

Introduction

Freedom and healthcare: Turning interconnections into relations

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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.

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