next step is to understand and learn how to break the cycle and to implement relationships between genders and generations based on solidarity, respect, equality and dignity. Therefore, synergistic actions among institutions, social and educational services are needed as well as theoretical and empirical contributions which can ‘interfere’ with social structures (such as family, school, religion, politics, economy etc.) and ‘undermine’ the cultural roots of gender violence (Lombardi, 2016c). An example of this commitment is given by the measures which fight violence against women, implemented by the municipalities we targeted in our project. The experience of these municipalities started in 2009 with the widespread aim to fight violence against women by establishing a “Women’s Help Desk” and a territorial network of public administrations and services, non profit associations, hospitals, healthcare centres and workers’ unions. Municipalities have implemented a model of active governance by providing: a) training courses for social workers, psychologists, solicitors, teachers, policemen; b) information and awareness campaigns for students and for citizens; c) help and support for women victims of violence[14].

The governance action has had a very positive effect in the local area: since 2009, over 400 women have been received and supported in their path of sensitization regarding violent actions and they have been helped to exit from the violent contexts. The “Women’s Help Desk” is still active and the services' network has expanded and consolidated. Alongside the daily actions of the services to support women, awareness-raising activities have been intensified towards the population as well as the educational and cultural activities with adolescents and their teachers, about gender discrimination and violence.

---

[14] For more information on the processes for construction of networks and policies to fight violence against women, cf. Deriu (2015).

References

Adami C., and Basaglia A. (2002) “Riconoscere la violenza contro le donne. Il contesto dei servizi e degli operatori nelle città urban”. In Adami C., Basaglia A., and Tola V. [Eds.] *Dentro la violenza: cultura, pregiudizi, stereotipi.* National Report by “Rete antiviolenza Urban”, 73-98. Milan: FrancoAngeli.

Adami C., Basaglia A., and Tola V. [Eds.] (2002) Dentro la violenza: cultura, pregiudizi, stereotipi. National Report by “Rete antiviolenza Urban”. Milan: Franco Angeli.

Andersen M.L., and Taylor H.F. (2004) L’essenziale di sociologia, Bologna: Zanichelli.

——— (2013) Sociology: The Essentials. Wadsworth: Belmont.

Balbo L. (1978) “La doppia presenza”. *Inchiesta*, 32: 3-6.

Bartholini I. (2013) *Violenza di prossimità. La vittima, il carnefice, lo spettatore, il “grande occhio”*. Milan: Franco Angeli.

Bimbi F. [Ed.] (2003) *Differenze e disuguaglianze*. Bologna: Il Mulino.

——— (2015) “Onore e vergogna. Il ritorno di un paradigma mediterraneo nel dibattito europeo”. In Bartholini I. [Ed.] *Violenza di genere e percorsi mediterranei*, 27-44. Milan: Guerini e Associati.

Bourdieu P. (1998) *Il dominio maschile*. Milan: Feltrinelli.

Bozzoli A., Merelli M., and Ruggerini M.G. [Eds.] (2013) *Il lato oscuro degli uomini. La violenza maschile contro le donne: modelli culturali d'intervento*. Roma: EDIESSE.

Brownmiller S. (1975) *Against Our Will: Men, Women, Rape*. London: Secker and Warburg.

Chafetz J. (1984) *Sex and advantage*. Totowa, NJ: Rowman Allanheld.

Council of Europe (2011) Convention on preventing and combating violence against women and domestic violence. Council of Europe Treaty Series, No. 210, available at: https://rm.coe.int/168008482e.

Creazzo G. (2000) “I luoghi dell'accoglienza. Un punto di vista privilegiato sul fenomeno della violenza”. In Romito P. [Ed.] *Violenze alle donne e risposte delle istituzioni*, 65-82. Milan: Franco Angeli.

Deriu F. (2015) “L'osservatorio sulle donne vittime di violenza della Provincia di Roma: processi di costruzione della rete locale Solidea”. In Bartholini I. [Ed.] *Violenza di genere e percorsi mediterranei*, 135-50. Milan: Guerini e Associati.

EIGE [European Institute for Gender Equality] (2014) Estimating the costs of gender-based violence in the European Union. Luxembourg: Publications Office of the European Union.

Eisenstein Z. (1979) “Developing a theory of capitalist patriarchy and socialist feminism”. In Eisenstein Z. [Ed.] *Capitalist patriarchy and the case for socialist feminism*, 5-40. New York: Monthly Review Press.

EU FRA [European Union Fundamental Rights Agency] (2014) *Violenza contro le donne: un’indagine a livello di Unione europea*, available at: http://fra.europa.eu/sites/default/files/fra-2014-vaw-survey-factsheet_it.pdf.

EU Council (2014) *Preventing and combating all forms of violence against women and girls, including female genital mutilation*, Justice and Home Affairs Council Conclusions, available at: http://ec.europa.eu/justice/genderequality/files/jha_violence_girls_council_conclusions_2014_en.pdf.

Filosof F. (2000) “Violenza economica come contesto alla violenza domestica”. In Romito P. [Ed.] *Violenze alle donne e risposte delle istituzioni*, 39-48. Milan: Franco Angeli.

Giddens A. (2000) *Fondamenti di Sociologia.* Bologna: Il Mulino.

Gillioz L., De Puy J., and Ducret V. (2000) “La violenza domestica in Svizzera: nuovi dati su un fenomeno antico”. In Romito P. [Ed.] *Violenze alle donne e risposte delle istituzioni*, 83-96. Milan: Franco Angeli.

Giulini P., Xella C.M. [Eds.] (2011) Buttare la chiave? La sfida del trattamento per gli autori di reati sessuali. Milan: Raffaello Cortina Ed.

Grimaldi T. (2013) “La violenza domestica contro le donne: caratteristiche e frequenza”. In Romito P. [Ed.] Violenze alle donne e risposte delle istituzioni, 141-8. Milan: Franco Angeli.

ISTAT [Istituto Italiano di Statistica] (2007) *La violenza e i maltrattamenti contro le donne dentro e fuori la famiglia*. Roma: ISTAT.

——— (2015) *La violenza e i maltrattamenti contro le donne dentro e fuori la famiglia*. Roma: ISTAT.

Lombardi L. (2005) *Società, culture e differenze di genere. Percorsi migratori e stati di salute*. Milan: Franco Angeli.

——— (2016a) “Genere, salute e politiche sociali in Europa. La salute delle donne migranti tra diritti, accesso ai servizi, disuguaglianze”. *Fondazione ISMU Paper*, available at:

http://www.ismu.org/wp-contentuploads/2015/11/Merotta_fact sheet_ita_novembre_2015_Pagina_1.jpg.

——— (2016b) “Discriminazioni professionali e di genere in Libano: uno studio esplorativo”. In Bartholini I. [Ed.] *Radicamenti, discriminazioni e narrazioni di genere nel Mediterraneo*, 129-44. Milan: Franco Angeli.

——— (2016c) “La violenza contro le donne, tra riproduzione e mutamento sociale”. *Autonomie locali e servizi sociali*, 39(2): 211-34.

——— (2017) “Violence Against Refugee and Migrant Women. The Reproduction of Gender Discrimination and Inequality”. *Fondazione ISMU Paper*, available at: http://www.ismu. org/2017/05/violence-against-refugee-and-migrant-women.

Misiti M., and Palomba R. (2002) “La percezione della violenza contro le donne tra stereotipi e tolleranza”. In Adami C., Basaglia A., Tola V. [Eds.] *Dentro la violenza: cultura, pregiudizi, stereotipi*. National Report by “Rete antiviolenza Urban”, 41-72. Milan: Franco Angeli.

Nardacchione D. (2009) *Psicologia per l’autodifesa femminile*. Milan: Il dito e la luna Ed.

Reale E. (2000) “Vita quotidiana delle donne: rischi di violenza e di disagio psichico”. In Romito P. [Ed.] *Violenze alle donne e risposte delle istituzioni*, 49-64. Milan: Franco Angeli.

Romito P. (2000) *Violenze alle donne e risposte delle istituzioni*. Milan: FrancoAngeli.

——— (2005) *Un silenzio assordante. La violenza occulta su donne e minori*. Milan: FrancoAngeli.

Ruspini E. (2003) *Le identità di genere*. Roma: Carocci.

UN CEDAW [United Nation Committee on the Elimination of Discrimination against Women] (1992) *General Recommendation No. 19. Violence against women*, available at: http://www.refworld.org/docid/52d920c54.html.

UN OHCHR [United Nations Office for the High Commissioner for Human Rights] (2011) *Report of the Special Rapporteur on violence against women*, available at: http://www. ohchr.org/EN/Issues/Women/SRWomen/Pages/AnnualReports.aspx.

UN Women (2015) *Facts and Figures: Ending Violence against Women*, available at: http:// www.unwomen.org/en/what-we-do/ending-violence-against-women/facts-and-figures.

Zanfrini L. (2005) *La rivoluzione incompiuta. Il lavoro delle donne tra retorica della femminilità e nuove disuguaglianze*. Milan: Lavoro Ed.

——— (2016) *Introduzione alla sociologia delle migrazioni*. Bari/Rome: Laterza.

Sharing health information on Instagram: The patients' right to privacy

Leonardo S. de MORAIS[*]
Federal University of Pelotas

Vinícius A. DARGÉL
Pontifical Catholic University of Rio Grande do Sul

Márcia S. FERNANDES
Pontifical Catholic University of Rio Grande do Sul

José R. GOLDIM
Federal University of Rio Grande do Sul

ABSTRACT: This is a retrospective study with a qualitative-quantitative design whose main aim was how patients' right to privacy is handled by health professionals who post on Instagram images taken in restricted healthcare settings. Over a total of 1.574 free-access images analysed, 325 images violated patient's right to privacy as ruled by the Brazilian Civil Code. This finding adds evidence to the need that professionals working in intensive care units and surgical units receive a specific training on extent and implications of professional duties of confidentiality issues, and in particular the protection of patients' privacy. In addition, it is recommendable that the use of social media platforms by healthcare professionals at work should be restricted to those situations in which it may be justifiable in virtue of specific, predetermined reasons, and to condition that is fully compliant to privacy protection's requirements and the ethical principles of medical practice.

1. Overview

The popularity of social media is constantly increasing worldwide. Social media platforms like Facebook, Twitter, YouTube and Instagram provide a large panel of functionalities that allow users to collectively share data and personal information, including photos, audio, and videos. Social media platforms are frequently used by health professionals to share, in real time, images and videos that contain patient health records, patient

---

[*] Corresponding author: Leonardo S. de MORAIS | leonardostollm@gmail.com

identifiable data (Sullivan *et al.*, 2012; Williams *et al.*, 2014). Although Instagram is one of the most popular social media platforms[1], only few studies have explored the use of image sharing with patients depicted in healthcare settings (Moreno *et al.*, 2016). In this regard, preliminary research findings have showed that psychiatric patients may be negatively affected by image sharing on social media platforms (Cavazos-Rehg *et al.*, 2016; Correia *et al.*, 2016; Holland & Tiggemann, 2016). The aim of our study was to observe how individuals' right to privacy is handled in Instagram, given that, to our knowledge, a limited number of studies have been conducted in this field (Rozenblum & Bates, 2013), and none of them in Brazil.

2. The right to privacy in Brazil

In Brazil, privacy is considered a fundamental right; this includes privacy as a right of the human personality, expressed in specific codes, acts or laws. In Title II (Fundamental Rights and Guarantees), Chapter I (On Individual and Collective Rights and Duties), Article 5, the Federal Constitution (CRFB) of 1988 grants fundamental rights to the inviolability of the right to life and freedom and paragraph X specifically guarantees the inviolability of privacy, honour and the image of people (Brazil, 1988).

The Civil Code (Law 10,406 / 2002), General Part, Chapter II, articles 11 to 21, states the rights to personality of all human beings. The right to privacy is acknowledged in article 21: The private life of the natural person is inviolable, and the judge, at the request of the interested party, will adopt the necessary measures to prevent or terminate the contrary to this rule (Brazil, 2002). Right to privacy includes the protection of identifiable data, image and personal information, and foresees, among the other, preventive actions directed to avoid damage as established by article 12 of the Civil Code (Brazil, 2002). In the same way, the Civil Code established, in article 187, a general clause of unlawfulness act that is exercised with manifest violation of the limits imposed by its economic or social purpose, good faith or good customs (Brazil, 2002). In this case, it would mean the unauthorized transmission,

---

[1] Only in 2017, the platform had 700 million active users per month. See Instagram info center at: https://instagram-press.com/blog/2017/04/26/700-million/.

dissemination or publication of information, images, data or any source of information related to the patient's medical condition.

In Brazil, privacy’s protection of and confidentiality are also highlighted by the constitutional command in favour of children, adolescents and elderly. For instance, the protection of children and adolescents is regulated by the Child and Adolescent Act, Law 8.069/1990, while elderly’s protection is regulated by the Elderly Act, Law 10.741/2003 (Brazil, 1990; Brazil, 2003).

Taking deontological principles into consideration, health professionals, especially physicians, must respect the confidentiality of their patients’ personal and medical information as well as data and images that have been entrusted to them by patients. This obligation is emphasised in the Code of Medical Ethics issued by the Brazilian Medical Council (*Conselho Federal de Medicina* - CFM). The CFM Resolution n. 1.931/2009 (see Articles 73 to 79), as a rule, prohibits the physician from disclosing any information obtained by virtue of the exercise of the profession, except in cases in which the disclosure is due for legally established purposes. For example, if the patient consents to disclose their data, or disclosure is needed to protect concerned minors. However, it is prohibited to provide information to private subjects as insurance companies or to employers without patient’s consent and to cease confidentiality’ duty for reasons unrelated to professional needs (CFM, 2009).

It is important to emphasise article 75 of the Brazilian Code of Medical Ethics, which states that it is forbidden for the physician to refer to identifiable clinical cases, to display patients or their portraits in professional advertisements or in the disclosure of medical matters in general media, even with the consent of the patient (CFM, 2009). Depending on the severity and the circumstances of the case, a violation to the Code’ provisions may lead concerned professionals to a temporary or permanently loss of medical license. However, the respective punishment does not interfere with the civil or criminal responsibilities provided by law.

Brazilian legislation regarding protection of personality rights, including privacy, does not distinguish between dead or alive individuals. Therefore, the duty of confidentiality by healthcare professionals is valid even after the death of the patient. This situation is regulated in the Brazilian Civil Code (Brazil, 2002: art. 12), and also foreseen by the Code of Medical

Ethics (CFM, 2009: art. 73). Nonetheless, the prohibition of sharing identifiable data, personal information and images, and of breaching confidentiality or privacy has some exceptions. Breaching confidentiality or privacy may be justified for epidemiological reasons, such as reporting diseases or when there is a potential for abuses to children, adolescents and elderly people (Brazil, 2001: 86). It is important to note that in both circumstances the health institutions and professionals with whom the information is shared have the same responsibility to preserve this information, and this communication cannot be intended as a crime report (Morais, 2013; Saliba *et al.*, 2007). Its aim is indeed to inform authorities in order to allow them to take decisions with a view to protect individuals' rights.

It is worth reminding that even when a physician is called to testify in legal trial, the disclosure of information obtained for professional reasons is not acceptable according to the Code of Medical Ethics (CFM, 2009: art. 73), which protects professional secrecy and prevent professionals from revealing any information spontaneously or under intimidation. Lastly, in Brazil, the protection of confidentiality and preservation of patient information is not only a legal obligation under the civil law and the deontological code, but it is also ruled by the Penal Code. Revealing data to someone without just cause, or secrecy of which had knowledge because of its duties, ministry, trade or profession, and whose disclosure may cause harm to another, shall be punished with imprisonment from three months to a year (Brazil, 1940: art. 154).

3. Methods: a qualitative-quantitative design

This is a retrospective study with a qualitative-quantitative design. The research was carried out in August 2014 in the Laboratory of Research in Bioethics and Ethics of Science, Porto Alegre, Brazil. Images were identified through the Google search tool using the 7 descriptors listed in Table n. 1.

The descriptors were chosen because they potentially identify images of restricted access hospital areas that were published in Instagram. We selected images that were published in a 24-hour range (from 14th August, at 10am to 15th August, at 10am). A preliminary data analysis was done in January 2015. The qualitative study included only public images obtained by the Google search tool and posted by health professionals. For the analysis of images, we used the following categories: (A) identified patient, minor or of legal age of majority; (B) identified medical act, procedure exposure; (C) restricted circulation environment, with health institution identification involved. The images were pooled and evaluated based on its content.

DESCRIPTORS IN PORTUGUESE LANGUAGE	DESCRIPTORS TRANSLATED IN ENGLISH LANGUAGE	DESCRIPTORS ALLOCATED IN GROUPS
#BLOCOCIRURGICO	#OPERATINGTHEATRE	(a) OPERCENTER
#BLOCOCIRÚRGICO	#OPERATINGTHEATRE	(a) OPERCENTER
#UTINEO	#NEONATALICU - neonatal intensive care unit	(b) NEOICU
#UTINEONATAL	#NEONATALICU - neonatal intensive care unit	(b) NEOICU
#UTIPED	#PEDIATRICITU - pediatric intensive treatment unit	(c) PEDICU
#UTIPEDIATRICA	#PEDIATRICITU - pediatric intensive treatment unit	(c) PEDICU
#UTIPEDIÁTRICA	#PEDIATRICITU - pediatric intensive treatment unit	(c) PEDICU

Table n. 1 - Descriptors used during the research

Data was organized in three groups: (a) OPERCENTER, corresponding to the 2 descriptors #OPERATINGTHEATRE; (b) NEOICU, corresponding to the 2 descriptors #NEONATALICU; and (c) PEDICU, corresponding to the 3 descriptors #PEDIATRICITU. Image counting was done using the Counter Report program by Apple®. Data obtained were evaluated qualitatively using Bardin's approach on content analysis (Bardin, 2011), and the inferences were obtained through numerical descriptions generated statistically through the SPSS® program, version 18.0.

The study has collected data using public users' profiles available on Instagram, thus not involving direct contact with individuals. The project complies with the Brazilian national standards of research ethics established by the Brazilian National Health Council (CNS, 2012; 2016).

4. Sharing health information on Instagram: results

In total, 4 765 published images were identified, and 3 191 (64.08%) of the total were published on Instagram with restricted access. Therefore, most of the images published were not included in this study. However, this does not exclude ethical considerations on the potential disclosure of these images. An image being restricted in Instagram means that fewer users have access to it, however it is not possible to ensure that the privacy of patients and institutions involved are being kept confidential.

After applying the inclusion and exclusion criteria, 1 574 images with free access were found (33.03%) of the total collected photos remained for analysis. In the first group, called OPERCENTER, a total of 459 images (29.16%) were included. Of these, 102 images (19.61%) violated the right to privacy according to provisions of the Brazilian Civil Code (Brazil, 2002: articles 12 and 21); 81 out of 459 images (24.92%) identified a hospital environment of restricted access in which the health institution was exposed; and 21 out of 459 images (6.46%) allowed identification of the medical act by exposing the procedure in some way. In the second group, corresponding to the NEOICU, a total number of 835 images (53.05%) were identified; of these, 168 (20.12%) directly identified a patient seemingly underage. In the third group, denominated PEDICU, a total number of 280 images (17.79%) were identified; of these, 55 (19.64%) violated the patient's right to privacy, according to the Brazilian Civil Code; 39 images (12%) were related to children; and 16 images (4.92%) allowed identifying the medical act by exposing the procedure.

Over a total of 1 574 free-access images analysed, 325 images violated patient's right to privacy according to the Civil Code (Brazil, 2002) and the CFM Deontological Code (2009). Of the images, 63% identified a minor patient; 11.38% exposed a medical act, with demonstration of the surgical procedure; 24.92% registered a restricted access environment, with the identification of the health institution involved.

In category 1, the images were classified as violating the right to privacy because they contained patients' details allowing them to be identified. Images containing new-borns and/or children who were clearly underage, were also classified as an image of a minor patient. In category 2, images were classified as violating the right to privacy according to the above mentioned legal provisions and deontological obligations (Brazil, 2002; CFM, 2009) because they showed tissues or human body parts during a surgical procedure. In category 3, the images were classified as violating the right to privacy because they showed the health institution's logo and they had an exact location of the ICU or the surgical block, due to the use of check-in tools.

	IMAGES VIOLATING INDIVIDUALS' PRIVACY			
Category/Sub-category	GROUP			
	OPERCENTER	NEOICU	PEDICU	Total
Cat. 1: Images allowing patient being identifiable	0	168 (51.69%)	39 (12%)	207 (63.69%)
Sub. 1.1: patient underage	0	168 (5.69%)	39 (12%)	207 (63.69%)
Sub. 1.2: patient of age	0	0	0	0
Cat. 2: Images allowing identification of medical act	21 (6.46%)	0	16 (4.92%)	37 (11.38%)
Sub. 2.2: identification of medical procedure	21 (6.46%)	0	16 (4.92%)	37 (11.38%)
Cat. 3: Images taken from restricted access environment	81 (24.92%)	0	0	81 (24.92%)
Sub. 3.1: identification of the health institution	81 (24.92%)	0	0	81 (24.92%)
Total images	102 (31.38%)	168 (51.69%)	55 (16.92%)	
OTHER IMAGES				
Cat.4: Images compliant to privacy's rules	354 (28.34%)	667 (53.40%)	225 (18.01%)	1 246 (100%)
Sub. 4.1: images shared for sensationalist purposes	354 (28.34%)	667 (53.40%)	225 (18.01%)	1 246 (100%)
Sub. 4.2: images shared for educational purposes	0	0	0	0
Total images	354 (28.34%)	667 (53.40%)	225 (18.01%)	1 246 (100%)

Table n. 2 - Data Results

Results show that NEOICU is the setting with the highest incidence of published images on Instagram. As well, NEOICU is the setting in which underage patients may see their privacy violated more frequently (Table n. 2). In addition, some images were recorded during high complexity medical procedures, when the patients were visibly vulnerable and sedated in environments with restricted access (ICUs and surgical centers).

5. Discussion: the patients' right to privacy on Instagram

According to available literature in this field, the kind of health information shared online varies according to the specific features of each social media platform. For example, on YouTube, content analysis surveys show that health issues are mostly shared with the purpose of disseminating information on disease's prevention campaigns (Williams *et al.*, 2014). On Twitter, shared news involves predominantly alerts on new health treatments (Holland & Tiggemann, 2016). Facebook is used to promote support of colleagues and patients with health problems or rare diseases (Jain, 2009). However, it is important, to emphasise that none of the major social platforms may guarantee full protection against violation privacy breach.

Although it has been claimed that sharing images related to healthcare settings may have a fundamental role in educating professionals, promoting prevention activities and fostering health promotion (Eckler *et al.*, 2010), health professionals should be aware of patient's rights as well as of the provisions of medical ethics that provide patients with specific needs of protection. From a legal point of view, Brazilian legislation (Brazil, 1988; 2002) and the Code of Medical Ethics (CFM, 2009) guarantee the right to privacy of patients also by stigmatising images-related sensationalism and personal self-promotion through sharing content taken by healthcare settings (CFM, 2015: 131). The protection of right to privacy in the Brazilian legal order includes patient' self-determination, i.e. the right to determine who can use and access data and information related to them (Fernandes *et al.*, 2015). However, there is growing evidence that privacy protection in healthcare settings is deficient, especially due to frequent use of social media by healthcare professionals (McKee, 2013; Sullivan *et al.*, 2012; Villas-Bôas, 2015). As a matter of fact, many training scholars and health professionals lose sight of ethical requirements associated with the profession, among which the fundamental values underlying right to privacy and duty of confidentiality.

The results of our study indicate healthcare professionals publish more images in the following hospital settings: intensive care units (ICUs) and surgical blocks (see Table n. 2).

These sites are characterised as ‘restricted access’ sites to ensure the integrity and control of infections in patient care and health care. More in general, the results show that health professionals underestimate image-sharing on social media platforms, which have been described as ‘open public spaces’ (Lévy, 2012). Therefore, it is recommended that professionals working in intensive care units and surgical units receive a specific training on ethical and legal issues ensuing from professional duty of confidentiality and the needs of protecting patients’ privacy. Moreover, the use of social media platforms by healthcare professionals at work should be restricted to those situations in which it may be justifiable in virtue of specific reasons – e.g. for educational purposes –, and it is compliant to privacy protection’s requirements and ethical principles of medical practice (Eshah, 2018).

Despite we metaphorically live in a ‘Spectacle Society’ in which ‘being seen’ can be more important than merely ‘be’ (Debord, 1967), we conclude that healthcare professionals cannot elude its pivotal role and the special responsibility they assume with regard to observing ethical principles and guaranteeing that patients’ rights are respected.

6. Final considerations

The main finding of our study is that from every five images published in Instagram related to healthcare’ settings, at least one appears to violate individual right to privacy. This finding adds evidence to the fact that healthcare institutions should promote a specific education of professionals in regard of images sharing, use of social media platforms at work. This kind of educational activities may improve the overall awareness by healthcare professionals on the ethical implications of their actions, which are especially relevant for the protection of privacy and confidentiality of patients’ health information. This is especially due when considering paediatric patients, as insofar they are to be seen as a very vulnerable category of patients[2].

---

[2] The right of children and adolescents’ to privacy is supported by the Brazilian Society of Paediatrics and the Brazilian Federation of Gynaecology and Obstetrics’ Societies (Brazil, 1995) and is also regulated by the Statute of the Child and Adolescent ‘ECA’ (Brazil, 1990) and the Code of Medical Ethics (CFM, 2009). Although the Brazilian Civil Code (Brazil, 2002) establishes the civilian majority at 18 years (a definition that changes the legal requirements related to autonomy), the right to privacy is guaranteed to all human persons, including adolescents and children.

Acknowledgments

This work was supported by the Laboratory of Research in Bioethics and Ethics in Science based at Porto Alegre Clínicas Hospital (LAPEBEC/HCPA).

We sincerely thank Louise Delaney, Júlia Delaney and Aroldo A. Dargél, for the reviews and valuable comments and suggestions.

References

Bardin L. (2011) *Análise de conteúdo*. São Paulo: Edições 70.

Brazil (1940) *Brazilian Penal Code*, available at: http://www.planalto.gov.br/ccivil_03/decreto-lei/Del2848compilado.htm.

Brazil (1988) *Federal Constitution of Brazil*, available at: http://www.planalto.gov.br/ccivil_03/ constituicao/ConstituicaoCompilado.htm.

Brazil (1990) *Statute of the Child and Adolescent,* available at: http://www.planalto.gov.br/ccivil_03/leis/L8069Compilado.htm.

Brazil (1995) *Resolution n. 41 of October 13th on Rights of Hospitalized Children and Adolescents*, available at: http://www.mpdft.mp.br/portal/pdf/unidades/promotorias/pdij/Legislacao%20e%20Jurisprudencia/Res_41_95_Conanda.pdf.

Brazil (2001) *Ordinance by Ministry of Health n. 1,968 of October 25th*, concerning the notification to the competent authorities of cases of suspected or confirmed maltreatment against children and adolescents, available at: http://bvsms.saude.gov.br/bvs/saudelegis/gm/2001/prt1968_25_10_2001_rep.html.

Brazil (2002) *Brazilian Civil Code*, available at: http://www.planalto.gov.br/CCivil_03/leis/2002/L10406.htm.

Brazil (2003) *Brazilian Act. Senior Citizens' Statute. n. 10.741*, available at: http://www.planalto. gov.br/ccivil_03/leis/2003/l10.741.htm.

CNS [Conselho Nacional de Saúde] (2012) *Resolution n. 466/2012*, available at: http://conselho.saude.gov.br/resolucoes/2012/Reso466.pdf.

——— (2016) *Resolution n. 510/2016*, available at: http://conselho.saude.gov.br/resolucoes/2016/Reso510.pdf.

Cavazos-Rehg P.A., Krauss M.J., Sowles S.J., and Bierut L.J. (2016) "Marijuana-Related Posts on Instagram". *Prevention science*, 7(6): 710-20.

CFM [Conselho Federal da Medicina] (2009) *Code of Medical Ethics*, available at: http://www.rcem.cfm.org.br/index.php/cem-atual.

——— (2015) *Resolution n. 2.126/2015*, available at: http://www.portalmedico.org.br/resolucoes/CFM/2015/2126_2015.pdf.

Correia R.B. LI L., and Rocha L.M. (2016) "Monitoring potential drug interactions and reactions via network analysis of instagram user timelines". *Pacific Symposium on Biocomputing*, 21: 492-503.

Debord G. (1967) *La societé du spectacle*. Paris: Gallimard.

Eckler P. Worsowicz G., and Rayburn J.W. (2010) "Social media and health care: an overview". *PM R*, 2(11): 1046-50.

Eshah N.F. (2018) "Investigating Cardiovascular Patients' Preferences and Expectations regarding the Use of Social Media in Health Education". *Contemporary nurse*, 54(1): 52-63.

Fernandes M.S. Ashton-Prolla P., Moraes S.L., Matte U.S., Goldim J.R., and Martins-Costa J. (2015) "Genetic information and biobanking: a Brazilian perspective on biological and biographical issues". *Journal of community genetics*; 6(3): 295-99.

Holland G., and Tiggemann M. (2016) ""Strong beats skinny every time": Disordered eating and compulsive exercise in women who post fitspiration on Instagram". *The International journal of eating disorders*, 50(1):76-9.

Jain S.H. (2009) "Practicing Medicine in the Age of Facebook". *New England Journal of Medicine*, 361(7): 649-51.

Lévy P. (2012) "The Unfinished Mutation of the Public Sphere". *Signo y Pensamiento*, 31(60): 96-103.

Martorell L.B., Nascimento W.F., Garrafa V. (2016) "Redes sociais, privacidade, confidencialidade e ética: a exposição de imagens de pacientes no facebook". *Interface - Comunicação, Saúde, Educação*, 20(56): 13-23.

Mckee R. (2013) “Ethical issues in using social media for health and health care research”. *Health policy*, 110(2-3): 298-301.

Morais L.S., Fernandes N.C., Genro B.P., Fernandes M.S., Goldim J.R. (2013) “Revelação de diagnóstico de AIDS para terceiros: aspectos éticos, morais, legais e sociais”. *Revista HCPA*, 33(3-4): 279-85.

Moreno M.A., Ton A., Selkie E., and Evans Y. (2016) “Secret Society 123: Understanding the Language of Self-Harm on Instagram”. *The Journal of adolescent health*, 58(1): 78-84.

Rozenblum R., and Bates D.W. (2013) “Patient-centred healthcare, social media and the internet: the perfect storm?” *BMJ quality & safety*, 22(3): 183-6.

Saliba O., Garbin C.A.S., Garbin A.J.I., and Dossi A.P. (2007) “Responsabilidade do profissional de saúde sobre a notificação de casos de violência doméstica”. *Revista de Saúde Pública*, 41(3): 472-477.

Sullivan S.J., Schneiders A.G., Cheang C., Kitto E., Lee H., Redhead J., Ward S., Ahmed O.H., and McCrory P.R. (2012) “What”s happening?’ A content analysis of concussion-related traffic on Twitter. *British Journal of Sports Medicine*, 46(4): 258-63.

Villas-Bôas M. E. (2015) “O direito-dever de sigilo na proteção ao paciente”. *Revista Bioética*, 23(3): 513-23.

Williams D., Sullivan S.J., Schneiders A.G., Ahmed O.H., Lee H., Balasundaram A.P., and McCrory P.R. (2014). “Big hits on the small screen: an evaluation of concussion-related videos on YouTube”. *British journal of sports medicine*, 48(2): 107-11.

Authors' bionote

Carlo Botrugno is postdoctoral researcher at L'Altro Diritto Interuniversity Research Centre on Penitentiary, Deviance, Marginality and Migrations' Management, which is based at the Department of Legal Sciences of the University of Florence. He established and currently co-coordinates the Research Unit on Everyday Bioethics and Ethics of Science (RUEBES) together with Joana R. Zózimo. Among his main research interests are: biolaw, bioethics and medical ethics; information technologies and technological innovation in healthcare; human rights, discrimination and citizenship; migrations, vulnerability and social determinants of health.

Graça Carapinheiro is full professor at the Department of Sociology of the School of Sociology and Public Policy of ISCTE-Lisbon University Institute. In the 80s has made part of the Center for Research and Studies in Sociology's (CIES) foundation, where she has been developing research in Sociology of Health and is nowadays co-coordinator of Group 3: "Family, Generations and Health". She has inaugurated the Sociology of Health in Portugal with the doctoral thesis, later on published in book, "Knowledge and power in the hospital. A sociology of hospital wards" (1st edition: 1993). Her current research topics include health and illness in current societies; medical profession; power in caring professions; health policies and health governance; patients careers in the health systems. She has received three scientific awards: in 2011, the Paulo Elias Prize by the Paulista Public Health Association (Brazil) and two Ciência-IUL Awards, in 2015 and 2017.

Vinícius A. Dargél is a general practitioner who works for the Brazilian Government in the Public Health System and a researcher at the Laboratory of Research in Bioethics and Ethics in Science (LAPEBEC / UFRGS) at the Hospital de Clínicas de Porto Alegre (HCPA). His main areas of interest are Medicine, Ethics, Memory and neuroprotective strategies.

Inês Faria has a PhD in Medical Anthropology from the University of Amsterdam. In 2016 she started working as a post-doc fellow at the Research Centre in Economic and Organizational Sociology of the Lisbon School of Economics and Management of University of Lisbon, where she is developing research about ‘alternative’ and mainstream financial uses of blockchain technology. Within the area of medical anthropology her interests are currently focused on Mozambican couples’ processes of coping with infertility, their national and transnational therapeutic quests for fertility, and the social and medical aspects that influence, and are affected by, couples’ therapeutic navigations.

Marcia S. Fernandes is doctor in Law and post doc in Medicine: Health Sciences, UFRGS. Researcher at Research Laboratory of Bioethics and Ethics in Science (LAPEBEC) and Professor of Post-Graduate Program (Masters Degree) in Clinical Research at Hospital de Clínicas de Porto Alegre (HCPA). She is a post-doc researcher at Catholic University of Rio Grande do Sul (PUCRS). She does research on the interface of Law with Bioethics, focussing on genetics, biobanks, technological innovation in healthcare, intellectual property, privacy and data protection.

Stefano Fuselli is full professor of Philosophy of Law at the University of Padua (Italy), where he currently teaches Philosophy of Law, Legal Argumentation and Legal Logic. His main research fields are related to Hegel’s logic and philosophy of punishment; Theory of evidence and legal reasoning; Law and Neuroscience.

José R. Goldim is doctor of Medicine: Medical Clinical Science, head of Bioethics Service, and head of Research Laboratory of Bioethics and Ethics in Science (LAPEBEC) at Hospital de Clínicas de Porto Alegre (HCPA). Professor in the School of Medicine for the Post-graduation degree, Master's and PhD level at Federal University (UFRGS) and Catholic University of Rio Grande do Sul (PUCRS). He coordinates research lines on clinical bioethics in its various aspects, among them decision-making processes and informed consent.

LIA LOMBARDI is adjunct professor in Sociology and Sociology of Health and Medicine at University of Milan; senior researcher and project manager at Fondazione ISMU, Health and Welfare Department. Gender, Health, and Migration are the main fields of her studies, with special attention on Mediterranean countries. She is member of ESA RN16 (Sociology of Health and Illness) board, and of SISS (*Società Italiana di Sociologia della Salute*) board. For the ISMU Foundation, she currently is scientific leader and coordinator of two international JUST projects: PROVIDE (Proximity On VIolence: Defence and Equity", and SWIM (Safe Women in Migration. Strengthen GBV protection for migrant and asylum seeker women).

LETIZIA MINGARDO is professor on contract in Methodology and Legal Informatics at the University of Padua (Italy). Her main research fields are related to Critics of Law & High-Tech, Biolaw and Bioethics. In this field, in 2012 she won the Ruffini Prize awarded by the Italian *Accademia dei Lincei* (Italy).

LEONARDO S. DE MORAIS is professor of Civil Law at the Lato Sensu Postgraduate Program in Civil Law at the Catholic University of Pelotas (UCPEL). He is a researcher at the Laboratory of Research in Bioethics and Ethics in Science (LAPEBEC/UFRGS) at the Hospital de Clínicas de Porto Alegre (HCPA). His area of study and concentration is Civil Law, Bioethics and Methodology.

ANNA PROKOP-DORNER is a sociologist and psychologist researching and teaching at the Jagiellonian University Medical College in Krakow, Poland. Her scientific interests lie in the field of medical sociology and research methodology. Her research has been focused on mental health-related stigma, family caregivers' experience, cross-cultural comparisons of programs of health promotion as well as development of qualitative and quantitative research tools.

INÊS VIEIRA has a BSE in Childhood Education (ESE/P. Porto), and a MSc in Human Ecology and Contemporary Social Problems (FCSH/NOVA). She is currently a PhD candidate with a project in Human Ecology (FCSH/NOVA), and a researcher at CICS.NOVA, FCSH/NOVA, having received research and science management grants in European and national projects on issues related to mobilities/migrations, territory, education and youth representations. Her current research interests include the mobility-environment nexus, the Mediterranean area as a territory of mobility, and intercultural issues in urban areas.

JOANA R. ZÓZIMO is a researcher at the Lisbon Institute of Global Mental Health from NOVA University of Lisbon. She co-coordinates, with Carlo Botrugno, the L'Altro Diritto Research Unit on Everyday Bioethics and Ethics of Science (RUEBES), based at the University of Florence. Her main research interests are related to mental health and illness, care, medicalization and psychopharmaceuticalization, ethics, epistemology and methodology. She is currently finishing her doctoral thesis, in Sociology, on 'good' care for people with severe mental illness, for which she collaborates with *Centro de Estudos Sociais* from the University of Coimbra.

L’altro diritto. Rivista
Edited by Pacini Giuridica, Pisa - ISSN 1827-0565
Issued on November 2018