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Phone: +(351) 217 903 024 | e-mail: administrador.repositorio@iscte-iul.pt
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Preface

Graça CARAPINHEIRO

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