# IN THE "ETHICAL CROSSROADS" OF ETHNOGRAPHY: OBSERVING THE "CARE ENCOUNTER" AT THE ELDER'S HOME

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## INTRODUCTION

This chapter intends to reveal the "ethical crossroads" found by two ethnographers in their fieldwork involving observations of the "care encounters" which take place at elders' homes, as well as to describe and discuss the decisions that were taken in order to advance in the research process. Based on their fieldwork experiences, the authors conclude that they are in favour of a model of research ethics regulation which is flexible, inclusive (taking into account the perspectives of all intervenient actors in the research process), sensitive to all research methods, and confident in the "ethical sensitivity" of the researchers and professional organisations.

Following Hammersley and Atkinson (2007, 3), ethnography is a qualitative research approach in which the research work is undertaken "in the field"—that is, in real social settings rather than in artificial ones. In the process of gathering data, participant observation and informal conversations play a determinant role. Still following the same authors, data is collected according to a flexible and "open" research design, implying that the researcher defines some initial dimensions to observe and certain methods to use, but she/he remains conscious of other dimensions (some of them will unexpectedly emerge during her/his presence in the field and may require the mobilisation of other methods). The "open" and "on-going" nature of ethnography requires dealing with situations not initially foreseen, which can pose ethical issues that are difficult to resolve.

In the social sciences domain, the ethical regulation of research practices has developed over the last three decades, with "The Belmont Report" (NCPHSBBR 1979) standing as one of the fundamental milestones. This report established three basic ethical principles—respect for persons, beneficence, and justice—which inspired the creation of subsequent frameworks to address the ethicality of research issues across the Western world (Christians 2000, 140; Israel and Hay 2006, 35). However, the principles of "The Belmont Report" were established within the biomedical research context, making it difficult to transfer them to the context of social science research.

Concerning the specific domain of sociological research, we verify that currently the norm is that each national sociological association has its own code of ethics. At the European level, there is the "RESPECT code of Practice for Socio-Economic Research" (RESPECT project 2004), which intends to function as a voluntary code of ethics for the practice of socio-economic research in Europe. It is an "aspirational code" rather than a prescriptive one.

In addition to the professional codes of ethics, there is a wide range of literature on ethics in the social sciences. With regard to qualitative research—and more specifically, ethnographic research—a consensus has been reached on the need to respect privacy, to guarantee confidentiality, and to respect the principles of non-maleficence and beneficence (to avoid causing harm to participants and to try to provide benefits to participants and/or society).These ethical issues are enshrined in the RESPECT code and in the codes of ethics of national sociological associations.

However, there is another ethical issue addressed by the literature and professional codes of ethics on which there is no consensus. It is the issue of informed consent, defined as the voluntary participation in research on the basis of information about the research purpose and its processes, as well as about the participants' role and the potential risks for participants. Adler and colleagues (1986) called our attention to the divergence between the Chicago school of symbolic interactionism and existential sociology on the issue of informed consent. The Chicago school advocated that ethnographic research should be the result of a "joint venture" between the researcher and the participants, which implies complying with the principle of informed consent. According to the followers of this school, deception should be avoided and used only in very exceptional situations (Adler et al. 1986, 365). Bryman (2004, 508) designates this stance on research ethics as "universalism", which advocates that ethical principles should never be infringed upon. The RESPECT code and the codes of ethics of the Portuguese Sociological Association (APS 1992, 8) and the British Society of Gerontology (BSG, 212) are in favour of "overt" research on the basis of informed consent.

Contrarily, as outlined by Adler and colleagues (1986), authors in existential sociology, such as Jack D. Douglas, stand in favour of using "covert" ethnography and some sort of manipulation to "dig behind people's superficial self-presentations" (Adler et al. 1986, 367). Existential sociological theories justify these strategies on the grounds of utility: if covert ethnography was not used, some worlds would be unreachable (Adler et al. 1986, 368). According to Bryman (2004, 508), Douglas' stance with respect for deception is like saying, "anything goes (more or less)".This philosophy is followed by very few researchers and does not appear in any professional codes of ethics.

Some authors take a more moderate position regarding these issues (e.g. Fine 1993; Punch 1994; Descombe 2010), accepting that some level of deception might be necessary for the success of the research as the full disclosure of the research objectives could lead participants to change their behaviour—a phenomenon known as "reactivity" to the researcher. Punch (1994, 91) advocates the use of deception in certain circumstances because "some dissimulation is intrinsic to social life and, therefore, to fieldwork". Bryman (2004, 508) designates this stance as "situation ethics", in which deception can be admitted on a "case-by-case basis". The codes of ethics of the International Sociological Association (ISA 2001, 3) and the British Sociological Association (BSA 2004, 4-5) admit to resorting to "covert" research in situations where there is a reasonable expectation of reactivity to the researcher or when access to information is denied by those in power.

Nevertheless, there is an aspect of informed consent that generates greater consensus. It is the aspect related to the amount and type of information that should be given by the researcher to the participants at the beginning of the ethnographic research process. Since a lot of information is discovered in the course of the research (because the researcher cannot anticipate all the possible issues and potential risks to participants), the information given to participants prior to the stage of collecting data is inevitably incomplete and even vague (Fine 1993, 274; Larossa et al. 1994, 111; Murphy and Dingwall 2007, 2224-2225; Parker 2007, 2252-2253). Anticipatory informed consent, typical in the biomedical research context (in which it is possible to specify in advance the themes that will be addressed and the potential risks for participants), is not suitable to the qualitative social science research context, especially in the case of ethnography (Murphy and Dingwall 2007, 2230; Parker 2007, 2253). In ethnographic research, informed consent entails a developmental and creative process in which the researcher, as an ethical thinker, uses her/his "ethical sensitivity" to negotiate the research process and to minimize the potential risks to participants (Jokinen et al. 2002, 166; Murphy and Dingwall 2007, 2225; Parker 2007, 2253). Researcher access to some spaces and interactions could be allowed as the trust between her/him and the participants develop over time (Murphy and Dingwall 2007, 2225). Therefore, rather than a contractual and initial act, informed consent in ethnography is a relational and dynamic process that starts at the beginning of fieldwork and ends at the conclusion of it. This is the reason why Murphy and Dingwall stated that "ethical conduct of ethnographic research ultimately depends upon the personal integrity and ethical education of the researcher" (2007, 2231). The code of ethics of the BSA also stipulates that in field research, obtaining informed consent may be a process "subject to renegotiation over time" and not a "once-and-for-all prior event" (BSA 2004, 3). Moreover, it is important to add that sometimes consent is reached not on the basis of information but rather on the basis of trust (Israel and Hay 2006, 69).

In the following sections of this chapter, we will briefly characterise the Portuguese framework with respect to research ethics in the domain of the social sciences and will then describe the main elements of the fieldwork in which we found the "ethical crossroads". The largest section will be dedicated to the description of the "ethical crossroads", to the decisions made in order to advance in the research process, and to the justifications for these decisions. In the last section, we will discuss the "ethical crossroads" and the respective decisions, keeping in mind the national cultural context, relevant literature, and some professional codes of ethics.

## SOCIAL SCIENCE RESEARCH ETHICS IN PORTUGAL

In this section, we briefly present the ethics framework for social sciences research in Portugal. In this country, the issue of research ethics in the domain of the social sciences has not been fully debated, and the RECs are not institutionalised contrary to what happens in other European countries, such as the United Kingdom.

Table 1—The ethics framework for social science research in Portugal

| **European Level** |
|---|
| **Codes and Principles** |
| RESPECT Code of Practice |
| **National Level** |
| **Law** |
| Act on the Protection of Personal Data (Act 67/98of 26 October) |
| **Ethics Commissions/Councils** |
| National Commission on Data Protection |
| National Council on Ethics for the Sciences of Life |
| **Codes of Ethics of Research Funding Agencies** |
| The Foundation for Science and Technology does not have a code of ethics and does not request approval from an REC (Research Ethics Committee) when a research proposal is submitted in the domain of social sciences |
| **Professional Codes of Ethics** |
| Typically, each professional association, including the Portuguese Sociological Association, has its own code of ethics |
| **Local Level** |
| **Research Ethics Committees in the Domain of Social Sciences at Universities and Research Organisations** |
| Portugal has no traditions. Some were created very recently. |
| **Research Ethics Committees at Social Care Organisations** |
| They do not exist. Only the healthcare sector has some traditions regarding RECs. |

As we can see in Table 1, at the local level, there is no tradition of research ethics committees (RECs) at universities and research organisations with respect to the social sciences. For the past few decades, only the educational and research organisations in the domain of "life sciences" (medicine, biology, etc.) have had their own RECs. The largest Portuguese universities began to create RECs for social sciences only very recently. This is the case, for example, of the University of Oporto, which created an Ethics Commission in 2007 with the objective of promoting the creation of RECs in each Faculty and Research Centre. The University of Algarve and the Research Centre for Spatial and Organizational Dynamics, the host organisations of the authors of this chapter, still do not have an REC for social sciences. The RECs also do not exist in the Portuguese social care organisations. Only the organisations in the domain of healthcare—primarily the hospitals—have one or more REC.

At the national level, the main law related to research ethics is Act 67/98 of 26 October on the protection of personal data, which transposed Directive 95/46/EC of the European Parliament and the Council related to personal data and circulation of this data into the Portuguese legal system. One of the main issues addressed by Act 67/98 is the conditions under which personal data can be processed/analysed. It stipulates that this data may be processed only if their holders have given explicit consent. Other important issues are related to confidentiality and circulation of data, as well as to the access of information by its holders. The National Commission on Data Protection is the entity responsible for supervising compliance with this act.

In Portugal, there is no national commission/council on ethics for the social sciences, contrary to the treatment of the "sciences of life" (medicine, biology, and the health sciences in general). The National Council on Ethics for the Sciences of Life was created in 1990, one of the first councils of its kind in Europe.

Regarding research funding agencies, the Foundation for Science and Technology (FST) is the largest Portuguese agency for funding research, including social sciences research. Unlike the Economic and Social Research Council (ESRC), the largest organisation for funding social sciences research in the United Kingdom, the FST has not yet created a code of ethics; in the domain of the social sciences, the decision for funding does not depend on the level of ethical sensitivity of the proposals regarding the typical ethical issues found in the social sciences.[1]

In the domain of the social sciences, the oldest ethical frameworks were created by professional associations such as the Portuguese Sociological Association. The code of ethics of this association was introduced in 1992 and calls for guarantees related to confidentiality, anonymity, and avoidance of harm to participants. Concerning informed consent, this code states that "(…) sociologists should not violate the principle of willingness of providing information by individuals, populations and institutions" (APS 1992, 8). Thus, although the term "informed

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[1] The ESRC introduced its Framework for Research Ethics (FRE) in 2006, and since then, it has only funded research that demonstrates compliance with it.

consent" is not mentioned, this code argues that it should be obtained before proceeding with data collection.

Finally, at the European level, the only ethical tool in the domain of social sciences is the RESPECT code. As previously mentioned, this code is a voluntary code of practice, not a prescriptive one, and establishes three main principles: upholding scientific standards, compliance with the law, and avoidance of social and personal harm. Concerning the issue of informed consent, it advocates that participation in research should be voluntary and based on informed consent.

The under-discussion of ethical issues in the domain of the social sciences in comparison to the situations of other countries is also seen in the practices of reporting research results. Typically, the reports and articles disseminating social sciences research, in which human beings and personal data are involved, do not provide a section where ethical issues are identified and fully discussed. This does not necessarily mean that such research has a dubious ethical status. We believe that the great majority of the Portuguese research in the domain of the social sciences is ethical, as there are no known cases of social research with doubtful ethical integrity. Nevertheless, the lack of discussion on ethical issues in research reports and articles does not facilitate open and public discussion of ethical issues and codes of conduct.

In the next section we will present the main elements of the ethnographic fieldwork along which we have encountered several "ethical crossroads".

## THE ETHNOGRAPHIC FIELDWORK

Ethnography is one of the methods of collecting data that we used and it integrates our qualitative research project on the elders' experiences and various perspectives of receiving social care. This project, titled "The other side of the caring relation: the views of the older person" (ElderViews), is funded by the Foundation for Science and Technology (FST) and should be completed by late 2013.[2]

Within this research project, ethnography was chosen to observe the "care encounters" which take place at the elders' homes. In all of these encounters, there were home-care workers present, and in some cases, there were also family caregivers present. Thus, the elders' homes—or, more precisely, the elders' bedrooms in the majority of the cases—are the settings in which we undertake participant observations and have informal conversations.

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[2] The project website is http://elderviews.info/website/. Reports and other publications will be available in this website.

The access to research settings (elders' homes) was previously negotiated with a not-for-profit institution that provides social care, including home care, for older people. The first action we took was to request, by mail, a meeting with the institution's administration in order to explain the research objectives, the research practices involved, and the type of collaboration we would like to have from the institution. This request was accompanied by a photocopy of the research plan approved for funding by the FST. The meeting was conducted in the presence of the administrator and the directors of the day care centre responsible for home care. During the meeting, the ethnographers explained the "open" and flexible nature of qualitative research and underlined the fact that fieldwork did not have the goal of evaluating the quality of the services provided. The administration did not ask for specific guarantees. We also were not required to obtain the approval of an REC to undertake our research, because, as mentioned earlier, in Portugal, social care institutions do not have RECs. Permission to conduct the research was informally obtained during the meeting and later formalized by e-mail. It is important to add that the coordinator of this research, which is funded by the FST, had only to sign a form in which he declared that the research project did not involve animal experiments or tests on human tissues and cells (practices which do not exist in social sciences research projects).

In order to carry out the observations, we followed the home-care workers, who belonged to a not-for-profit institution that provides social care services for older people, in their home visits. We already followed visits to fourteen elders, a total of 108 visits until now (the field work is still in progress). Each visit lasts up to 15 minutes (making a total of about 1620 minutes of observations) and a majority of the elders receive two visits per day. In the cases of elders who receive two visits per day, these visits include providing body hygiene (including changing nappies) once in the morning and once in the afternoon (when the home-care workers go for body hygiene visits, they pick up dirty clothes from the elders, wash them at the day care centre, and bring them back to the elders' homes).The elders receive more than two visits per day when there is a need for body hygiene visits (one visit in the morning and the other in the afternoon) and for the delivery of meals (once or twice a day).Finally, there are elders who receive one visit per day (they do not receive body hygiene) and others who receive only one visit per week (for help with bathing only).

Therefore, while a majority of the elders receive intimate care in the most private rooms of the house (8 receive body hygiene, including changing nappies, and two receive help with bathing), others (4 cases) receive only socio-emotional care in the most public rooms of the house (conversation, checking if everything is well, etc.). We have been observing all of these latter "care encounters" and half of the former "care encounters" (in the other half, the elders did not give us permission to see the provision of body hygiene).

Regarding data collection, it should be noted that "jotted" notes were taken during or immediately after the home-care visits. In these latter cases, they were taken in the presence of the home-care workers. Nevertheless, it is important to emphasize that in the presence of the elders, the notes were taken with sensitivity and discretion.

In the following section, we reveal the six main "ethical crossroads" that we faced, some of which are still unresolved, and the decisions we made in order to advance in the research process, seeking, at the same time, to protect the participants' interests.

## THE "ETHICAL CROSSROADS"

We use the term "crossroads" instead of "dilemmas" because we feel that the former translates more accurately to the real situations we encountered, which correspond to ethical moments, where we felt uncomfortable, but had multiple possible "escapes". The decisions were made with the Portuguese Law and the code of ethics of the Portuguese Sociological Association in mind, but we were also sensitive to other codes, such as the codes of the ISA, BSA, and BSG, and the RESPECT code. The codes of ethics establish sets of principles, not sets of rules of conduct. As stated by Descombe (2010, 61), "The point is not that each principle should be *followed*, but that it should be taken into account and *considered*". This means that practical decisions should be based on the interpretation of the principles. A decision could be close to the "spirit of the principle" or distant from it. The higher the distance from the principle, the more attention should be given to the respective justification by the researcher (Descombe 2010, 61).

### Ethical crossroad I: Should we obtain informed consent only from the elders or also from other participants in the "care encounters" at the elders' homes?

Before we went to the field, we were tempted to obtain informed consent only from the elders, given that they are the central participants in the research. In this case, we would only ensure the anonymity of the other persons present in the "care encounters", such as the home-care workers and the elders' relatives, and try to make sure that the "secondary" participation of these participants does not cause them any harm. However, a doubt was growing in our minds: Who should we classify as a "research participant"—only the elders or also their caregivers too? On the other hand, who should we classify as a "caregiver"? This is the typical problem of "Where to set the limits"?

Concerning the first question, we finally decided that all the caregivers would be conceived as research participants, although they can be conceived as "secondary research participants". Considering that the objective of the fieldwork is to capture "what is going on" in the "care encounters" at the elders’ homes, it would be unfair, unjustifiable, and even discriminatory to obtain informed consent only from some of the actors. It would be impossible to examine the elders’ experiences of receiving care without looking also at the caregivers’ practice of providing care. In other words, data is collected from the caregivers and the elders.

In relation to the insertion of people into the category of "caregiver", we decided that only those who effectively provide care during the "care encounters" would be classified as caregivers. Someone we know to be an caregiver but who does not participate in the provision of care during the home-care visits would not be classified as a caregiver for the purpose of this fieldwork. For example, in one case we have information that there is a relative who is the main caregiver but she is not present during our visits. As this caregiver is not under ethnographic observation, there are no ethical issues in relation to her.

## Ethical crossroad II: Should we obtain an initial informed consent only from the elders or also from their caregivers?

In relation to the elders, we decided to obtain an initial informed consent as soon as possible at the beginning of the fieldwork, although with incomplete information, but in relation to the caregivers, including home-care workers, we decided to obtain informed consent after the end of the fieldwork. This means that during the fieldwork, the caregivers were under the impression that we were not observing them but were only observing the elders. This latter decision was made because we were concerned that by telling the truth to the caregivers, we could generate alterations in their behaviours (reactivity). Thus, between the possibility of obtaining consent from the caregivers early in the research process or not obtaining it at all, we decided to pursue a third "road": obtain it at the end. This issue will be further addressed later.

## Ethical crossroad III: In order to obtain informed consent, should we provide general information or detailed information?

Starting with the elders, we were unsure whether they had been informed by the directors of the day care centre before we began following the home-care workers. However, regardless of whether or not they were consulted, we had previously decided that we would seek informed consent directly from the elders.

The next decision to make was, "What kind and amount of information should we give them"? The first time we visited each elder, the home-care workers informed the elders that they were accompanied by people from the university and asked the elders if we could gain entrance.[3] All of the elders agreed. In the first encounter with each elder, we introduced ourselves, clarified our roles, and revealed the central research objective. On this last point, we could have provided more detailed information, but we decided to just give general information in a simple and clear manner, omitting the identification of potential risks resulting from participation in the research (e.g.: discomfort and stress), but guaranteeing confidentiality and anonymity. This decision has several justifications. First, we were convinced that except for very few cases, the elders would not fully understand the detailed information about the research objectives and could be even a bit confused (it is important to say that the vast majority have low levels of schooling). Second, the literature tells us that the potential risks of participation in social science research, particularly in ethnographic research, are primarily associated with discomfort, stress, and reduced self-esteem, and not with situations that seriously threaten the physical and psychological integrity of the participants (Larossa et al. 1994, 110; Murphy and Dingwall 2007, 2228). In addition, we thought that the potential harm of participating in our research, such as discomfort and stress, would be temporary and would disappear as the trust among participants and researchers strengthens. Thus, balancing the severity and duration of potential harm to participants, on the one hand, and potential risks to the research resulting from the disclosure of potential harm, on the other, we decided not to disclose the potential harm. Rather than providing detailed information, we believed that it would be more important to obtain the trust of the elders. In the first visits, our goal was to make the elders feel they could trust us. Finally, the detailed disclosure of the research objectives in the presence of the home-care workers (inevitable presence) and other caregivers could lead these people to think that we would assess their performance, which, with a high probability, would produce significant changes in their behaviour. A brief parenthesis to state that "reactivity" is a methodological issue which, in accordance with Hammersley (2003), should be addressed through a reflexive orientation from the part of the researcher. However, still following Hammersley, a concern with reactivity does

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[3] On some occasions (very few), the home-care workers presented us as "doctors" in order to easily obtain the elders' permission for our entry into their homes. However, we immediately corrected this "therapeutic misconception" (Locher et al. 2006, 161), clarifying our roles as academic researchers.

not imply a commitment with "naturalism", given that the researchers are not separated from the social reality.

In relation to the home-care workers, we know that all of them received information about our research from the directors of the day care centre and we assumed they gave consent to participate in the research. Nevertheless, we reaffirmed the research objectives to the home-care workers to gain understanding of the elders’ experiences and perspectives of receiving social care and asked them if they would be willing to "collaborate" with us. All of them showed willingness to collaborate.

Thus, we did not explicitly ask the home-care workers to give us their consent to participate in the research. Asking for their consent would implicate to inform them that they would also be observed by us. This disguised strategy is based on the following reasons. If we had informed the home-care workers that their behaviour would also be observed and recorded, this would lead to a significant change in their behaviour, as they would probably think that the collected information could be used by the administration to assess their performance. In a more pessimistic scenario, telling the truth to home-care workers could lead them to feel the need to boycott our research. The first author's experience as a performance evaluator of teachers showed him that the evaluator's presence changes, inevitably and significantly, the behaviour of the individuals. On the other hand, the disclosure of detailed information about research objectives and procedures, as well as the potential risks derived from participation, would produce unnecessary distress in the home-care workers.

As previously mentioned, we will disclose general information to home-care workers after the fieldwork is finished in order to obtain their "post-hoc" consent. The information that we are considering giving them will focus primarily on the unveiling that their behaviour was also observed and registered, on the clarification of the central objective of the fieldwork and on assurances about confidentiality, anonymity, and their right to access data related to them. Additionally, we will ask them for feedback on the final report (in the form of a summary) prior to sending it to the administration. Finally, as recommended by the code of ethics of BSG(2012), we will send a letter thanking them for their participation.

Regarding other caregivers, the situation is similar to that of the elders—that is, we are uncertain if these caregivers, such as family caregivers, were informed before we began following the home-care workers. Thus, we used the same strategy we used with the home-care workers: we clarified the research objective, in general terms, and asked them if they would mind "collaborating" with us. All of them agreed to collaborate. After finishing the fieldwork, we will adopt the same procedures with family caregivers as we will adopt with the home-care workers.

## Ethical crossroad IV: Should we obtain an initial and definitive informed consent or a "continuous" one from the elders?

Larossa and colleagues (1994, 117) emphasize that "… observing a family in their native habitat raises special ethical considerations.... The ambience of the home and the serendipitous quality of the setting and interaction thus raise special ethical dilemmas for [the] qualitative family researcher". Still following these authors, this means that the informal atmosphere of the home, which tends to be propitious to self-disclosure and friendliness, and the serendipity of family life (e.g. an unexpected event, such as a visit) could create some problems in terms of confidentiality, anonymity, and management of the relationship between the researcher and the participants.

Primarily, it is because of these characteristic of the home and family life that informed consent, once obtained at the beginning of the fieldwork, needs to be updated during the research process. These kinds of unexpected events have already taken place in our fieldwork. However, there are other aspects that lead us to negotiate informed consent in a gradual and tactful manner, as, for example, our initial timidity in asking the elders if we could assist with the provision of intimate care. In the first visits to the elders who require intimate care (body hygiene, including changing nappies), we could not even gain access to the bedroom. This space was presented to us as being very private and "sacred". Therefore, during the first visits, we stayed near the bedroom doors and moved away when the elders began receiving intimate care. As trust and rapport between the elders and us started building, we began to feel more at ease in asking the elders if we could stay in their bedrooms during the provision of intimate care. This type of process also occurred in relation to the informal conversations. However, the inverse process also occurred. In one case, after we felt confident in requesting permission to stay in the bedroom during the provision of intimate care, we obtained permission from the elder, but after observing the provision of intimate care twice, the elder’s spouse informed us that the elder did not feel comfortable with our presence. After this episode, we always exited the bedroom when home-care workers started the provision of intimate care.

Therefore, "on-going" informed consent was not an option, but a need—that is, something that was imposed upon us during the fieldwork.

## Ethical crossroad V: Should we obtain written informed consent or just oral consent?

In Portuguese society, signing a contract means that the issue in question is serious and that breaching of duties can lead to severe consequences for the parties involved. It is not typical, for example, for a person to sign a contract with a bricklayer when it is agreed that the bricklayer will perform a certain service in his/her house. It is also not typical for a person to sign a contract with a domestic employee in order to obtain domestic services from her/him.

With this in mind, we felt that asking the research participants to sign a piece of paper like a contract would generate apprehension, suspicion, and even distrust. In addition, not all of the elders would be able to sign due to their disabilities. Thus, we asked for oral consent from the elders and decided that we would also ask oral consent from the home-care workers and other caregivers present during the home-care visits. The request of consent was done (in the case of the elders) and it will be done (in the case of caregivers) in the presence of two ethnographers.[4]

## Ethical crossroad VI: Should we report negligence against an elder, or should we preserve his/her autonomy?

In one casein which the elder lives with a close relative, we identified indicators of negligence. At almost every visit (in the morning and afternoon),we found that the elder had fallen on the bedroom floor and was lying there with his pyjamas full of urine and faeces. In one visit, we found that he had a large hematoma on his head. In addition, the home-care workers suspect that he is underfed.

Given this situation of human indignity, we had two main options: to respect the autonomy of the elder and report the situation only at the elder's request, or to report it without the elder's request. However, there are several questions that are difficult to resolve: To what extent is the elder autonomous enough to make a decision? Do we need an explicit request or

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[4] One elder cannot speak due to his disability, but he can understand the conversations very well. In this case, consent was given through nonverbal communication. In another case, we were not sure whether the elder properly understood the information we gave him in order to obtain his consent. Consequently, when we had the opportunity to talk to the relative responsible for him, we obtained oral informed consent from this relative.

just an implicit one? Our informal conversations with the elder showed us that he was aware of the "terrible" situation he was in, but he did not have the capacity/courage to speak openly about it, much less to ask us for help. From an emotional point of view, it would be difficult to report neglect from a close relative.

In this situation, we decided to raise the awareness of the home-care workers to the fact that the elder is being neglected and that they should report the situation to the day care centre. We were informed that they had already done this. We decided not to report the situation directly to the directors of the day care centre in order to safeguard the position of the home-care workers. Had we proceeded with that, they could be accused of poor professional conduct by not reporting the situation.

## DISCUSSION AND CONCLUSIONS

Everett Hughes (1971), cited by Fine (1993, 267), had noted that there is an "underside" in all professional activities, that is, a certain "*modus operandi*" which is unknown to the general public. For example, in the medical surgeries there are some procedures which do not transpose the doors of the "theatre of operations". With respect to research, we suggest that this "underside" should be avoided, agreeing with Fine (1993, 268) when he advocates that "… it is crucial for us to be cognizant of the choices that we make and to share these choices with readers". This is what we have tried to do in this chapter.

All the "ethical crossroads" that we have found, except one which is primarily related to the protection of the elders’ autonomy, are related to informed consent. This confirms Fine’s statement (1993,274) that "The grail of informed consent is at the end of the twisted road of most ethical discussions".

Regarding informed consent, the "ethical crossroads" we found are as follows: From whom should we obtain informed consent? Should we obtain initial consent only from the elders or also from their caregivers? What kind of information should be given? Should we obtain initial and definite consent or "on-going" consent? Should we obtain written consent or oral consent? In turn, the respective decisions were as follows: We would obtain informed consent from the elders and the caregivers present at the home-care visits—an initial consent from the elders and a "post-hoc" consent from the elders’ caregivers; We would provide general information, omitting the potential risks in participating; We would obtain "on-going" and oral consent.

In our opinion, the decisions that raise more problems are as follows: asking for the consent of caregivers only after the fieldwork has been completed, and providing general information (to the elders and caregivers) without referring to the potential risks arising from participation in the research. The first decision implies a certain degree of deception and "covert observation", while the second decision implies omission of some information. The first decision was made for fear of causing harm to and reactivity in the caregivers, and the second decision was made for fear of causing harm both to the elders and caregivers, reactivity in the caregivers (via revealing detailed information to the elders), and misunderstanding of detailed information by the elders.

The fear of causing harm to the caregivers benefits their interests, whilst the fear of causing reactivity in the caregivers benefits the researchers' interests. However, if by protecting the researchers' interests we are simultaneously protecting the participants' interests, we think that the ethical status of the research is guaranteed. The question remains as to whether the caregivers will or will not be harmed after they learn the truth (that they were also observed). With the strategies we are planning to implement, we hope and remain optimistic that there will be no harm.

Therefore, regarding informed consent, our experiences in fieldwork lead us to agree with the "situation ethics" stance mentioned by Bryman (2004, 508), given that if we had not used some deception in relation to the elders' caregivers, we would not have been able to gather "genuine" data, or worse, we would not even have been able to conduct the fieldwork. In addition, if we had not omitted some of the information, we probably would have caused harm in both the elders and the caregivers. Consequently, we think it is reasonable to admit, in certain situations, to using some form of deception and disguising, as do the codes of ethics of the ISA and BSA. If we consider it unethical to resort to deception in any circumstance, we run the risk of contributing to the maintenance of the social invisibility of certain realities that threaten the rights and interests of the people involved.

With regard to definitive or "on-going" consent, we agree with the authors who defend the practice that in qualitative research, especially if it involves fieldwork, obtaining the participants' consent should be an "on-going" process in which the researchers use their "ethical sensitivity" to avoid social and personal harm. As we have seen, the code of ethics of the BSA foresees and advocates this procedure in the case of fieldwork. In our view, the process of obtaining consent ends only after we have obtained consent to publish the main results after the participants have had contact with them.

In relation to the form through which consent is obtained—whether written, verbal, or nonverbal—we suggest that we should be guided by the "situation ethics" stance. Regarding the forms, the real situation should be taken into account. The most important thing in our view is to provide the participants with enough space to think and decide. There is, however, an issue that is difficult to evaluate: To what extent are the participants truly free to think and decide? In our fieldwork, we are conscious that it would be difficult for the home-care workers to say "no" to the administration, as well as for the elders to say "no" to us, because, at least initially, they were likely to associate us with the "services side"—that is, they saw us as allies of the home-care workers. This means that power dynamics are always present in this kind of situation. In light of this, it is critical that after finishing the research process, participation has brought more benefits than harm (and if possible, no harm)to the participants.

Finally, there is the issue of "reporting or not reporting" the elder abuse and negligence. This is probably the most difficult decision a researcher has to make. Whenever possible, we think that we should try to conciliate the interests of all parties involved. As mentioned earlier, we tried to conciliate the elder's interest (protecting his autonomy to decide) with the home-care workers' interests (protecting their professional integrity). However, sometimes this conciliation is not possible. In these cases, we are inclined to say that the elders' interests should come first, because they tend to be in a vulnerable position.

To conclude, we feel that the most important factor regarding research ethics over the course of our fieldwork experience has been acting honestly and decently, always avoiding doing something that we would not like others to do to us if we were in the same situation, and not allowing our interests to outweigh the interests of the participants.

In this vein, contrary to the claims made by Hedgecoe (2008), we think that in qualitative research, especially if it involves fieldwork, the researchers are in the best position to decide on the ethical issues. This does not mean that we are against the existence of organisations and mechanisms of ethics regulation. Nevertheless, we agree that the existence of ethics frameworks with narrow and inflexible principles and guidelines-one of the components of what Haggerty (2004) termed "ethics creep", concept followed by other authors such as Fogel (2007) and Murphy and Dingwall (2007)-not only does not ensure a full respect for ethical principles from the beginning to the end of the research process, but also may result in other perverse effects. These include, for example, fewer innovative research projects from a methodological point of view (Haggerty 2004; Fogel 2007, ); less daring research projects in terms of settings and aims (Haggerty 2004; Fogel 2007), and preference for research that uses secondary data rather than primary data (Fogel 2007). But perhaps the most negative perverse effect is to maintain several social worlds characterised by human indignity and the violation of basic human rights invisible to society. This is the same as to say that strict ethics frameworks could go against the rights and interests of those they purport to protect. The solution for the "ethics creep" could be, in accordance with some authors, to "strength 'professional' models of regulation which emphasise education, training and mutual accountability" (Murphy and Dingwall 2007, 2231), to make the RECs more sensitive to qualitative research proposals (van den Hoonaard 2001, 32), and to evaluate the research proposals not only from the perspective of "universal" moral codes but also from the perspective of the research participants (van den Hoonaard 2001, 33). The promotion of a platform to share experiences and discuss ideas, either in basic training (Murphy and Dingwall 2007, 2231) or within the RECs (van den Hoonaard 2001, 33), in order to avoid the "moral panic" (van den Hoonaard 2001, 33) normally associated with the submission of research proposals to "scary" RECs, is another suggested solution. Concluding, we are in favour of a model of research ethics regulation which we could designate by "ethics friend", that is flexible, open to the perspectives of all intervenient actors in the research process (including the perspectives of those being studied), more sensitive to qualitative research and more confident in the "ethical sensitivity" of researchers and professional bodies.

# ACKNOWLEDGMENTS

This paper has been partially supported by the Portuguese Foundation for Science and Technology (FCT).

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## Legislation

Act 67/98 of 26 October on the Protection of Personal Data,
http://www.cnpd.pt/english/bin/legislation/Law6798EN.HTM

Directive 95/46/EC of the European Parliament and of the Council of 24 October 1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data, http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:31995L0046:EN:NOT