"Patient's lived experience"

New insights from the "scene" of deep-brain stimulation medical care

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Abstract

This editorial presents a special issue gathering four contributions about the patient's lived experience in the context of deep-brain stimulation. It aims at clarifying the meaning of such an experience and its scope for medical practice, the health system and its legal frame.

Keywords Patient's lived experience · Deep-brain stimulation · Chronic condition · Medical care · Research

Today, the idea that patient's lived experience is to be taken into consideration by medical teams becomes a standard to assess the goals and the quality of patient care in many societies and health care systems. In the academic field, it has become a core element of narrative ethics, Medical Humanities and the more recent Health Humanities. This perspective sometimes goes along with the idea that "Medicine" has somehow become "inhuman" (Gaille 2010; Ferry-Danini 2018); it is also associated with the conviction that "Humanities"—whatever disciplines this term may relate to within each society—may contribute to a special degree to reform patient care (Greaves and Evans 2000). Social sciences, philosophy, literature and psychology seem especially committed to deal with this topic, in relationship with questions and matters about the human experience often viewed as central to them as disciplines.

Several reasons may account for the expression of the lived experience of illness and for the attention given to it in present times. First of all, within the context of the significant development of chronic conditions worldwide, sociological and psychological investigations have been carried out on the daily impact of disease since the 1960s. These investigations have often emphasized that "behind" the patient or the sick individual, there is always a person

that should be reminded of and placed to the fore of medical and social concern. The interest for the lived experience of illness, and specifically that of the patient, has also developed in relationship with the growing role of the patient in the medical decision for the past 40 years. This dynamics has also directed attention toward the patient's voice. Finally, the development of patient care based on the participation of the patient may also have contributed to the growing attention paid to patient's lived experience: a better understanding of this lived experience has been seen as a means to involve the patient as an actor of medical care.

However, what are patients' lived experience and its normative scope remain unclear. As a "one size fits all formula", the "patients' lived experience" must be examined in order to go beyond its apparent obviousness and to understand its present meaning and scope. The patient has an experience which may be seen as a source of a knowledge about the disease, but in the same time, she is an "object" of medical intervention. Without confusing it with that of a sick person (who is not necessarily a patient), we thus need to clarify its content and to examine how and to which extent it changes medical care. We also need to grasp how it is elaborated within the "medical work" and beyond the medical area: in both cases, it may contribute to tailor medical care and in the same moment, be modelled by it (Meyers 2010, 2013; Gaille 2019).

This understanding, to us, requires an investigation based in specific medical contexts, in order to avoid adventurous generalities. In the present issue, we propose to contribute to it with a focus on a specific medical practice based on

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deep-brain stimulation care in the fields of neurology. This focus was made possible thanks to NormaStim, a project aiming at determining the ethical, legal and anthropological issues of deep-brain stimulation. Funded by the French National Research Agency,¹ it took place between 2014 and 2017. In order to elaborate a multidisciplinary approach to these issues, this project gathered researchers from various disciplines—legal experts, philosophers, anthropologists and sociologists, all interested in the history of neurosciences and in the epistemology and ethical issues of a medical practice that is at the interface between experiment and daily clinic.

One of the goals of the project was to investigate the forms of life and the forms of care associated with deep brain stimulation. Two issues appeared to be crucial in this respect: how the medical teams could meet the challenge of having to deal with long-term patients whose disease cannot be cured and for which, ultimately, deep-brain stimulation would cease to be efficient? How patients would experience a care that is, as we said earlier, at the interface between experiment and daily clinic?

We dedicated an international workshop to exploring the lived experience of the patient in such a context (December 6th 2016, Paris, France). This workshop showed how necessary is both an international and multidisciplinary approach in order to acknowledge that the meaning of patients' lived experience and its normative scope are shared matters but that it cannot receive a simple or general answer. Each economic, social, institutional, and cultural context gives its own "tints" to every aspect of this lived experience. In this workshop, the questions raised about the forms of life and the forms of care associated with deep brain stimulation were also approached with a special attention to the literature on chronic condition and the insights it offered to examine them. The shared analysis of the strategies elaborated by the medical teams to take into account the patients' lived experience proved enlightening: deep brain stimulation care has determined specific organisations in terms of medical, psychological and technological competences and space arrangements within the hospitals for the past 10 years. In addition, the workshop made it clear that the patients' relationship to technologies is an essential and complex part of their lived experience. Finally, the workshop hinted at the fact that a "solipsist" approach of the patient's experience makes no sense. It appeared necessary to develop an approach of the "patients' lived experience" that could go

beyond its conception as a self-contained world, and reveal its social dimension.

This special issue is an attempt to display, highlight and examine the complexity of the patients' lived experience in the context of deep-brain stimulation care in the fields of neurology, such as foreseen in this workshop. It aims at giving a picture that will make us able to assess its specificity, to formulate questions that may be relevant for other clinical contexts, and to consider the normative scope of such an experience, not only from an ethical but also legal including from a legal point of view. The four papers gathered here offer an examination on different levels: (1) sociological and anthropological exploration of practices; (2) epistemological and conceptual examination based on fieldwork's results; (3) study of legal system.

Anthropologist Aurélien Troisoeufs' contribution highlights the necessity to go beyond the medical setting to find sources about this patients' lived experience. His study, "*Deep Brain Stimulation on Internet forums: what type of lived experiences do they tell us about?*", aims at describing the experiences of deep brain stimulation as discussed on Internet forums (Troisoeufs 2019). Since the 2000s, increasing attention has been paid to health practices associated with the use of the Internet, whether by medical professionals, public authorities or researchers in the social sciences. Indeed, the Internet is used by patients with Parkinson's disease, in order to discuss their lived experiences. This contribution presents how these Internet users address the specific theme of deep brain stimulation. It examines how their use and the information sharing associated to it participate in the "shaping" of the lived experience of deep cerebral stimulation. Without seeing the Internet in isolation from their broader social life, it also considers if the web allows them to tackle some of their issues in a specific way. On the basis of the state-of-the-art in sociological and anthropological international research on the topic of "Internet health", A. Troisoeufs proposes a framework to describe and understand the various uses of the web that are made to give an account of the experience of stimulation. For our present reflection, this study is of special interest first as it examines discussions that fully express a desire to share this lived experience, and thus show their social dimension; second, even if these discussions take place outside of a medical setting, they maintain a medical view of Parkinson's disease and of its contemporary treatments. One cannot say that Internet forums are a "space" for patients' expression cut from the medical stage.

In her contribution, "*The multiple temporalities of deep brain stimulation (DBS) in Greece*", historian of science Marilena Pateraki reveals an essential dimension of patients' lived experience that the previous contribution let us foresee: the temporal dimension (Pateraki 2019). On the basis of a qualitative study that led her to interview persons with

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Parkinson's disease, caregivers, and medical professionals, she develops an empirical and philosophical investigation about the temporalities surrounding the implementation of deep brain stimulation in contemporary Greece. This investigation leads her to raise the issue of access to deep brain stimulation medical care, and to show how distinct temporalities are implied when the patients are faced with the disease and the issue of care access: that of linear time, linked with the medical discourse; the broken time linked to bureaucratic and financial hurdles in the implementation and maintenance of deep brain stimulation; and what she calls the technological time of the body/technology fusion. She both analyses the impact of technology and health care settings on the lived experience of patients and the enactment of multiple bodies, which are interrelated with the social world. The latter aspect allows her to elaborate the idea that the patient's lived experience cannot be a solipsistic one, or specific to one physician/patient relationship, but is fully socially shaped.

Sociologists John Gardner and Narrene Warren examine how medical action proceeds in order to take into account the patient's experience with a concrete example. In their contribution, "*Learning from Deep Brain Stimulation - The fallacy of techno-solutionism and the need for 'regimes of care'*", they start from the apparent paradox according to which deep brain stimulation is an effective treatment for the debilitating motor symptoms of Parkinson's disease and other neurological disorders (Gardner and Warren 2019). However, clinicians and commentators have noted that deep brain stimulation recipients have not necessarily experienced the improvements in quality of life that would be expected, due in large part to what have been described as the 'psychosocial' impacts of stimulation. They argue that, in order to realise its full potential and similar interventions, clinical services need to be arranged in such a way that these psychosocial dimensions are recognised and managed. Drawing on ethnographic research of a paediatric deep brain stimulation clinical service, they stress that the psychosocial effects of stimulation present us with analytically useful disruptions: they disturb and foreground deeply held assumptions relating to the individual, health and its treatment. Drawing on scholarship in medical sociology and Science and Technology Studies, they intend to show that clinical services should not ignore the relational dimensions of personhood brought to the fore, but rather develop a *regime of care* to take them into account. They finally provide an example of a regime of care, and conclude by reflecting on what other deep brain stimulation services might learn from this paediatric service.

Finally, the legal expert Sonia Desmoulin-Canselier sheds light on the necessity to integrate the research dimension of this medical care to the reflection and the correlative implications for the legal frame of deep brain stimulation (Desmoulin-Canselier 2019). Her contribution,

"*Patient's lived experience between medical research and care: Some legal implications*", shows that we cannot be fully content with the ethical-legal boundary that has been drawn between treatment and research for the past 50 years. According to this vision, treatment is aimed at achieving optimal therapeutic benefits for the individual patient, whereas the goal of scientific research is to increase knowledge, in the public interest. From this viewpoint, the patient's experience should be clearly distinguished from that of a participant in a clinical trial. In the case of deep brain stimulation, this presentation is a poor fit, for both the patient's lived experience and medical practice and research. The frictions may be explained by the specificities of the treatment (including surgery and medical devices) and of the pathologies concerned (chronic and evolutive), and by the characteristics of the medical team implementing the treatment. These particularities challenge the dominant frame of reference in medical bioethics and cause difficulties for the current legal framework in fulfilling its dual role: to protect patients while supporting the development of innovative treatments. This contribution begins with these observations, and suggests that we review legal provisions (especially in French and United States law) so that they are better adapted to the first-person needs and experience of the patient undergoing brain stimulation.

This multidisciplinary approach results in a critical and descriptive assessment of the idea of the "patient's lived experience", of the ways it is conveyed, and of the challenges it raises for the medical teams and for the health care systems, including its legal frame. On the basis of these contributions, the patient's lived experience in the context of deep-brain stimulation care in the fields of neurology appears as a complex chronic condition. Its temporal dimension is crucial: this condition evolves and its present care ends up in being helpless, though it allows a substantial improvement of the condition for years and longer lives for patients; it is also an experience of various timelines, that of treatment, that of the economic and institutional conditions of the treatment, and that of technology. Its social dimension also appears essential: first, the patient's lived experience is a shared experience to other persons, be it her proxies, her medical teams or anonymous correspondents on Internet. It is not a soliloquy. And it has some effect: the challenge of the patient's lived experience's integration into medical care has given place to imaginative and innovative experiments of new types of care. It is a challenge medical teams still face and will have to face in the future, as well as society at large through its healthcare system and legal framework. These insights about the patients' lived experience from the "scene" of deep-brain stimulation medical care are not necessarily to be generalised. However, besides highlighting identity or recognition issues, they allow us to reflect on

the production of new forms of life based on efficient and innovative forms of medical care.

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