

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

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**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.

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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<sup>1</sup> work on what is ‘good care’ for severe mental illness<sup>2</sup>, 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

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<sup>2</sup> 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”<sup>3</sup>. 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<sup>4</sup>.

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

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

<sup>4</sup> 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 20<sup>th</sup> 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<sup>5</sup> 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

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<sup>5</sup> 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 19<sup>th</sup> 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<sup>6</sup> 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<sup>7</sup> for?

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<sup>6</sup> 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&file Name= IB2015\\_Destaques.pdf](http://www.dgeec.mec.pt/np4/210/%7B$clientServletPath%7D/?newsId=116&file Name= IB2015_Destaques.pdf).

<sup>7</sup> 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'<sup>8</sup> 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<sup>9</sup>, 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<sup>10</sup>.

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).

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<sup>8</sup> 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.

<sup>9</sup> 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.

<sup>10</sup> 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<sup>11</sup>.

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

<sup>11</sup> 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<sup>12</sup>, 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.

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<sup>12</sup> 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 much 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<sup>13</sup>.

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,

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<sup>13</sup> 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<sup>14</sup>, 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

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<sup>14</sup> 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<sup>15</sup>.

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<sup>16</sup>? 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

<sup>15</sup> 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.

<sup>16</sup> 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<sup>17</sup>.

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

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<sup>17</sup> 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 reevaluating



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.



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