

PRACTICES OF ETHICS

An Empirical
Approach to Ethics
in Social Sciences
Research

Edited by

Isabella Paoletti, Maria Isabel Tomás
and Fernanda Menéndez

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CAMBRIDGE
SCHOLARS

P U B L I S H I N G

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Edited by Isabella Paoletti, Maria Isabel Tomás and Fernanda Menéndez

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To Fernanda and her joy of life, no matter what

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CHAPTER ONE

INTRODUCTION: PROBLEMATIZING A NORMATIVE APPROACH TO ETHICS

ISABELLA PAOLETTI, MARIA ISABEL TOMÁS
AND FERNANDA MENÉNDEZ

Ethics so far as it springs from the desire to say something about the ultimate meaning of life, the absolute good, the absolute valuable, can be no science. What it says does not add to our knowledge in any sense. But it is a document of a tendency in the human mind which I personally cannot help respecting deeply and I would not for my life ridicule it.

(Ludwig Wittgenstein, *Lecture on Ethics*,
1929/1965, 12)

This book proposes to look at ethical problems in social sciences research from an empirical perspective, describing actual moral problems researchers encountered during data collection and analysis. The different chapters present and discuss very specific ethical problems, the decisions that were taken and the reasoning that led to them, specifying the methodological solutions that were adopted and discussing them critically. First of all, these studies are exercises in documenting practical moral reasoning (Garfinkel 1967; Jayyusi 1984; 1991). Ethnomethodology has highlighted the centrality of moral reasoning in the very organization of social activities:

A society's members encounter and know the moral order as perceivedly normal courses of action—familiar scenes of everyday affairs, the world of daily life known in common with others and with other taken for granted.

They refer to this world as “the natural facts of life” which, for members, are through and through moral fact of life. For members not only are matters so about familiar scenes, but they are so because it is morally right or wrong that they are so. (Garfinkel 1967, 35)

Practical moral reasoning is ubiquitous. As Jayyusi (1984, 207) points out: “Logic and morality are the twin guardians of our discourse and activities; they provide our fundamental source of normative criteria for the conduct of our practical human life.” Research activities are no exception. Data collection and analysis in social sciences research are social activities, and moral reasoning is intrinsic to them as in any other social activity.

The studies in this book aim at contributing to the present debate on ethical issues in social sciences research, problematizing a normative approach to ethics, and highlighting the importance of considering the social character of research activities when applying ethical guidelines or Research Ethics Committees’ prescriptive procedures and methodological solutions. Ethical guidelines in social sciences research are normative in character. Established codes of practices define acceptable standards of conduct within the profession in sociology, linguistics, anthropology, psychology, etc. Virtually every social sciences association worldwide has established a professional code of ethics, such as the code of ethics of the International Sociological Association (ISA 2001), the British Sociological Association code (BSA 2002), the American Anthropological Association (AAA, 1998) and, at the European level, the RESPECT code (RESPECT, 2004), just to provide some examples. These codes aim to define general principles and orientations. A large part of the literature in ethics discusses general principles and their applications in practices (see, for example, Mertens and Ginsberg [2009] for an overview).

In many countries, a specific legislation is required to protect human participants in research activities. This legislation protects the rights of research participants in various ways. The institution of ethics committees, the so-called Institutional Review Board (IRB), Research Ethics Board (REB), Research Ethics Committee (REC), subject data collection and other research activities to obtaining authorization, and prescribe specific procedures and methodological solutions to insure that research activities are conducted ethically. These ethics committees appear to materialize professional ethical codes into specific forms, practices and procedures. Ethics are bureaucratized, and institutionally organized activities are designed to define what is ethical and what is not. Conforming to practices, such as obtaining informed consent from participants, anonymizing data, etc. has become part of the ordinary activities of conducting social

sciences research. Probably the greatest risk in bureaucratizing ethics is creating the impression that when one has complied with the ethical requirements one is “done” with ethics and can forget about it.

The ethical status of research up until recently was based, and in some countries still is, on the conduct and the professional standing of individual research scientists. It was based mainly on a “‘trust us’ approach” (Boser 2007), a commitment to be loyal and protect the interests of research participants to the best of one’s capacities. Recently, this approach has come to be seen as insufficient and supplanted by institutional control and oversight. As Haggerty (2004, 393) points out:

The training that academics received in research methods, ethics, and, most importantly, their practical experience in conducting research were previously presumed to offer sufficient protections against unethical behavior. That system has now been supplanted and effectively replaced by a formal process of bureaucratic oversight. This marks a move away from a system based on an assumption of professional competence and responsibility to one based on institutionalized distrust, where researchers are presumed to require an additional level of oversight to ensure that they act ethically.

A heated debate has recently developed on the utility of ethics committees and review boards (Tilley *et al.* 2009) with opponents and defenders. One needs to understand the main features of this debate to grasp the problems inherent to a normative approach to ethics in social sciences research.

Ethics Committees—the Debate

Ethics committees are often criticized for limiting and threatening academic freedom (Bledsoe *et al.* 2007; Lewis 2008; Rambo 2007; Tierney & Blumberg-Corwin 2007; Tilley *et al.* 2009): “institutional ethical oversight has the potential to limit the creative process of scientific enquiry and censor academics” (Taylor & Patterson 2010, 165). They are perceived as infringing on professional autonomy (Taylor & Patterson 2010) and even as being an instrument for harassment in the academic workplace (Mueller 2004; Fogel 2007; Patterson 2008). Many authors describe ethics committees more as institutional instruments for implementing an audit culture in universities than as a means to improve the actual protection of research participants: “Social scientists have been attentive to the rise of institutional ethical oversight specifically, seeing it as one of the more intrusive and demanding instances of audit culture in

the university” (Taylor & Patterson 2010, 161–162). The interviews with sociologists conducted by Taylor & Patterson (2010) on the impact of the ethical review process on their work show how sociologists understand and act strategically in relation to it, showing different attitudes, active engagement, “creative compliance” and open opposition. Defenders, instead, tend to highlight the relevance of the review process as offering researchers the opportunity to systematically reflect on the potential risks to participants in relation to the specific research activities at the beginning of their research. Specific problems in the workings of ethics committees may be described, but they are framed as mendable problems (Gunsalus *et al.* 2007). Overall, ethics reviews are constructed as acquired institutional practices.

Opponents

The main arguments among the opponents focus on the difficult and lengthy ethics application process (Fogel 2007, 111) and in the often unnecessary regulation, as Haggerty (2004, 403) points out: “such well-intentioned but onerous regulations are justified on the basis of hypothetical worst-case scenarios and then normalized across a vast range of research.” Above all, critics sustain that ethics committees go far beyond regulating ethical practices in academia. They describe ethical review practices often used (or mis-used) as instruments to control the type of research that is funded and developed in the university. In their study on the impact of institutional ethical reviews on research work, Taylor & Patterson (2010, 169) state that: “opposers frame it as an instrument of powerful elites—universities and administrators worried about institutional liability, or local business interests trying to keep nosy researchers at bay.”

The ethical review process generally involves defining practices related to the protection of participants during the pursuit of research activities, such as eliciting informed consent from participants and ensuring anonymity, but at times the reviewing process goes far beyond this focus. Taking into consideration the issue of balancing costs and benefits in relation to human participation in social sciences research, the ethical review process often evaluates research “quality.” Many opponents strongly object to the use of ethics committees and institutional review processes in this fashion. Tierney & Blumberg-Corwin (2007, 396) affirm that: “The quality of the research design should have nothing to do with an individual receiving approval to do a study as it pertains to human subjects.” In this respect, there is at least one important step that could be

taken towards ensuring fairer REC reviews—the reviewers should belong to the same disciplinary approach of research examining the research proposals; that is, they should have the expertise necessary to judge the proposal. Many of the complaints to REC come from researchers working with qualitative methods who have to judge a proposal this way and just do not have the right expertise.

Methodological conservatism (Lincoln 2005) and the proliferation of “accommodating strategies,” only apparently conforming to review requirements (Halse & Honey 2007; Taylor & Patterson 2010), are described as the direct consequences of institutional ethical review processes. As Haggerty (2004, 412) clearly points out:

An unfortunate consequence of these developments will likely be that researchers will choose to employ certain types of unproblematic and often predictable research methodologies rather than deal with the uncertainty and delays associated with qualitative, ethnographic, or critical scholarship which do not fit easily into the existing research ethics template.

Students are often encouraged to avoid primary research to not get stuck in lengthy review processes (Taylor & Patterson 2010).

Some specific research approaches face great difficulties. For example, Wiles and his colleagues (2010) discuss the impact of REC on the use of visual methods, pointing out how an ethics review often makes it practically impossible to use this approach. Vulnerable groups can actually be silenced as a consequence of an ethical board’s “protection,” as Swauger (2011, 497) points out, describing the difficulties she had in following REC procedures in obtaining consent from parents of adolescent girls:

The IRB’s commitment to fixed procedures and rules and its discourse about the vulnerability of certain populations inadvertently blocks the ability of scholars to represent girls’ voices, and homogenizes youth subjects by assuming a shared familial experience, particularly that both biological parents are present and capable of consenting for their child.

A frequent tendency among researchers goes towards an apparent accommodation, or “creative compliance” (Taylor & Patterson 2010, 162), including practices such as formal adherence to ethical guidelines: “The ability to fill forms in the approved way, to deploy ‘ethics speak’ as required” (Halse & Honey 2007, 344), as well as the minimal provision of information to avoid conflicts with ethics committees. In this way, as Taylor & Patterson (2010, 166) observed, some academics “left the formal

ethics regulations unchallenged, while getting around them through informal ‘collusion’ with regulators.”

Some authors describe ethics committees as primarily being instruments for institutional self-protection (Lieberman 1999). In Taylor & Patterson’s (2010, 166) study on the impact of ethics committees on sociologists’ research work, an interviewee wittily comments: “If there were any truth in advertising, the university ethics review would be called the how not to get the university sued committee.” Other authors portray ethics committees as accomplishing a double mission—protecting research participants and universities from legal suits, for example. Cloke *et al.* (2000, 138) says that “the raising of ethical consciousness by government agencies is as likely to be a political act of self-defence as a process by which complex discussion of the ethics of self and other is welcomed.” Institutional self protection is certainly nothing to be critical about, and universities have the right to ensure that their staff and students comply with the law and do not put the institution at risk of fines and prosecution. The issue is that institutional self protection should be clearly distinguished from research participants’ protection. Ethical issues in social sciences research are described as complex and context specific (Cloke *et al.* 2000, 149), posing thorny questions with no simple answers (González-López 2011, 457), impossible to predict (Swauger 2011, 498). Are the existing ethical research committees able to assist researchers and students in facing ethical issues emerging from their research work?

Defenders

Among the defenders of the present ethical review system there is a general acceptance of the existing legislation and the desire to improve the ethics review process working with the rules already in place (Ells & Gutfreund 2006; Hedgecoe 2008; Stark 2007; Tilley *et al.* 2009; Tilley & Gormley 2007), in particular, studying and developing specific local practices (Stark 2007). As Taylor & Patterson, (2010, 164) point out: “many of the defenders of ethics policies have advocated local reforms rather than total rejection of ethical oversight.” The ethical review process is seen primarily as a useful occasion for researchers to reflect systematically on the ethical issues involved in their project at its beginning:

... it can at least be said that procedural ethics offers researchers an ethics “checklist” by reminding the researcher to consider such issues as the potential risks to participants, the balancing of the benefits of the research against those risks, the steps needed to ensure confidentiality of data, and

the inclusion of consent forms and plain language statements in the material provided to participants. This is a helpful aid in designing a research project that will be ethically acceptable in its broad methodology. (Guillemin & Gillam 2004, 268)

The review process forces researchers to reflect on issues that may be overlooked in research design. It is a useful exercise to make sure that ethical issues are carefully addressed and specific methodological solutions are pondered and evaluated. Most defenders agree on the fact that the researchers “are not the best people to decide on the risks and benefits of their research” (Hedgecoe 2008, 874), and therefore the need for an independent review process. An interesting point that is put forward among defenders is that human subject regulations are not only about preventing harm to research participants, but about “protecting people’s rights not to be researched, even when anyone regarded the practices as harmless by any definition” (Stark 2007, 778).

Among the defenders of procedural ethics there are authors who conducted research on ethics committees and on the reviewing process (Connolly & Reid 2007; Hedgecoe 2008; Stark 2007; Tilley *et al.* 2009; Tilley & Gormley 2007). These studies are generally aimed at showing how the ethics review system could be usefully improved (Connolly & Reid 2007; Hedgecoe 2008; Stark 2007). Connolly & Reid (2007, 1032) present two case studies of review process in a Canadian University, showing that “an approach to ethics reviews that attempts to encourage, engage, and support qualitative researchers in their various research initiatives” was adopted. Hedgecoe (2008) conducted an ethnographic study on the review activities of the Research Ethics Committee (REC) in the UK. In his studies, he points out that RECs are not biased against qualitative approaches and it is important to empirically study the review process. Moreover, he enters into a debate contesting Murphy & Dingwall’s (2007) claim regarding the difficulties ethnographers have in defining the research design of their studies in advance. However, in discussing his own research he actually appears to have encountered the same difficulties most ethnographers find in designing their research plan. In describing his own research project on research ethics committees, Hedgecoe (2008, 877) affirms: “Interviews were sought with members towards the end of the observation period, when some form of relationship had been established and I had enough experience of the way in which committees went about their work.” Only as the research progressed was he able to take decisions about who should be interviewed and on what topic. As an ethnographer, he had difficulties in making these decisions at the beginning of the research. Moreover, he describes how most applicants

discussing their project were not even informed of the presence of a researcher in their committee. Although his project received REC approval, its ethicality remains doubtful. In this case, applicants' right not to be researched was certainly not protected, since participants were not even informed about the data collection.

The Main Issues Emerging from the Debate Problematizing Procedural Ethics

Ethics committee procedures appear to be unsuitable for certain types of research, in particular for ethnographic research and participatory research (Boser 2007; Haggerty 2004; Janoviceck 2006; Murphy & Dingwall 2001; Richards & Schwartz 2002; Williamson & Prosser 2002). As Taylor & Patterson (2010, 164) point out: "standard ethical requirements that may fit relatively easily into experimental or quantitative research are far more problematic for qualitative researchers." In general, ethical research committees have difficulties in understanding qualitative research projects (Lincoln & Tierney 2004; Nelson 2004; Pritchard 2002): "The qualitative research process ... is less predictable, harder to outline ahead of time, and the projects' risks are more hypothetical in nature" (Taylor & Patterson 2010, 164). As pointed out above, ethnographers are most likely to identify risks for their research participants during the course of the project (Murphy & Dingwall 2007; Cloke *et al.* 2000). It is rarely possible to take all the ethical decisions at the beginning of the research, in particular in the case of providing guaranteed anonymity (Van den Hoonaard 2003) and fully-informed consent (Murphy & Dingwall 2007; Barrett & Parker 2003; Thorne 1980). Each research situation poses its unique contingencies; moreover, ethical issues "are shaped contextually, and therefore need to be addressed in a situated manner" (Cloke *et al.* 2000, 136).

Recent studies (Einwohner 2011; González-López 2011; Czymoniewicz-Klippel 2010; Swauger 2011; Tilley & Gormley 2007) discuss how the very ethical procedures, adopted in compliance with ethical review processes, could create actual ethical problems during data collection and analysis. In her study, based on the testimonies of holocaust survivors, Einwohner (2011) describes how she felt increasingly uncomfortable towards the anonymising procedure she had designed for her project, a procedure approved by the ethical review board. Removing the name of individual holocaust survivors felt inappropriate in a moral sense, and she points out that: "In the case of Holocaust survivors, given the kinds of conditions they endured, maintaining confidentiality may also serve to undermine their dignity" (Einwohner 2011, 425). In her project on incest,

González-López (2011) realized that asking research participants to sign informed consent forms would put them at risk: “I had to protect them from the potential consequences of complying with an institutional procedure paradoxically designed to protect them” (González-López 2011, 447–448).

The procedures adopted to comply with ethical review boards appear insufficient to deal with ethical problems in social sciences research that may often arise quite unexpectedly in any phase of the research process (Currier 2011; Czymoniewicz-Klippel *et al.* 2010; Guillemin & Gillam 2004). Researchers are practically left alone to deal with complex ethical issues. The same authors highlight the importance of distinguishing between moral responsibility and compliance with institutional regulations; as Koro-Ljungberg and her colleagues (2007, 1075) state: “Research ethical decision making and freedom of choice needs to be separate from discussion related to researchers’ compliance, duties and institutional responsibilities.” If compliance with the ethical review process can help researchers to systematically reflect on the ethical implications of research activities at the beginning of the project, it certainly does not spare them from having ethical responsibility towards research participants and from the need for self reflection during the whole research process, from the formulation of the research questions to publication and beyond.

Nespor & Groenke (2009), discussing a research on heat death, point out the ethical relevance of the initial framing of the research questions, in particular which questions are asked and which are not. Nespor & Groenke (2009) refer to studies on the Chicago heat wave of 1995 that resulted in more than seven hundred deaths. The case-control designed used by the U.S. Centers for Disease Control and Prevention (CDC) focused on individual variables, such as living alone, medical conditions etc. Klinenberg (2002, quoted in Nespor & Groenke 2009) pointed out the limitations of this research design: “If there were risks of living in an impoverished, institutionally depleted, or politically neglected neighbourhood or region, the CDC analysis would not help to identify them. The CDC study directs the attention of public health agencies to the particular set of individuals who are more vulnerable to heat related problems, but not to the places where such problems are likely to be concentrated” (Klinenberg 2002, quoted in Nespor & Groenke 2009, 1001). Nespor & Groenke (2009) strongly appeal to consider problem framing as a key issue when examining ethicality in research, pointing out the importance of taking into account the effects of research, not only on

direct research participants but also on extended participants who are affected by research results.

During data collection, researchers become part of the social and institutional settings they are studying and cannot avoid having an impact on those settings, as Cloke *et al.* (2000, 151) point out:

For good or ill, the very act of entering the worlds of other people means that the research and the researcher become part co-constituents of those worlds. Therefore we cannot *but* have impact on those with whom we come into contact, and indeed on those with whom we have not had direct contact, but who belong in the social worlds of those we have talked to.

The researchers become part of a social world and, as any other professionals, have to constantly work out what is ethically right or wrong within their professional activities. There is no escape from it and there are often no easy answers to ethical dilemmas. Normative ethics appear to conceal the complexity of the ethical dimension of research activities, as Murphy & Dingwall, (2007, 2231) point out: “When ethics become institutionalized, rule-following replaces a commitment to working out the ‘right thing to do’ as researchers negotiate the complex moral territory of fieldwork” (Murphy & Dingwall, 2007, 2231). In fact, one aspect that has not been sufficiently highlighted in the debate on normative ethics is that ethical guidelines and procedures generally ignore the social dimension of research activities.

Research activities are social activities; issues of face, relevance, pertinence, appropriateness, courtesy, cultural significance, etc. are relevant for research activities as for any other social activity. Activities related to ethical procedures, such as obtaining informed consent, have to be negotiated in actual situations (Paoletti, forthcoming). Presenting the research objectives and obtaining the signature of participants in a consent form has to be managed in relation to the actual situation in which the consent is asked, often during ongoing participants’ activities; the consent procedures often appear to be at odds with the participants’ order of priorities (Paoletti, forthcoming). Obtaining consent is made possible by the level of trust that has been built in the relationship between researcher and participants (Bhattacharya 2007). The cultural meaning attached to the signing of a document in specific cultural contexts is also a significant aspect of this process (Barrett & Parker 2003). To ask a participant to sign an informed consent form can be very awkward and problematic, as is often pointed out in the literature (Cloke 2000; Haggerty 2004; Murphy & Dingwall 2007; Paoletti, forthcoming; Swauger 2011; van den Hoonaard 2001; 2002) and in some of the studies in this collection (e.g. Gil *et al.*). In

some cases, signing an informed consent form is considered dangerous for informants, as was pointed out above (González-López 2011), but is mainly perceived as not appropriate to the character of the occasion. As Haggerty (2004) points out:

Consent forms can unnecessarily color interview or ethnographic situations, transforming encounters that are routinely more informal and exploratory into unnecessarily official and legalistic exchanges. These apprehensions are particularly germane to research on large groups of people. (Haggerty 2004, 404)

There is an increasing interest and a pressing need towards the study of ethical problems as they emerge unpredictably during research activities, reflecting the complexities of the actual research situation (Goodwin *et al.* 2003; Guillemin & Gillan 2004; Ellis 2007).

Ethics in Practice

Recent studies (Barton 2011; Blee & Currier 2011; Czymoniewicz-Klippel *et al.* 2010; Clark & Sharf 2007; Cloke *et al.* 2000; Conrad 2006; Currier 2011; Dougherty & Atkinson 2006; Einwohner 2011; Ellis 2007; Etherington 2007; González-López 2011; Goodwin *et al.* 2003; Guillemin & Gillan 2004; Hurdley 2010; Irwin 2006; Kohler Riessman & Mattingly 2005; Medford 2006; Poulos 2008; Rupp and Taylor 2011; Stein 2010; Sultana 2007; Wood 2006; Wyatt 2006) empirically describe actual ethical problems researchers face during research activities. “Ethics in practice” (Ellis 2007, 4), “situational ethics” (Ellis 2007, 4), “ethics as a process” (Swauger 2011, 500), “important moments” (Guillemin & Gillan 2004), “microethics” (Komesaroff 2008), “context based ethics” (Kohler Riessman & Mattingly 2005) and “participatory ethics” (Sultana 2007) are some of the labels used to define an approach to ethical problems in social science research based on the detailed description of ethical problems as they emerge in actual research situations: “They point to the need to go beyond general ethical goals and develop an understanding of ethics as an ongoing process and of ethical dilemmas that arise in ways that are impossible to predict” (Swauger 2011, 498). The journals *Qualitative Inquiry* and *Qualitative Sociology* have given a particularly significant contribution to this line of research. A common aspect to all these studies is a concern for ethics as an omnipresent and inescapable component of research in social sciences, from the framing of the research questions to data collection, storage, analysis of data, and publication of research results. Many ethical issues are described as emerging during research activities quite

unexpectedly, abruptly confronting the researcher who is often alone when taking a decision in this matter (Guillemin & Gillan 2004). This characterization of ethical practices is in open contrast with the ordinary practices of regulatory review boards. For the ethics committees, ethical problems are generally planned and dealt with at the beginning of the research. Researchers are responsible for adopting the prescribed procedures by the relevant ethics committee and they are then done with it. As Cannella (2007, 316) points out: “This global move towards regulation of research ethics as enterprise (although imposed somewhat differently within various nations) can also result in the belief and the creation of the illusion that moral concerns, power issues, justice, protecting other human beings (and so on) have been addressed with no farther need for concern.” Ethical issues involve individual moral responsibility and ongoing self reflection during the whole research process. Empirical studies of ethical problems in social sciences research aim to document this process of self reflection and the actual solutions that were taken in relation to specific ethical dilemmas emerging during research activities. The chapters in this collection contribute to this line of research, documenting empirically specific ethical issues when conducting social sciences research in a variety of social and institutional contexts.

Practices of Ethics—The Forthcoming Chapters

This book is intended for social sciences researchers in a variety of disciplines (sociology, sociolinguistics, psychology, gerontology, ethnography etc.) who, during all the stages of their research, be it quantitative or qualitative, are confronted with ethical dilemmas. As such, the chapters in this book attempt to provide the reader with examples of ethical reflection within the research process. The selection does not cover all the possible ethical issues they may face, but all of the chapters deal with the complex, unexpected but fundamental, ethical questions that arise before, during and after fieldwork, and which do not always find clear guidance from the professional ethical codes they submit to. The dilemmas between mandatory ethical codes practice in the field and intellectual outcomes are particularly salient in chapter two.

Rosalina Pisco Costa, in her chapter for this volume entitled “Ethics on the Move. Methodological Dilemmas on the Qualitative Scientific Writing Process,” focuses on the issues at the end of project stage, when writing reports, papers and theses, or preparing publications, communications or any other forms of intellectual outcomes result in a conflict with anonymity prescriptions, in data deriving from studies in small communities.

The mandatory procedures in ethical codes concerning informed consent are often problematic for researchers dealing with special subject groups who are in a vulnerable position because of age, victimization, illegality or marginality. José de São José and Ana Rita Teixeira, in their study of a vulnerable group in a particular context, “At the ‘Ethical Crossroads’ of Ethnography—Observing the ‘Care Encounter’ at the Elder’s Home,” centre their discussion on the issues of “informed consent”: from whom (primary and/or secondary participants) should it be obtained, how much information should be given and when? The authors also discuss their decisions when faced with other “ethical crossroads”—the social and moral responsibility of the researcher and the legal issues of reporting negligence or violence.

A discussion of the issues brought forward when obtaining consent from other types of fragile or disadvantaged subjects is also the focus of Jessica Nina Lester and Abraham Barouch’s chapter entitled “Inviting the Assent of Children Described as Functionally Nonverbal.” How do researchers acquire the assent (or dissent) of young children, many of whom do not use words to communicate in a society that privileges (and assumes) verbal communication as the norm?

Ana Paula Gil, Ana João Santos and César Santos, in “Ethical and Methodological Issues in Violence against Elderly People in Portugal—an Intersection between Sociological and Epidemiological Research,” deal with the difficulty of balancing ethical procedures within a national regulatory ethical review system and the challenges faced when working with vulnerable research subjects, particularly informed consent and confidentiality in a victim survey.

In some contexts, research subjects may feel insecure or threatened because of their illegal or marginal status in the society they live in. Their insecurity and the real or perceived threat their participation may bring to them can affect the research data. Georgiana Anton and Marian Preda in their contribution to this volume, “Ethical and Methodological Dilemmas in Researching Vulnerable Groups in Romania,” outline some of the ethical issues they had to deal with in two studies, one with refugees and immigrants, and the other with young drug users and sex workers. Informed consent “by the book” was again put into question by insufficient knowledge of the language, illiteracy and fear of disclosure of personal information.

The three last chapters focus on researcher roles and their ethical implications. Larissa Kosygina, in “The Researcher in the Field—Navigating Networks of Relationships,” describes how researcher identity and positionality may be construed and misconstrued by participants, in this

case the heads and staff of NGOs and migrants without citizenship in Russia. The complex network of relationships already existent in the field often affects trust from participants, while dissemination of research outcomes may influence those who remain in the field, as anonymization may not guarantee preservation of anonymity in small towns.

Dominika Baran, in “Working with Adolescents—Identity, Power and Responsibility in Sociolinguistic Ethnography,” supplies a look at the complex construction and reconstruction of the researcher identity and roles in a different research context, that of adolescents in a high school in the Taipei City area. Baran discusses the ethical management of researcher roles, the ethical impact of the researcher’s everyday actions and choices on research participants, the researcher’s “divided loyalties” and the misperceptions of cultural gender roles and status.

The context described by Yutaka Sato, in the chapter entitled “Exploitation versus ‘Going Back’ to the Field—The Ethics of Doing Participatory Research in India’s Urban Slums,” is a diverse one. His research subjects are slum dwellers in Ahmedabad, India, and the staff of a local NGO. His research framework presents different challenges and limitations, such as the often-present conflict between interests and expectations of the different participants (NGO policies, NGO staff, researcher and slum dwellers), the misconstruction of researcher identity and roles, and the reliance on gatekeepers (NGO staff) hindering trust from participants.

By necessity, the issues discussed in this volume are by no means exhaustive and do not present the full range of ethical challenges and choices researchers face in the practice of research. We hope, however, that reading about the “practices of ethics” offered by the authors of these chapters may provide researchers with an opportunity to reflect and learn about themselves, as social and moral beings, and as researchers, because it is in those moments that:

... the researcher’s ethical competence comes to the fore. By this we mean the researcher’s willingness to acknowledge the ethical dimension of research practice, his or her ability to actually recognise this ethical dimension when it comes into play, and his or her ability to think through ethical issues and respond appropriately. (Guillemin & Gillam 2004, 269)

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CHAPTER TWO

ETHICS ON THE MOVE: METHODOLOGICAL DILEMMAS ON THE QUALITATIVE SCIENTIFIC WRITING PROCESS

ROSALINA PISCO COSTA

Naiveté [about ethics] itself is unethical.
(Mirvis & Seashore 1982, 100)

Introduction

There are many historical explanations (and examples) that justify current interest in ethics research. The new millennium has brought with it a wave of ethical challenges, as methods of data collection, analysis and dissemination have become more and more sophisticated and widespread in recent years (e.g. software development, internet-based research, and data dissemination via ICTs). The words of Mirvis & Seashore, the motto of this text, are not only as true as ever; they also invite us to rethink ethics as crosscutting and a global issue in the twenty-first century (Tilley & Woodthorpe 2011).

Ethical issues are pervasive along all dimensions of scientific practice. Since the very beginning of any research project, from the choice of a topic until the publication of research findings, ethical issues are a matter of constant thought, discussion and, finally, decision. Just as it is understood that scientific research truly engaged with social responsibility cannot overlook the ethical implications of its practice, so widespread is the understanding that any complete research proposal will have exhaustively anticipated the ethical issues involved, as well as shown ways to deal with them (Creswell 1994; Denzin and Lincoln 2000; Denscombe 1998; Patton 2002).

Given that, as Berg points it, “social scientists delve into the social lives of other human beings” (Berg 2009, 60), social sciences raise special issues concerning ethics (Punch 1986; Punch 1994; Miles & Huberman 1994). Such excursions into private lives raise general awareness and concerns over the ethics of research and researchers, namely of how researchers must ensure the rights, privacy and welfare of people and communities, both as the basis and focus of their studies.

Research literature on ethical issues in social sciences agrees with major topics to be addressed.¹ Punch (1994) summarizes five key concerns: harm, consent, deception, privacy and confidentiality of data. In greater detail, Miles & Huberman (1994) discuss a variety of specific ethical issues and their implications for analysis: worthiness of the project; competence boundaries; informed consent; benefits, costs and reciprocity; harm and risk; honesty and trust; privacy, confidentiality, and anonymity; intervention and advocacy; research integrity and quality; ownership of data and conclusions; and use and misuse of results. At the same time, authors briefly outline each issue, pose key questions, illustrate with examples and suggest analysis-related implications, as well as presenting conflicts, dilemmas and trade-offs within and beyond the presented topics, thus raising awareness and making questions more visible to researchers.

Ethical issues are also pervasive within the social research paradigms of quantitative, qualitative or combined design study. Notwithstanding the general agreement on this, specific implications for practice are a matter of endless discussion in methodology books, scientific articles and conference debates. Lipson, for instance, argues that “ethical issues in qualitative research are often less visible and more subtle than issues in survey or experimental research” (Lipson 1994, 333). Punch, by contrast, remembers how those ethical issues are “more likely and more acute in some qualitative approaches” (1998, 281). Punch adds:

This is because, while all social research intrudes to some extent into people’s lives, qualitative research often intrudes more. Some qualitative research deals with the most sensitive, intimate and innermost matters in people’s lives, and ethical issues inevitably accompany the collection of such information. (*Ibid.*, 281)

After data gathering, ethical concerns expand to data analysis, regarded as being “more than a technical matter” (Miles & Huberman 1994, 288). In fact, the qualitative researcher cannot focus only on the quality of the

¹ See Punch (1994) for a better understanding of this area and its recent developments after moral and ethical questions raised by a number of notable studies.

knowledge they are producing. As these authors also remind us, the researcher must also consider the rightness or wrongness of their actions in relation to the people whose lives are being studied.

It is true that the kind of qualitative data gathered—interviews, observations or documents—is crucial to understanding specific ethical challenges stemming from research (Patton 2002). Nevertheless, it is our opinion that the arguments pointed out by Punch should also include the nature of qualitative writing itself. As “a method of inquiry” (Richardson 1994), qualitative writing blurs the line between data processing and analysis, reconstructing it through narrative interpretation. By doing so, it constantly challenges ethical issues as solved ones, particularly the commitment of the anonymity agreed between the researcher and the informants.

This chapter specifically examines ethical dilemmas arising not at the beginning of a research project, or at the very moment of data collection, but at the end, when writing reports, papers and theses, or preparing publications, communications or any other forms of intellectual outcomes deriving from data whose dissemination requires the safeguard of anonymity. To illustrate our argument, we turn to the analysis of a case taken from the conduction of a sociological qualitative study based on interviewing. Our aim is to show that behind a seemingly easy operation as the assignment of pseudonyms—often carried out at an early and previous stage of data analysis—may ultimately be an operation of complex contours. In the social responsibility of the scientist’s framework, we hope to contribute to the critical discussion of ethical and methodological issues in the collection and treatment of data gathered in academic research settings, stressing how pervasive ethical concerns are to data analysis and writing and, in that sense, are a never-ending process.

Ethics “By the Book” and Sociological Practice

Biomedical research, carried out by Nazi physicians and scientists during World War II, is commonly identified in the literature as being at the origin of most of these concerns, specifically in the establishment of an ethical canon—the formation of the Nuremberg Code in 1949. This code established principles for research on human subjects and paved the way for many other milestone documents such as the Declaration of Helsinki, adopted by the World Health Organization in 1964 and revised in 1975, also inspiring the creation of numerous codes of ethical conduct that

would be established throughout the world social science's professional organizations in the recent past.²

As far as the sociologist's work is concerned, research ethics not only derives from specific skills, first taught and learned in universities, and later acquired in social practice, but is also guided by ethical tenets shared amongst the sociologist community working in diverse scenarios and facing multiple challenges. Around the world, the International Sociological Association's (ISA) Code of Ethics (the latest version approved by the ISA Executive Committee in the autumn of 2001)³ is a symbol of sociologists' professional identity. It consists of a preamble and four sets of specific Ethical Standards, namely: (1) Sociology as a field of scientific study and practice; (2) Research procedures; (3) Publication and communication of data, and; (4) Extra-scientific use of research results, standards with which ISA membership implies sociologists' acceptance, respect and dissemination in their professional work. Approved to (1) protect the welfare of groups and individuals with whom and on whom sociologists work or who are involved in research efforts, and (2) to guide the behaviour and hence the expectations of ISA members, both between themselves and toward the society at large, the ISA's Code of Ethics is not only a document relegated to the realm of general standards of conduct, but a guiding instrument for research in practical terms. Even though the efficacy of a Code of Ethics relies mainly upon the self-discipline and self-control of those to whom it applies, by specifying how and under which conditions data gathering should be undertaken, the ISA's Code of Ethics plays a major role for the development of a reliable and valid body of scientific knowledge, based on research.

As prescribing ethical standards related with research procedures, the document is particularly clear when it compels sociologists to disclose the methods by which they proceed as well as the general sources of their data (Art. 2.3.1). The application of this principle requires security, anonymity and privacy as a counterpart for research subjects and informants, unless they have asked or agreed to be quoted. In the cases where informants can be easily identifiable, researchers should clearly remind them of the consequences that may follow from the publication of the research data and outcomes (Art. 2.3.2). As explicitly stated, advanced informed consent from research subjects and informants, prior to data gathering, and the obligation of thereafter respecting it are the main methodological

² See Berg (2009), for an interesting review of research ethics from a historical perspective.

³ Available online at http://www.isa-sociology.org/about/isa_code_of_ethics.htm (accessed August 29, 2011).

procedures suggested in the safeguard of security, anonymity and privacy. Additionally, sociologists are advised to avoid covert research unless it is made in smaller scale and specific conditions of information gathering.

At the national level, the Portuguese Sociological Association (APS), created in 1985 and with statutes since 1992, also unites its more than 2,000 associates around a single Code of Ethics, approved by the General Assembly on April 13, 1992.⁴ The document consists of a preamble and seven main topics related to: (1) Sociological Practice; (2) Data and Information Gathering; (3) Professional Relationships; (4) Teaching and Guidance; (5) Authorship and Publications; (6) Peer Relationships, and; (7) Ethics Council. APS summarizes in this last section what is considered to be most important in relation to data and information gathering:

Sociologists must respect all data providers by not violating the principles of volunteering; while gathering data, sociologists must not act or be a target of coerciveness or manipulation; if established sociologists must guarantee the right to privacy, safety anonymity, and confidentiality of information and results; it is mandatory the protection of databases or archives subjected to confidentiality or anonymity; while gathering data sociologists must explain to data providers who they are, the nature, objectives, procedures and institutional framing of their work (Sect. B – APS, 1992).⁵

Consistent with the ISA's Code of Ethics, once again issues related with anonymity and privacy of research subjects and informants are central amongst the standards of conduct that sociologists must follow in their professional activity. By respecting them, sociological practice meets the expectations of relational responsibilities not only to sociology and the sociologist community, but also to society as a whole.

In the same way that social reality is complex, multidimensional and in permanent change, so research is not as simple and linear as the straight lines in a code of ethical conduct. As Miles & Huberman put it, "if ethical issues were clear-cut and totally approachable on a deontological basis, life would be simple" (Miles & Huberman 1994, 296). Addressing ethical issues thus inevitably involves making choices. Often, those are difficult choices because they always put the researcher in the face of a decision

⁴ English version available online from http://www.aps.pt/index_uk.php?area=000&marea=001 (accessed August 15, 2011).

⁵ Associação Portuguesa de Sociologia, "Code of Ethics of the Portuguese Sociological Association, 1992," APS, http://www.aps.pt/index_uk.php?area=000&marea=001 (accessed August 15, 2011).

where they have to choose between two goods. In this case, we face an ethical dilemma, and Miles & Huberman briefly outline some of them: validity versus avoiding harm; anonymity versus visibility; scientific understanding versus individual rights; detached inquiry versus help; help-giving versus confidentiality, and; freedom of inquiry versus political advantage.

Whilst this is an illustrative list of dilemmas, it gives us food for thought regarding the object of this chapter. Though commonly associated with research procedures, issues related with the anonymity of research subjects are not closed matters when finishing fieldwork, data gathering or obtaining advanced informed consent. The anonymity versus visibility dilemma (Shulman 1990) is usually used to refer to cases when participants claim for the visibility of their work or information, either tending to consciousness-raising or empowerment; while the researcher struggles to protect their anonymity, the opposite might be harmful or jeopardize their position in a group or a specific organization. In this chapter, we extend this dilemma into the researcher writing process. According to this dilemma, empirical data should be both transparent and accessible, as well as intricately linked to “real-world” examples, which requires bringing as much information as possible into reports. At the same time, while the researcher struggles to make “stories” visible, reliable and true, they have to be sure that such information doesn’t compromise the informants’ anonymity.

As we shall see, writing on interviews turns this process into a specially demanding task.⁶ Qualitative analysis claims for an in-depth understanding of the social world. Information coming from many sides adds texture to analysis, showing meanings and insights about problems and phenomena that would otherwise be unclear to the reader. However, the researcher cannot forget that they have a professional obligation to honour, that is to ensure the promise of confidentiality made to subjects to the best of their ability.

Empirical Scope, Data Collection and Analysis Based on the Episodic Interview

We rely on a qualitative inquiry carried out with middle-class individuals living in a middle-sized town in the south of Portugal (southern Europe). In this study, we’ve interviewed fifteen men and fifteen

⁶ See Patton (2002, 408–409), for an ethical issues checklist designed for challenges in qualitative interviewing.

women, recruited through a convenience and snowball sample, belonging to different family arrangements (e.g. nuclear and single-parent families), who had lived in such situation for at least two years and with at least one small child between the age of 3 and 14 years old. Our focus was to study family rituals, meaning any prescribed practice arising from family interaction, targeting a specific purpose and holding a symbolic or “special meaning” (Bossard & Boll 1950; Wolin & Bennett 1984; Imber-Black & Roberts 1993; Fiese *et al.* 2002; Fiese 2006). According to Wolin & Bennett, one can distinguish between family celebrations like rites of passage, annual religious celebrations, secular holiday observances; family traditions like summer vacations, visits to and from extended family members, birthday and anniversary habits, parties, family reunions; and patterned family interactions such as family meals, bedtime routines for children, and leisure activities on weekends or evenings (Wolin & Bennett 1984). In short, family rituals are moments in the daily routine or days and occasions in the life of the individuals, including both occasions from the most organized and rare to the most spontaneous and frequent (Wolin & Bennett 1984) or as Imber-Black & Roberts put it, from “the inside” to the “outside calendar” of the families (Imber-Black & Roberts 1993).

By using an episodic interview, we could explore family rituals in many instances, such as synchronic and diachronic practices and representations around actors, space, time, feelings, symbols and meanings. Episodic interviews were better conceptualized by Uwe Flick (Flick 1997; 1998) and can be summarized as semi-structured interviews aiming the detailed description of a concrete experience and related meaning through the form of a narrative.

Whereas episodic knowledge is organized closer to experiences and always linked to concrete situations and circumstances, semantic knowledge is based on multiple assumptions and relations which are abstracted from these and generalized. Episodic interviews were indeed a major instrument in order to capture the texture of family life through rituals. A key aspect was the interview’s protocol, which combined invitations to recount concrete events relating to the issue under study with more general questions aiming to capture in-depth accounts on the subjective relevance of the situation for the interviewee.

Collected data were then analyzed through a thematic and structural content analysis following Laurence Bardin’s methodological guidelines (Bardin 1977) using qualitative data analysis software (NVivo8, QSR International). Consistent with data gathering and analysis procedure, the final results on emerging themes and issues were textually presented through contextualized narratives, according to which interviewees’

accounts are not isolated from the broader context. Despite the inclusion of highlights in the text so that interviewees and researcher's words could always be perfectly identified, they are presented to the reader as a whole.

Among several preliminary procedures when writing contextualized narratives is the assignment of pseudonyms to interviewees. Let's see how easy or hard this task can be.

How Easy is it to Assign a Pseudonym?

"Would you mind if I record this?" was the compelling question accompanying the beginning of all interviews. No written consent was asked, but prior to the interview,⁷ interviewees orally gave permission for audio recording and also for the use of excerpts from transcripts in a sociological PhD thesis, at that time yet to be written (Costa 2011). As a counterpart, the researcher committed herself to maintain confidentiality and anonymity of data.

It is true that researchers commonly assure subjects that anything discussed between them will be kept in strict confidence. What exactly does this mean? Although confidentiality and anonymity are sometimes mistakenly used as synonyms, they have quite distinct meanings. Confidentiality refers to the management of private information, communicated between two or more people in trust of confidence, disclosure of which could bring particular prejudice to informants. Anonymity basically means that the subjects remain nameless. It is usually referred to as the active attempt to remove or obscure from the research records the names of participants or places, as well as related elements that might indicate the subject's identities or lead to their identification. While confidentiality is commonly assured through the formal oral or written informed consent, and is "obligatory" from an ethics point of view, the truth is that in qualitative studies either this consent is often superficially presented and accepted, or subjects themselves don't plainly realize it would be difficult for someone to remain effectively anonymous, for instance, to acquaintances who eventually come to read publications resulting from research (Burgess 1984). Clearly, anonymity provides a useful tool to help ensure that confidentiality is maintained, which somehow justifies the confusion between the two concepts.

When recovering a previous research developed in schools, Miles & Huberman report this statement from an indignant principal: "There are

⁷ See Patton (2002) for an interesting insight on the debate around the "proper" timing in asking for consent.

111 high schools in this city and only one of them has a female principal. That's me." (Miles & Huberman 1994, 293). As authors assume that dealing with the question was resolved by moving the school to another city and changing the principal's gender in the final report, this case highlights three main sub-issues relating confidentiality and anonymity for further discussion on the problem, the solution and its implications for practice.

The temporary, circumscribed and formal nature of most quantitative data-gathering strategies makes them easier to ensure confidentiality. Even though researchers may know to whom surveys were distributed, if no identifying marks have been placed on the returned questionnaires, the respondents remain one hundred percent anonymous. Additionally, data analysis of surveys is mostly numerical, meaning that in a simple and quick way data can be separated from the original subject's information and replaced by a letter or case number (randomly assigned), a colour, or a chosen pseudonym. This way, in quantitative studies, "it becomes a simple task to ensure that names or other identifiers will not be connected in any way with the survey response sheets" (Berg 2009, 70). On the contrary, qualitative research presents greater challenges in this field. Because subjects are known to the investigators, anonymity is virtually non-existent. This is especially true for ethnographic strategies, where the relationship between researcher and subject is frequently ongoing and evolving. In qualitative inquiries, ethnographic studies or interviews, the amount, depth and richness of data gathering always implies, to some degree, the observation or taking part in the lives of the subjects.

To complicate the matter, qualitative studies carried out in small communities may seriously compromise efforts in the safeguard for anonymity. What is the potential benefit of a research project weighed against the potential harm? Unforeseen prejudice might result in the cases where the informant's identity might be revealed when dissemination or report feedback reaches the study subjects. In small communities, explicit or implicit identifiers such as gender, occupation, and names of places or streets can easily be triangulated and, in association with a description of certain features about an individual, association or setting, may make it possible to discover a subject's identity. Widespread use of the internet allows for even faster and wider dissemination to several audiences, both academic and non-academic. This means that research outputs can often be accessed by anyone and for a long (if not indefinite) period of time (Tilley & Woodthorpe 2011), which amplifies the identification possibilities.

Regarding the problem's solution, to avoid an informant being identified, qualitative studies often implement a series of diligent data safeguards, such as an accurate review of all possible identifiers beside the names of people and places, and its removal from text. Among the main procedures, researchers systematically change each subject's real name to fictitious names or a pseudonym when reporting data. Ethical guidelines advise researchers to keep a careful and precise record of the correspondence list between true names and pseudonyms. Literature shows this can be a very successful endeavour, as in some studies such as the classical *Street Corner Society* (Whyte 1943) in which the pseudonyms came to be as known as the study itself.

Finally, as far as implications are concerned, one might think to what extent do multiple and subsequent modifications of situations and events (e.g. geographical setting and gender) accomplish another important ethical issue, namely that relating the "truth" of the facts. While some researchers admit themselves to replace data such as gender, Burgess agrees that those changes represent a major distortion of the data and even a deception to the study reader (Burgess 1984). Damage done to truth when changing the principal's gender and school location is undeniable. Yet, authors admit "the basic lessons of the case were preserved" (Miles & Huberman 1994, 293). None of these solutions is indeed a perfect one. As Burgess also underlines, using these strategies does not immediately make people and places totally unrecognizable (Burgess 1984). Even in making careful and systematic changes, it is true that places might somehow (and unexpectedly) be identified, and assumptions may be made about the real identity of informants.

The question of how identifiable the studied individuals are is a rather important question as the researcher themselves—and no one else—has the responsibility of keeping informants anonymous. Whenever possible, the problem of identifiability "must be considered before and during report preparation" Miles and Huberman warn (1994, 293). If this is feasible with ethnography, where fieldwork and data gathering somehow overlap with writing up, it is much more difficult, if not impossible, when dealing with interviews, since in this last case opportunities to recover contacts and to renegotiate consent before the report is finalized are almost null. At this phase, alone with audio records, *verbatim* transcripts and field notes, the researcher has to decide whether and how to change data. Like a surgeon, their acts must be minimum, sharp but crucial and to the point. Minor changes in data may and should be done whenever the researcher realizes that privacy has been threatened, and anonymity is compromised. Let us remember that the various codes of ethical conduct do not specifically

indicate how to act, rather prescribe what principles should guide the action; the information should not be connected with an identifiable person.

As qualitative literature is full of references and discussions on ethical questions, our aim with this chapter is well-defined—to stress the importance and careful decision-making process behind seemingly easy operations such as the anonymization practices, as these issues strongly relate to analysis and scientific writing.

Differently from quantitative, qualitative writing calls for the mixing of several voices in context: the researcher, the interviewer and the studied subjects' own voices. Qualitative writing is related with themes, patterns, concepts, insights and understandings (Patton 2002, 5). It is an in-depth exercise, whose understanding requires a careful and thorough reading. Richardson argues that:

Unlike quantitative work, which can carry its meaning in its tables and summaries, qualitative work depends upon people's reading it. Just as a piece of literature is not equivalent to its "plot summary", qualitative research is not contained in its abstracts. Qualitative research has to be read, not scanned; its meaning is in the reading." (Richardson 1994, 517)

In this framework, we identify ourselves with the words of Denzin & Lincoln, for whom the qualitative researcher is a "bricoleur and quilt maker" (2000, 3). In short, writing on qualitative data "is not just a mopping-up activity at the end of a research project. Writing is also a way of 'knowing'—a method of discovery and analysis. By writing in different ways, we discover new aspects of our topic and our relationship to it" (Richardson 1994, 516).

We started qualitative data processing and analysis with thirty individuals whose anonymity we were committed to respect. For the purposes of our study, only basic biographical information was kept from each and this included gender, age, marital status, number and age of children. For that reason, the simple replacement of proper names was, in most cases, enough to safeguard anonymity during the entire work.

As a general procedure, we changed interviewee's names and kept the same initial. This had merely a mnemonic purpose, which was to facilitate the researcher task when analyzing and writing on data. Since the interviewer coincided with the researcher, not losing sight of "real" interviewees and interviews' settings frequently became a powerful insight to see and think beyond immediate verbatim transcriptions. Following this

procedure, for instance, Amílcar⁸ was replaced by Afonso, keeping the capital A, and Leonor by Lurdes, keeping the capital L.

However, this very simple and quick task can indeed constitute an ethical and methodological problem as we read transcripts as a whole and write contextualized narratives, often presenting data in several non-continuous fragments (e.g. interview excerpts). In fact, behind and beyond a name, a person exists, lives and interacts with others in a specific space, time and life span.

Where the episodic interview aims at contextualising experiences and events from the interviewee's point of view, it allows us to get information on many experiences related with their life. Since an episode is "a certain event or situation the interviewee remembers" (Flick 1997, 20), with no surprise, as we gather more episodes' narratives of the same interviewee, the greater the knowledge of the person is achieved. In bringing out childhood, adolescence and adult life experiences, it becomes increasingly more difficult for an interviewee to remain anonymous, even if we hide their real name.

We elaborate on this point through the illustration of a single case based on the accounts of a woman interviewed for our study. What seemed to be a very simple and quick substitution of a name by a pseudonym ended up as a complex and continuous work of discovery. The point about using a case to illustrate this is that it allows one to see the complexity of the anonymization practices, not only as a methodological procedure but also as a way of knowledge.

How many Marias do you know? An Overall Perspective on the Case of Maria dos Anjos

As for many countries, in Portugal there is a long tradition of assigning the name Maria⁹ to a baby girl¹⁰. Often, Maria as a first name is followed

⁸ All names used hereafter are pseudonyms.

⁹ The corresponding name in English is Mary.

¹⁰ This is indeed a long-lasting tradition. The Portuguese Society of Economic Information, SA (S.P.I.E.) provides an online tool to generate a graph that represents how often the word appears as the first name in Portuguese births between 1920 and the 90s. Despite the fact the S.P.I.E. does not maintain databases on names of minors for legal reasons, a small exercise with the name "Maria" easily demonstrates its importance in terms of chronological large numbers. Graph online available at:

by a second name perceived to be of great importance for their owners. In some cases, it is changed into a diminutive used among intimate relations; in other cases it is a way to distinguish several Marias, for instance in family, school or professional settings.

With no surprise, we had many Marias as real names. Four in fifteen women were named Maria—Maria do Rosário, Maria Luís, Maria Manuel and Maria dos Anjos. However, none of these women was recognized by others merely as Maria. Instead, for all of them a diminutive or the simultaneous combination of first and second name was always preferred. Apparently, replacing those names for another female name seemed unproblematic.¹¹ In fact, that is what happened with three of the four Marias. Maria dos Anjos was the exception.¹²

For the purposes of the greater research for which the data was collected, a short biography was prepared to keep only relevant information under focus—a 41 year old¹³ woman, with a Catholic wedding in 1994, and mother of two children, a girl of 13 years old and a boy of 11. Additional information came from accounts from the very beginning of the interview, when she was asked to talk about her childhood:

... I was born... a little out of time. Because ... my brother had a younger brother ... It wasn't a planned pregnancy. No. My mother had two boys two years apart: my brother and another boy who died at the age of 11. It was an "accident" and only then, after he died, was I born. I never met him or anything ... I was born in a very accidental way because the pregnancy wasn't planned. Although I was very much desired afterwards ... especially because I was a girl coming after two boys.

At the same time, this excerpt reveals Maria dos Anjos' place in a particular family setting; it also leads her to talk a bit about her mother and the relationship between them:

http://www.spie.pt/index.php?option=com_content&view=article&id=62&Itemid=107 (accessed August 29, 2011). According to information from the National Institute of Registration and Notary, Maria is at the top of the most chosen names in Portugal in 2010 (Jornal de Notícias 2010). List available online at <http://www.jn.pt/infos/pdf/nomes.pdf> (accessed August 29, 2011).

¹¹ To be rigorous, it was not always possible to follow the general procedure of name changes keeping the same initial. Among several reasons, to combine the safeguarding for the subject's anonymity in its multiple dimensions was the privileged one.

¹² A literal translation would be Mary of the Angels.

¹³ Data relate to 2009.

I always remember my mother as being a sad person ... she wasn't someone to play with me, for instance ... she was always a very sad person, with little desire to leave home

As detailed before, an episodic interview was designed to collect an in-depth understanding of what a family ritual is and its place and importance in the construction of the contemporary family. Interviewees were asked to highlight moments, days or occasions in their daily life throughout the year or during their life span which they considered to be "special." After identifying those moments, interviewees were then invited to describe them in detail. In this chapter, we present accounts related with detailed narratives on both vital moments of birth and death. In fact, the experiences surrounding the birth of a child and the death of a significant other were recognized by all interviewees as "special" moments or occasions. Though gathered as isolated experiences, writing connects them by way of a coherent narrative. Word by word, writing thus allows us to recognize, in this specific case, how an apparently ordinary and meaningless name is, in fact, a key element to deeply understand experiences and meanings reported by subjects in the interview.

Maria dos Anjos describes this way the day of birth of her first child, born with an unexpected malformation:

It was an important day, but it was a very bad day also. It was a great day ... happy and sad. Because ... I was in great anxiety about her birth. It wasn't the moment itself that scared me. I had ... I lived my pregnancy with great strain and almost forgot I was pregnant. I was always near my mother. And then when she died ... there were still two months left until the birth of my daughter and I thought I would somehow recover ... with the birth ... so I invested a lot in the birth and thought it would be very good for me and that ... things would get better ... then it was a great shock because I wasn't expecting anything like this! She was born with a malformation which hadn't been detected during pregnancy. A malformation of the spine that had to be surgically corrected and that despite me being a nurse was something I had never heard from anyone! I had never heard of ... only in nursing school ... but no ... I wasn't expecting it! I often thought in Down syndrome, stuff like that ... But that was something it never ... never, never, never crossed my mind!

Maria dos Anjos' first child birth experience cannot be isolated from the dual circumstance of the death of her mother during pregnancy and the unexpected birth of a child with a malformation. The latter took her completely by surprise. Despite being a nurse, until that moment she does

not even remember ever having heard in detail about what would come to affect the birth of her daughter. She goes on to say:

I've never been with her. Because she was born so, she was taken to neonatology ... She was born in the delivery room and was soon taken to neonatology. And I came here to the infirmary. After a bit, they came and told me that she had to go to Lisbon and I saw her briefly, right before she left. Only after, did I return to see her¹⁴

Accustomed to being “on the other side,” next to her nursing colleagues and medical staff, Maria dos Anjos remembers the difficult moment when she was surprised with the information on her baby birth:

People there said it all at one time ... when I was very weak and emotionally frail ... they came to me and said, “probably she cannot walk, she may have serious developmental problems, psychomotor and so on” There were times I just stood ... I could not think of anything! People talked to me. I listened. I was informed, but I was not able to process the information immediately. I just wanted to look at her and see her in the crib, to see that she was okay, moving her legs, moving her arms ... all the other things, it did not matter. Not at that time, no

A year later she had the professional opportunity to work in the hospital maternity ward. This contributed to reinforcing the “negative” image around her previous experience and, at the same time, gradually helped her to construct an even more powerful representation of a forthcoming pregnancy and birth. This would happen not long after with her second child.

Maria dos Anjos: All that post-partum phase, I didn't had. I didn't work here [hospital maternity] at the time. However, when I came to work here, my daughter was one-year-old at that time. I needed to live a normal post-partum. Tremendously! Because I looked to other women and said to myself: “I didn't have it!”

Interviewer: And what was “it”?

Maria dos Anjos: ... a child in a crib beside me, crying, to breast feed ... I had nothing like that. I had no visits. I had no congratulations and I felt I needed it. I felt it! I look at people in the maternity and thought: “I need to live it!”. Then I got pregnant. Spontaneously. And I was very happy! Very, very, very happy. And lived the pregnancy ... [emphasis added] although sometimes people said, “eh, but aren't

¹⁴ Adverbs of place in this excerpt disclose the setting of this interview, carried out in a hospital room.

you afraid the same would happen again?'. But no! I had a pregnancy ... very quiet, very peaceful, very positive, very enjoyed [emphasis added] ... and had a very good delivery ... and lived a normal maternity ... which I lived and enjoyed a hundred percent.

In this specific excerpt it is quite clear how Maria dos Anjos' occupation (nurse) is crucial to understand how her representation around birth is socially constructed, as well as the meaning she ascribes to the experience of a post-partum setting. At this point, one could think about the irrelevance of the interviewee's first name, but never the occupation. On the one hand, what other occupations could provide the framework for such an experience? What could be similar to this? On the other, would a simple name replacement be enough to safeguard the subject anonymity in a middle-sized town like the one where we collected the data? Which side to choose? And how to decide?

As we deepened data analysis and wrote about it, the dilemma of anonymity versus visibility's complexity increased. Accounts on the experiences around the death of a significant other came to underline challenges around safeguarding this interviewee's anonymity.

Displaying a general trend, Maria dos Anjos also referred to the death of a significant other and to funerals in general as family occasions. The quote below shows how her relation with death started early, during childhood:

... my mother took me to the cemetery when I was a child. My mother went to the cemetery every Sunday. To change the flowers, wash the grave ... Every, every, every Sunday. Initially she went every day. Then, after I was born, she started going every Sunday and took me with her. I only began to go to school when I was seven years old. Until that age, I was always with her. Every Sunday we went. Those were mechanized rituals, already incorporated.

We had already known that Maria dos Anjos had a brother who died at the age of 11. By now, she gave us more detail on the exact circumstances of her birth and the importance of that in her mother's life:

Maria dos Anjos: I felt I had come to occupy ... that somehow I had come to help her to overcome. Also because my mother frequently told me that. That I had come to help her overcome it. His lack. In everything. Inside the family, with my brother, my mother and my father. I always felt it ... I was not obliged to do certain things, or have to be exemplary in behaviour, but I felt it and felt it mostly through interdictions. Fear! Exactly ... because ... my brother died ... he had an accident. He went

out playing with some friends and had an accident. He had a fall; fell from a significant height, and ... I think my mother had an enormous fear that something awful happened to me. And ... it was a protection. She was always wondering where I was! And that ... somehow I understood that behaviour, but it was distressing to me ... I always felt it. Always. I felt that if my brother had not died, maybe I was not here now [Laughs]. Not that it bothered me, no, but I knew it, and I felt good because I felt that I came to help my mother and felt that I actually helped. Many things that she did, she only did it for me. If it wasn't for me, she had not done it... cut her hair, stop mourning, wear another colour. Because I told her ... "Mom, why don't you wear other clothes?". "Take off those!". "Stop using only black!". My mother kept her mourning until I was 9–10 years of age. Total mourning. Whole. All skirts! Everything black. And I always told her "Mom, for God's sake, take it off. Take off!".

Interviewer: What about your friends?

Maria dos Anjos: They asked me why and asked me if she changed clothes ... Because her clothing always looked the same. And myself, I remember asking her that.

Maria dos Anjos' accounts on her childhood are quite matter of fact regarding the issue that occupies us here. When describing an ordinary dialogue between her and her mother, a disclosure was made that would be crucial for handling our anonymity versus visibility dilemma:

For instance, if I had to go ... to the hospital, my mother did not come by the main Square. We walked the lanes to meet fewer people. Because she did not feel comfortable in the midst of many people. Then she began to have to do it ... but because I asked her. "Mom, let's not go here, let's take the other side." There was a parents' reunion in school, "mom, please come to reunion"... I think if I wasn't born my mother had entered a dark phase of depression, very bad. And I somehow came to force her to wake up and to live another way. And she also made me feel it. Sometimes, when we talked, she underlined it. Other times I asked my mother "mom, why did you call me Maria dos Anjos? I hate that name!". "Well ... because everybody said you had been an angel God send to our lives ... That's why you have that name."

By the end, when asked how her relationship with the cemeteries is currently, Maria dos Anjos stated:

I feel a great peace. When I go there I don't feel bad, I have no fear, I feel ... good. I do not go there every Sunday or every month, but I go there ... when I feel like, when I need to.

Maria dos Anjos' name is, after all, the key element to understand many aspects of her life—all the sadness and mourning she felt in her mother during her entire childhood and adolescence, but simultaneously a strange and over-protective behaviour; the expectation placed upon the birth of her first child, as if it might help to overcome her mother's death just like her birth did when her brother died; and finally, the peaceful relation she keeps with cemeteries, a physical space rejected by most of the interviewees.

A new challenge came our way as we wrote up the data. If initially Maria dos Anjos' name seemed an irrelevant attribute of this woman, doomed to a quick and easy replacement, now this replacement seemed almost impossible to make. What other names could we think about which could fit here? How, as scientists, can we choose a pseudonym which simultaneously allows for the safeguard of this interviewee's anonymity in these three dimensions: name, occupation and life experiences?

As Burgess (1984) reminds us, to make up pseudonyms is not an easy task. Names give meaning to actions and activities, he advocates. Often oversimplified in its meaning, proper names might, in fact, be windows for social understanding. Additionally, Betsy Rytnes pointedly formulates:

A proper name, then, is not simply a useful label, but a repository of accumulated meanings, practices, and beliefs, a powerful linguistic means of asserting identity (or defining someone else) and inhabiting a social world. (Rytnes 1999, 165)

At this moment, our responsibility is not only safeguarding for Maria dos Anjos' anonymity, but also, and above all else, to choose a pseudonym that, as Rytnes notes, might allow others to assert the identity of this woman in exactly the same way as her real name does.

By now we have to remind the most distracted readers that, as previously stated in a footnote, all names cited are pseudonyms. This is also true for Maria dos Anjos. In order to safeguard the subject's anonymity, a pseudonym was chosen and minor changes in *verbatim* transcripts were made. We shall feel somehow satisfied with our work if Maria dos Anjos was an effective pseudonym to illustrate our interviewee's real name. Since the reader does not know what the real name is, this evaluation can only be done through individual awareness of the complexity and richness of the case described.

Concluding Remarks: from Ethics “By the Book” to Ethics “On the Move”

With this chapter we have not sought to repudiate the importance of anonymization practices in view of safeguarding informants’ anonymity, nor do we intend to devalue the importance of ethics “by the book,” namely the one deriving from methodological literature or professionals organizations’ codes of ethical conduct. Instead, we argue that researchers should be aware that following ethics by the book does not prevent facing later ethical dilemmas.

In the framework of social sciences, most professions have well-defined codes of ethics. Sociology is no exception. Besides fieldwork, the writing process is a crucial moment where ethical issues arise, namely those regarding the safeguarding of subjects’ anonymity. This happens because in qualitative sociological inquiry there are no clear borders between data processing, analysis and writing. Writing is itself a method for discovering, analysis and knowledge that brings richness, colour and texture to social understanding. Specifically, when writing contextualized narratives, we realize there is no irrelevant information. *Verbatim* transcripts allow us to puzzle information, which might be crucial to deeply understand reported experiences and meanings ascribed by subjects.

As empirical evidence clearly shows, ethical issues are not closed matters when finishing fieldwork, data gathering or obtaining advanced informed consent; rather, they are moving issues. Pseudonym assignment is often presented as a simple procedure to overcome the anonymity versus visibility dilemma. However, behind it may ultimately be an operation of complex contours which brings many challenges to the researcher/writer. As illustrated previously through the accounts of a woman interviewed for the purposes of a major study, what seemed to be a very simple and quick substitution of a name by a pseudonym ended up as the key for a continuous work of discovery.

Awareness of the complexity of anonymization practices over a naive understanding of this common procedure should remind the researcher of the multiple and sometimes conflicting rights and duties to which they are committed. For this reason, it is important to keep ethical issues out there as a topic to be both contemplated and discussed.

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CHAPTER THREE

AT THE “ETHICAL CROSSROADS”
OF ETHNOGRAPHY:
OBSERVING THE “CARE ENCOUNTER”
AT THE ELDERLY PERSON’S HOME

JOSÉ DE SÃO JOSÉ AND ANA RITA TEIXEIRA

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 elderly person's homes, as well as to describe and discuss the decisions taken to advance 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 & 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 artificial ones. In the process of gathering data, participant observation and informal conversations play a determining 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 remains conscious of other dimensions (some of them will unexpectedly emerge during their presence in the field and may require the mobilisation of other methods). The "open" and "ongoing" 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" (NCPHSBRR 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 & 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 the current 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. This 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 *et al.* (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 *et al.* (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 to 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 & 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 their "ethical sensitivity" to negotiate the research process and to minimize the potential risks to participants (Jokinen *et al.* 2002, 166; Murphy & Dingwall 2007, 2225; Parker 2007, 2253). Researcher access to some spaces and interactions could be allowed as the trust between them and the participants develop over time (Murphy & 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 its conclusion. This is the reason why Murphy & 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 & 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 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 research ethics committees (RECs) are not institutionalised contrary to what happens in other European countries, such as the United Kingdom.

Table 3.1: The Ethics Framework for Social Science Research in Portugal	
European Level	RESPECT Code of Practice
National Level-Portugal	<p>Law Act on the Protection of Personal Data (Act 67/98of 26 October)</p> <p>Ethics Commissions/Councils National Commission on Data Protection National Council on Ethics for the Sciences of Life</p> <p>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</p> <p>Professional Codes of Ethics Typically, each professional association, including the Portuguese Sociological Association, has its own code of ethics</p>
Local Level	<p>Research Ethics Committees in the Domain of Social Sciences at Universities and Research Organisations Portugal has no traditions. Some were created very recently.</p> <p>Research Ethics Committees at Social Care Organisations They do not exist. Only the healthcare sector has some traditions regarding RECs</p>

As we can see in Table 3.1 above, at the local level there is no tradition of 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, at 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 in 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 been given explicit consent. Other important issues are related to the 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.¹⁵

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

¹⁵ The ESRC introduced its Framework for Research Ethics (FRE) in 2006, and since then, it has only funded research that demonstrates compliance with it.

and institutions" (APS 1992, 8). Thus, although the term "informed consent" is not mentioned, this code argues that it should be obtained before proceeding with data collection.

Finally, at the European level, the main 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 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, in Portugal 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 in 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 elderly person's 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 FST and should be completed by late 2013.¹⁶

Within this research project, ethnography was chosen to observe the "care encounters" which take place at elderly person's homes. In all of these encounters, there were home-care workers present, and in some cases there were also family caregivers present. Thus, the elderly people's

¹⁶ The project website is <http://elderviews.info/website/>. Reports and other publications will be available on this website.

homes—or, more precisely, their bedrooms in the majority of the cases—are the settings in which we undertake participant observations and have informal conversations.

The access to research settings (elderly person's homes) was 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 to explain the research objectives, the research practices involved, and the type of collaboration we would like to have with 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 were also 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 any case).

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 followed visits to fourteen elderly people, a total of 108 visits at the time of writing (the field work is still in progress). Each visit lasted up to fifteen minutes (making a total of about twenty-seven hours of observations) and a majority of the elderly people received two visits per day. In the cases of elderly people who received two visits per day, these visits included 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 elderly people, wash them at the day care centre, and bring them back to their homes). The elderly 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 those 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 elderly people receive intimate care in the most private rooms of the house (eight receive body hygiene, including changing nappies, and two receive help with bathing), others (four 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, they 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 elderly people, 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 "dilemma" 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 those 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 Elderly People or also from Other Participants in the "Care Encounters" at their Homes?

Before we went to the field, we were tempted to obtain informed consent only from the elderly people, 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 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," the elderly person only or their caregivers as well? On the other hand, who should we classify as a "caregiver"? This is a typical problem of "Where to set the limits?"

Concerning the first question, we finally decided that all 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 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 elderly people's experiences of receiving care without also looking at the caregivers' practice. In other words, data is collected from the caregivers and the elderly people.

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 a 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 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 Elderly People or also from their Caregivers?

In relation to the elderly people, 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, only the elderly people. 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 elderly people, 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 elderly.

The next decision to make was, "What kind and amount of information should we give them?" The first time we visited each elderly person, the home-care workers informed them that they were accompanied by people from the university and asked them if we could gain entrance.¹⁷ All of the elderly people agreed. In the first encounter with each, 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 elderly people would not fully understand the detailed information about the research objectives and could even be 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

¹⁷ On some occasions (very few), the home-care workers presented us as "doctors" to easily obtain the elderly people's 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.

physical and psychological integrity of the participants (Larossa *et al.* 1994, 110; Murphy & 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 elderly people. In the first visits, our goal was to make them feel that 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. "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 not imply a commitment to "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 elderly people's 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 informing them that they would also be observed by us. This disguised strategy was 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 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 to obtain their "post-hoc" consent. The information that we are considering giving them will focus primarily on revealing 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 elderly people—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 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, the same procedures are adopted with family caregivers as with the home-care workers.

Ethical Crossroad IV—Should we Obtain an Initial and Definitive Informed Consent or a "Continuous" One From the Elderly people?

Larossa *et al.* (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, such as our initial timidity in asking the elderly people if we could assist with the provision of intimate care. In the

first visits to the elderly people 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 they received intimate care. As trust and rapport started to build, we began to feel more at ease in asking the elderly people 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 elderly person, but after observing the provision of intimate care twice, their spouse informed us that they 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, "ongoing" 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 the 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 their house. It is also not typical for a person to sign a contract with a domestic employee in order to obtain domestic services from them.

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 elderly people would be able to sign due to their disabilities. Thus, we asked for oral consent from them 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 made (in the case of the elderly people) and will be made (in the case of caregivers) in the presence of two ethnographers.¹⁸

¹⁸ One elderly person cannot speak due to their disability, but can understand the conversations very well. In this case, consent was given through nonverbal communication. In another case, we were not sure whether the person properly understood the information we gave them to obtain their consent. Consequently,

Ethical Crossroad VI—Should We Report Negligence Against an Elder, or Should We Preserve his/her Autonomy?

In one case in which the elderly person lives with a close relative, we identified indicators of negligence. At almost every visit (in the morning and afternoon), we found that the elderly person had fallen on the bedroom floor and was lying there with their pyjamas full of urine and faeces. In one visit, we found that he had a large hematoma on their 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 elderly person and report the situation only at his request or to report it without the elderly person's request. However, there are several questions that are difficult to resolve: To what extent is the elderly person autonomous enough to make a decision? Do we need an explicit request or just an implicit one? Our informal conversations with the elderly person 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 by a close relative.

In this situation, we decided to raise the awareness of the home-care workers to the fact that the elder was 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 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), 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 transpire 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.

when we had the opportunity to talk to the relative responsible for them, we obtained oral informed consent from this relative.

All the "ethical crossroads" that we have found, except one which is primarily related to the protection of the elderly people's autonomy, are related to informed consent. This confirms Fine's statement (1993, 274): "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 elderly people or also from their caregivers? What kind of information should be given? Should we obtain initial and definite consent or "ongoing" consent? Should we obtain written consent or oral consent? In turn, the respective decisions were as follows: we would obtain informed consent from the elderly people and the caregivers present at the home-care visits—an initial consent from the elderly people and a "post-hoc" consent from their caregivers; we would provide general information, omitting the potential risks in participating; we would obtain "ongoing" 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 elderly people and their 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 elderly people and caregivers, reactivity in the caregivers (via revealing detailed information to the elderly), and misunderstanding of detailed information by the elderly people.

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 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 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 elderly people 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 "ongoing" consent, we agree with the authors who defend the practice in qualitative research, especially if it involves fieldwork, that obtaining the participants' consent should be an "ongoing" 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 elderly people 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 it is possible, no harm) to the participants.

Finally, there is the issue of "reporting or not reporting" 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 elderly person's interest (protecting his/her 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 elderly persons' 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 the guidelines version of the components of what Haggerty (2004) termed "ethics creep," the 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). However, 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 saying 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 "strengthen 'professional' models of regulation which emphasise education, training and mutual accountability" (Murphy & 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 & 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.

In conclusion, we are in favour of a model of research ethics regulation which we could designate through an "ethics friend," that is flexible, open to the perspectives of all intervenient actors in the research process (including the perspectives of those being studied), being more sensitive to

qualitative research and more confident in the "ethical sensitivity" of researchers and professional bodies.

Acknowledgments

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<http://eur->

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EN:NOT

CHAPTER FOUR

INVITING THE ASSENT OF CHILDREN DESCRIBED AS FUNCTIONALLY NON-VERBAL

JESSICA NINA LESTER
AND ABRAHAM BAROUCH

Introduction

Doing interactional research with children presents many ethical and methodological dilemmas; moreover, when working with children with communicative differences, particularly those who might be described as functionally nonverbal, additional challenges often emerge. Thus, in this chapter, we highlight the ethical dilemmas inherent to acquiring the assent of children with autism labels who have historically been described as functionally nonverbal or non-communicative. To date, minimal research has addressed the impact of communication challenges on qualitative data collection and analysis, with even less attention given to the ways in which assent and consent are acquired when communicative differences exist. Low (2006) has argued that much of this literature fails to take into account how both the research participant with a communicative difference and researcher must learn to navigate the communicative difference *equally*. Here, we build upon Low's proposal and describe the ways in which a researcher engaged in interactional research can go about acquiring (or not) the assent of children with communicative differences in ways that are responsive and reflexive.

As we proceed, we present the ethical dilemmas of inviting the assent of children with communicative differences in a twofold manner: (1) highlight the challenges common to acquiring the assent of children, particularly when engaging in the collection of video data, and (2) discuss the added challenge and possibility of working with children who communicate in non-normative ways. We also orient to fieldwork as a relational and always unfolding process and frame this discussion through

this, highlighting the ways in which recursive reflexivity (Hertz 1997; Pillow 2003) and a relational approach to data collection (Ellis 2007) were useful in navigating the challenges related to acquiring assent from children who used communicative modalities different from our own. Thus, throughout the chapter, we present examples of the ways in which the first author went about acquiring the assent of the children, emphasizing the time required, the reliance upon their therapists' and parents' communicative abilities, and the importance of "listening" beyond verbal communication. While the first author engaged in the data collection and analysis process, for clarity we use "we" throughout the chapter.

We first provide an overview of the research study from which we draw our data and then move to describe the ethical challenge of focus. After presenting the ethical dilemma in relation to our theoretical commitments and understandings, we link the dilemma to the broader body of literature focused on the ethics and approaches to including research participants with communicative differences.

The Research Project

The data for this discussion came from a two-year ethnographic study (Lester 2012a; Lester 2012b; Lester & Paulus 2012) of a pediatric therapy clinic exploring the discursive practices of children with autism labels and their parents and therapists. Over the course of two years, fifteen children, the majority of whom had diagnostic labels of "classic autism," participated in this study, along with twenty parents/primary caregivers and eight therapists who worked with the children at the clinic/research site; this included three speech-language pathologists, two occupational therapists, one physical therapist, one autism specialist, and one support group facilitator. The data set included interview data with the participating parents and therapists and 350 hours of audio and video data (e.g. from group and individual therapy sessions and waiting room conversations), observational field notes, a corpus of e-mail correspondence, and artifacts used during therapy sessions and administrative tasks.

The aim of this study was to examine the naturalistic talk of children with autism labels, as well as that of their therapists and parents, and when selecting a research site particular attention was given to those settings in which such data might be available. Further, with a broader interest in talk that occurs within institutionalized settings, a setting infused with specific, institutionally-specific practices was pursued. Thus, for the purposes of this study, the first author invited the participation of a private pediatric

therapeutic clinic (with a self-selected pseudonym of The Green Room) that provided a variety of educational and health-related therapies and support to children with developmental disability labels and their families. Located in a mid-sized city in the Midwest region of the United States, The Green Room offered group and individual therapeutic sessions in occupational therapy, physical therapy and speech-pathology therapy to well over eighty families and their children. The clinic also provided group therapy sessions for children with disability labels, often focused on the development of daily living and social skills within the context of group and structured and unstructured play settings.

Following Institutional Review Board approval (i.e. the ethics board), the first author travelled to the research site and worked closely with the clinical directors to identify and contact parents whose child: (1) had a diagnostic label of autism, and (2) participated in at least one of The Green Room's therapeutic activities, including group social activities, speech therapy, occupational therapy and physical therapy. The directors also identified those therapists who worked with the participating children/families. Through purposeful sampling, three speech therapists (two of whom were also the directors of the site), two occupational therapists, one physical therapist, one teacher/social group facilitator, and one medical secretary/sibling support group facilitator agreed to participate. Then, with the assistance of the clinical directors, the first author invited the participation of fourteen families with one or more children with autism labels who worked with the participating therapists. Each parent was individually approached by their primary therapists and was introduced to the first author and to the research project. Of those families invited, during year one a total of twelve agreed to participate, resulting in the participation of twelve children with autism labels, aged three to eleven. During the second year of the study, three additional families were invited to participate, resulting in a total of fifteen participating children. Acquiring the assent of the children required an ongoing negotiation and dialogue with each child participant, which is the focus of this chapter's discussion around ethical dilemmas.

Within our discussion, we draw on the observational notes and the researcher reflexivity journal maintained by the first author, specifically those entries documenting the ethical dilemmas and choices made during the two-year project. We give attention to those journal entries and observational notes that documented the ways in which acquiring the assent of those children with communicative differences was negotiated and co-produced in an ongoing fashion. The way we have come to make sense of how to ethically approach the acquisition of the assent of children

with communicative differences is guided by our theoretical commitments, which we explore next.

Theoretical Commitments

This study was positioned within a discursive psychology framework (Edwards & Potter 1993) and informed by critical notions of disability (Thomas 2004), as well as certain aspects of conversation analysis (Sacks 1992). Throughout, we presumed that the social world is built in and through talk, and assumed that the very ideas of “competent” versus “incompetent” communicator, “normal” versus “abnormal” child, or “autistic” versus “non-autistic” were constructs made “real” in and through the discursive and institutional practices that made them possible.

Our perspective on disability was informed by the social-relational model of disability (Thomas 2004), which positions disability as being relevant only when the activities of people with disabilities are restricted due to social norms. Disability, then, is a social construct, positioned at the nexus of biology and culture. Further, Thomas differentiated between impairment effects and disability, with impairment effects viewed as those restrictions of activity that result from living with an impairment of some kind. Disability, on the other hand, only comes in to play when “barriers to being” (i.e. behaviours, thoughts, or comments that have a negative effect on what an individual feels they are and can become) and/or “barriers to doing” (i.e. physical, economic, and material barriers which restrict people participating) are socially imposed and, thus, restrict the participation of an individual with an impairment. For instance, if an individual’s non-verbal communication status results in them not being able to participate in a research study that they desire to participate in, one might argue that a disability emerges.

Keeping this perspective in mind, when we considered how to go about acquiring the assent of child participants who were non-verbal, we made several important assumptions. First, we assumed that regardless of the mode of communication, it was the child’s right to give assent or dissent to participate. Thus, it was our responsibility to identify meaningful ways to communicate. Second, we took up a position that assumed individuals with autism were competent. In this way, we worked to eschew the deficit-based perspectives in which disability labels and communicative differences are so often embedded (Biklen *et al.* 2005). Third, we recognized that it was important to remain cognizant of our position of power and to work to align ourselves as co-producers of knowledge. Each

of these assumptions shaped how we made sense of the ethical issues that emerged, and we examine these ethical issues next.

Ethical Issue—Inviting Assent (or Dissent)

How do researchers invite the assent of young children, many of whom do not use words to communicate? This was the question that sat with us throughout this research project. When inviting the assent of the fifteen children to participate in the study, the typical ethical guidelines were in place, established by the overseeing institutional review board. Accordingly, only after gaining the consent of the children's parents did I (Jessica) seek the assent of the children. The institutional review board required that I read an "assent statement" to each child and wait for their written or verbal agreement. The approved assent statement was as follows:

Hello, (name of participant). Your mom and dad (or guardian) said that you are willing to help me in my project by letting me videotape and record all that you do when you are at The Green Room. You can help me by just doing what you always do when you are here. I think that I will learn lots from you. Are you willing to help with this project? (Child's response). Great! So, is it okay if I watch and type out the videotapes from your time at The Green Room after you finish up for the day? (Child's response). Thanks! Is it okay if I record what you are doing and saying? (Child's response). Thanks so much! Also, is it okay if I observe? (Child's response). Great! If you decide that you don't want me to record or observe you anymore, all you have to do is tell me. You can just say, "I don't want you to record me anymore or I don't want you to observe/watch me anymore." Okay? (Child's response). I will do my best to protect your identity and keep your sessions private. I will change your name when I type up all that you say and do in your sessions. Do you have any questions? (Child's response). I really appreciate your help!

The procedure was presumably straightforward, assuming that the parents actually spoke to the children about participating prior to their encounter with me ("Your mom and dad (or guardian) said that you are willing to help me").

Yet, the process of acquiring assent was anything but straightforward. Acquiring evidence of assent was much like learning a new dance—uncertainty pervaded. For instance, after meeting with the first potential child participant, simply reading an assent form and waiting for some kind of response resulted in a difficult-to-decipher stare and a barely audible "mm-hm." The next child I invited to participate used a communication device to communicate. When I invited her to participate, her speech

therapist assisted her in pressing a button that said “Y-E-S.” While I was well-versed in the literature around supportive typing (Broderick & Kasa-Hendrickson 2001; Calculator & Singer 1992; Cardinal, Hanson & Wakeham 1996) and recognized the competence of the child to communicate her assent to participate, when I asked if she had any questions, she walked away. I wondered if this was enough. Was it sufficient to simply ask her one time whether I could make observations and record her therapy sessions or did I need to continue to ask her each time I saw her? I was troubled and questioned whether “mm-hm” or a single “Y-E-S” truly indicated assent to participate. What indicated “true” assent?

The third child I spoke with confirmed my growing concerns. When the nine-year old boy arrived at the clinic, his therapist introduced me to him. I recognized immediately that he was non-verbal and seemed to use body language to communicate. His mother and therapist appeared to know what he desired and engaged with him through a variety of modalities (written, verbal, nonverbal). When I sat by him in the waiting room, with my piece of paper with the official “assent script” in hand, he only briefly glanced at me and then turned his body away from me. I quietly read the assent and paused at the appropriate places to wait for some type of affirmation. He did not speak, move or shift his gaze. His therapist kneeled down in front of him and outstretched her palms. She tapped her right palm and said, “Yes,” and then tapped her left palm and said “No.” With her palms still outstretched, she asked, “Can Jessica record and observe our session?” He tapped her right palm, jumped up, and ran toward the therapy room. The therapist looked at me and said, “Come on! He is okay with you joining us and recording.”

Indeed, each child I invited to participate displayed a unique communication pattern, one that challenged me to move beyond simply reading the assent form. It became quite clear that:

There is no direct or necessary relationship between ethics committee approval of a research project and what actually happens when the research is undertaken. The committee does not have direct control over what the researcher actually does. Ultimately, responsibility falls back to the researchers themselves—they are the ones on whom the conduct of ethical research depends. (Guillemim & Gillam 2004, 269)

As the individual who determined the parameters of the project and how the final claims were made public, I held a position of privilege and power. Yet, I was compelled to examine more carefully how to systematically and thoroughly invite, acquire and verify the assent (or

dissent) of the participating children. In determining how to ethically acquire the assent of the participating children, I turned to the literature.

Learning from the Literature

According to Ellis (2007), ethics boards, such as the Institutional Review Boards in the United States, certainly offer helpful guidelines to researchers. However, there are specific procedures and research situations that are beyond the confines of these guidelines, requiring the researcher to remain sensitive to the research context and the individuality of the participants. As we searched the literature in relation to our ethical concerns, we considered two bodies of literature. First, we examined the literature specific to acquiring the assent (or dissent) of child participants, specifically related to those with communicative differences. Second, we examined some of the literature focused on the communicative preferences of people with autism labels, making links to the process of acquiring assent. While much of the literature around the communicative differences of people with autism labels is centred on adult populations, we grounded our ethical decision-making process in what can be learned from such bodies of literature.

Acquiring Assent (or Dissent)

When seeking the inclusion of children in qualitative research projects, issues related to acquiring assent inevitably arise. For instance, there is typically a significant age difference and presumed power differential between a child and an adult researcher. This differential can result in children not freely expressing their dissent or perhaps not transparently sharing their lack of understanding in relation to what they are assenting to participate in. Despite such concerns, research suggests that when researchers build a relationship centred on trust, children are more apt to transparently engage in the assent process (Dockett & Perry 2011). Abramovitch, Freeman, Liioden and Nikotich (1991) conducted a series of studies examining the capacity of children aged five to twelve to give assent (or dissent) to participating in psychological research. They concluded that children do have the capacity to assent, but that there are issues that bring their free acceptance of participation into question. For instance, the researchers pointed to how children might feel pressured to assent, knowing that the researcher acquired their parent's consent prior to speaking with them. In that most children know whether their parent agreed for an outside researcher to speak with them, they might perceive

that their parent will be frustrated if they fail to provide assent. As such, the “true assent” of a child may be difficult, if not impossible, to claim. Ultimately, building a trusting relationship and being willing to orient to assent as an ongoing process (e.g. asking for assent throughout the research study versus one time) is critical.

Some researchers have emphasized the importance of evaluating the cognitive capacities of children when seeking their assent. For example, Broome, Marion and Stieglitz (1992) suggested that researchers must assess children’s cognitive ability on an individual basis so that they know how to provide them with information regarding a given research study. Indeed, this is a difficult “thing” (i.e. cognitive ability) to assess, particularly for researchers, like ourselves, who recognize that verbal capacities and intelligence are not inherently linked (Biklen *et al.* 2005).

Engaging with Communicative Differences

When engaging in research with children with communicative differences, relationships of trust and respect are perhaps even more critical to the research process. Low (2006) argued that much of the literature, however, fails to take into account how both the researcher and the participant with a communicative difference must equally learn to navigate the communication difficulty, including the process of negotiating the assent process. Kasa-Hendrickson, Broderick and Hanson (2009) described the multiple methods of communication of people with autism and other developmental disabilities and the importance of viewing non-normative communication patterns as meaningful and purposeful. Such a perspective on communication aids in navigating the ethical challenges raised when researchers have a limited ability to understand and/or communicate with participants about the purposes of a research study. While Kasa-Hendrickson *et al.*’s research is not explicitly linked to acquiring the assent of children with autism labels, it does highlight possibilities for engaging with children with communicative differences in individualized ways.

Linguistic research has reported that in very young children who have little speech (Ochs, Schieffelin & Platt 1979) and in adults with aphasia (Goodwin 1995), caretakers and peers often work to collaboratively establish what young children or adults with aphasia are attempting to communicate. Carlsson, Paterson, Scott-Findlay, Ehnfors and Ehrenberg (2007) examined methodological issues that arise when interviewing people with communicative impairments due to brain injuries. They argued that a third person, such as a nurse, played an important and

supportive role during the interview process, particularly as the third person was viewed by the research participant as being able to interpret their statements correctly. Such research points to the importance of researchers inviting people trusted by the child-participants into the conversations about research assent. Not only will the trusted third person be able to assist with interpreting the communication patterns of the child, but they will also (and perhaps more importantly) be a source of comfort and familiarity for the child participant.

It is particularly important for researchers working with children with autism labels who exhibit non-normative communication patterns to recognize that behaviour of any kind is potentially meaningful and communicative in nature. Rossetti, Ashby, Arndt, Chadwick and Kasahara (2008) conducted an interpretivist study in which they explored the actions and/or performances of individuals labelled with autism during communication “training” sessions. More particularly, they considered notions of competency and agency “amid behaviors and actions traditionally linked with incompetence” (Rossetti *et al.* 2008, 364). All eight of the participants (three teenagers and five adults) in this study were labelled with autism and used typing to communicate. Over a nine-month period, the researchers interviewed and observed the participants working with various professionals who were assisting them in learning how to communicate via typing. Through a phenomenological analysis, the researchers suggested that the participants “troubled traditional notions of independence by re-conceptualizing independence as including supports from other people and objects” (Rossetti *et al.* 2008, 368). Further, the participants performed agency through their non-verbal actions that could easily be misinterpreted by non-autistic professionals as moments of incompetence or purposeless behaviour. Challenging the view that dependence in some tasks or communicative “oddities,” such as humming in a rhythmic pattern or laughing loudly in response to a question or command, are signs of incompetence, this study offers a new reading of the behaviours of individuals with autism labels. Laughing loudly or humming, for example, were interpreted by the researchers “as meaningful and necessary for communication” (Rossetti *et al.* 2008, 370). This particular perspective, then, exploring the experiences of individuals traditionally considered as “low functioning” due to their differing form of communication patterns, points to the importance of researchers assuming all verbal and non-verbal actions are communicative and worthy of attention.

Relatedly, Ashby and Causton-Theoharis used seven published autobiographical accounts of adults and adolescents with autism as a

source of qualitative data. They specifically selected those texts that (1) had more than eight passages focused on “competence, intelligence or smartness,” (2) focused on childhood and adolescent years, and (3) represented a wide communication range, including alternative communication systems (e.g. typing) (2009, 504). Using a narrative inquiry approach, the researchers explored the ways in which the texts addressed issues of competence, noting how the participants made sense of the constructs of intelligence and mental retardation in relation to broader institutional practices, such as intelligence testing. Across the texts, the researchers noted that there was a problematic performance of knowing versus doing. Further, what was often assessed was not understanding but performing, or the ability to do something in a particular way, with the correct way being specific to a given test and assessor. For example, many of the participants described experiences where they failed to comply with a professional assessor who then named them incompetent. For them, it was not that they did not understand; they simply did not perform as they were asked.

Many of the authors of the analyzed texts described an awareness of how their speech was not conventional, as they did not always use words to convey their ideas. Consequently, this inability “to convey” ideas “through speech” frequently resulted in constructions of incompetence (2009, 506). The researchers of this study pointed to the ways in which communication and competence function as intersecting concepts, often resulting in the exclusion of those individuals who communicate in nonverbal or simply non-normative ways. They suggested that educators and researchers alike should expand their definitions of intelligence and normative performance, with an intent to “no longer disqualify people from this thing we call the human race” (2009, 514).

Considering these various literature bases, when approaching the issue of acquiring the assent of children with autism labels, particularly those children who have historically been constructed as “nonverbal,” we were committed to the following: (1) assuming that each child participant’s verbal and non-verbal actions are meaningful and communicative; (2) inviting a third person (e.g. therapist or parent) to be part of the conversation about the research project; and (3) acquiring assent in an ongoing manner across the research process. We next discuss how we applied these understandings to make sense of and navigate the process of acquiring, in an ongoing way, the assent of the child participants.

Methodological Solution

We structure our discussion of the “solution” around the three commitments noted in the section above. Throughout this section, we aim to emphasize the importance of engaging in recursive reflexivity across the research process (Pillow 2003). That is, we recognize that we are always a part of the research we conduct; thus, as we go about making decisions, we acknowledge that our conscious and unconscious choices, assumptions, and biases impact how we “solve” ethical dilemmas. Indeed, it was through our reflexive stance that we worked our way to an ethical solution; a solution that began with realizing that all behaviour is communicative and important to attend to.

Assume All Action is Meaningful

One of the primary ways that we made sense of our dilemma was by returning to our own conceptions of what it meant to communicate. Historically, communication has often been aligned with notions of verbalness and/or written forms of communication. Typically, oral communication has been privileged, with one’s verbal capacity often assumed to reveal intelligence and the capacity to function independently (Biklen *et al.* 2005). However, there has been a wealth of research that has questioned the very practices (e.g. intelligence tests) that reify and perpetuate myths about communicative competence. Further, there is evidence that communicative competence is not directly correlated with one’s verbalness (Biklen *et al.* 2005). While verbal communication continues to be privileged by society at large, what counts as communicative competence is always already socially contingent.

Within our research study, many of the child participants engaged in non-normative communicative patterns, including longer than expected silences (Lester 2012a). In interaction, pauses, nonresponses and silences often signal a problem within a conversation (Pomerantz 1984). Across much “Westernized” talk, there is a preference for one speaker to speak and the next speaker to respond with little to no gap between the conversational turns (Sacks, Schegloff & Jefferson 1974). While silence in conversations may display some “trouble” or even “misunderstanding”, for many of the participating children “silence” did not point to “trouble” or “misunderstanding.” Rather, in that many of the children used something other than audible words to communicate, silence was often just a part of the way they communicated. For example, a speaker might ask them a question and thirty seconds later (instead of the often expected

one to two second delay) they would respond through gestures, written communication, a shift in eye gaze, and/or by using another alternative form of communication.

As such, those who interact with child participants, particularly those described as functionally nonverbal, need to be willing and ready to learn a conversational style that does not necessarily match the expected norm. In many ways, individuals who are often positioned as “non-communicative,” particularly when communication is presumed to be verbal, are indeed communicative; however, they are communicating in a way that challenges the “perceived wisdom of those at society’s center” (Solorzano & Yosso 2002, 156). For instance, in this research study, the first author worked closely with the therapists to make sense of the various nonverbal means by which the children communicated their preferences. Behaviour, both verbal and nonverbal, is always already communicative (Greenspan & Wieder 1998); thus, central to any research process involving children with communicative differences must be a commitment to learning and making sense of the ways in which child participants share their desires, requests and perspectives.

Thus, we suggest that a key step to acquiring a methodological solution is early recognition in the research process of the need to learn how to communicate with children who use something other than verbal communication. Learning requires a commitment to making sense of the non-normative ways that the child participants share their desire to participate or not participate in the study. This requires the researcher to observe the verbal and/or non-verbal communication patterns of the potential child participant and presume that each of their behaviours is communicative, even if they are not understood by the researcher. A child’s use of gestures, gaze shifts, written forms of communication (e.g. writing a request or response), and/or alternative communication devices (e.g. iPad, Dynavox) must be accounted for when inviting their assent. A researcher cannot rely on how they have always communicated in the past, but instead must be willing to learn new ways to interact and interpret the responses and perspectives of the child participants. This, of course, is not a simple task, but requires reliance on those who are closest to the child and know their communicative style best. We discuss this further below.

Invite a Third Person

Quite often, researchers do not possess the skills and/or training to make sense of the various ways in which child participants might interact with others. This is particularly true for child participants who communicate

in non-normative ways (e.g. use communication devices to share their intent/desire) that are frequently unfamiliar to the average researcher. Additionally, child participants in general often hesitate to communicate with adults who they are unfamiliar with. Much of the literature about interacting with children and people with communicative differences points to the importance and benefit of having a third person present (Carlsson *et al.* 2007). The third person can be an individual who possesses skills and knowledge that the researcher lacks, such as knowing how to effectively interpret a request from a child participant or simply how to make a child feel more comfortable in the presence of an unknown researcher. Thus, when engaging in research that involves children, it is often useful to involve a third person, such as a parent, therapist or teacher, in the assent process.

Within our research, we found that through involving a third person, our concerns regarding assent were assuaged, at least to some extent. For instance, there were times when we were unsure whether a child's nodding head or shift in gaze indicated "yes." An individual close to the child, particularly someone intimately familiar with their communicative preferences, was able to guide us in knowing how best to interpret the child's non-verbal behaviour and respond to and invite more elaborated responses from the child participant. Across our research process, we decided to consistently involve a third person, recognizing that: (1) a third person, in our case a therapist or parent, understood the child's communication style far better than we ever would, and (2) the third person interacted with the children in the way that they preferred, likely increasing their comfort level. More particularly, we consistently observed the third person, most often the participating therapists, inviting the children to use sign (individually invented or American Sign Language), communication devices, pictures/symbols, writing or drawing to communicate. The child participant was always invited to communicate however they desired, thereby constructing communication as being something far more than verbal speech. Self-expression created possibilities for the child's way of communicating and being in the world to be privileged (at least partially). While we were committed to inviting and creating space for self-expression, we realized early on that our commitment to embracing varied ways of communicating often resulted in us not knowing whether a child really agreed to participate in the study. Living and working in a society that privileges verbal communication, we were challenged to move beyond our own reliance upon verbal behaviour, particularly as we sought to invite assent with the use of communication

devices and/or alongside individuals more familiar with the gestural patterns of the children.

For us, with a third person present, reading the assent form became more about having a conversation at the appropriate level and in a modality preferred by the child (e.g. using an iPad to type). As such, we did not just read the assent statement verbatim (as described above), but found ways to meaningfully adapt and adjust our delivery to connect better with the child. For example, for one young child participant, we used a communication device with pictures that depicted what we hoped to do (i.e. video record their therapy session) and why (e.g. “we hoped to learn about how you work with your therapist”). The therapist then assisted us in using visual cues that represented “yes” and “no,” as we invited the assent or dissent of the child. Not only did this allow us to confirm that we were doing as much as possible to communicate in an understandable and responsive way, it also served to build rapport with the child. While we made it clear to the children that they did not have to have a third party, each child requested for their therapist and/or parents to be present.

Our intent in inviting a third person to be present aligned closely with Lewiecki-Wilson’s (2003) idea of “mediated rhetoricity”; that is, “language used for the benefit” of the person with a communicative difference. According to Lewiecki-Wilson, “mediated rhetoricity” is communication that invites others to attend to the individual’s “embodied nonverbal performances and gestures,” as their friends, family and advocates work to “carefully and ethically co-construct narratives and arguments from” their perspective (Lewiecki-Wilson 2003, 161). This is the task of the researcher—to identify ways to communicate with the participant in ways that allow for their perspectives to be heard, understood, and responded to. This requires, then, that the researcher does whatever it takes to learn how a child uses “nonverbal performances” to share their preferences, particularly in relation to the research process. We suggest that engaging in research with children described as functionally non-verbal demands that the researcher (not the child) work to accommodate and support the self-expression and participation of children in non-normative ways. In other words, it is the ethical responsibility of the researcher to adapt their communicative style and invite the participation of a knowledgeable and trusted other. Ultimately, such an approach will lead a researcher to orient to the assent process as ongoing.

Acquiring Assent in an Ongoing Manner

While assent could be viewed as something that a researcher simply checks off their list, we argue here that acquiring the assent of a child participant should be viewed as relational and ongoing. First, inviting the assent of a child participant begins by recognizing that there is an inherent power differential between the child and adult researcher. Further, when working with children who are non-verbal, living in a world that privileges verbalness, there is a potential privilege in the very way that a (presumably verbal) researcher communicates. Thus, for us, we realized early on that it was important to find ways to let the children know that we planned to learn from and about them; we were interested in knowing how they communicated, with whom they communicated, and what they enjoyed communicating about. Long before asking for assent to video record the therapy sessions, we spent time letting the children know that: (1) their parents agreed for us to speak with them, and (2) they could ask us to leave; yet (3) we hoped they would allow us to stay, and eventually learn from them. Because the therapy sessions often involved the children engaging in activities that placed them in vulnerable positions (e.g. working on skills that centred around weaknesses), we felt it was important for the children to know us as people first who were not there to judge, but to learn from them. Conveying such a message to the children varied depending upon their age and their communicative preference. Nonetheless, when introducing the research to the children, we worked to frame the research study as an opportunity to learn with and from them. For instance, many of the children were learning “eating” and/or “toileting skills,” resulting in therapy activities and discussions that were highly personal. Thus, we were careful to position the purpose of this research as being about learning from their developing abilities, leaving open the possibility that at any time they could ask us to leave.

Accordingly, in lieu of simply reading the assent statement (as described above), when the first author initially met the children, she began by sharing that she wanted to observe and video record their therapy sessions because they “had a lot to teach me.” She also worked carefully to position herself in a non-expert role. One of the ways she did this was by: (1) observing what activities the children were engaged in when she was first introduced to them, and (2) joining them in their free play. For some children this included playing (when invited) with Legos, while for others it meant sitting on the sidewalk and commenting on the ants they appeared to be studying. For one child, an eleven-year-old, the free-play time was used to have a conversation about the meaning of “research” and “audio and video recorders.”

Finally, even after the child participants gave their assent to participate in the study, we regularly checked in with them and their parents to assure that they were still comfortable with our presence. We often asked: “Can I observe your session today?” Sometimes, children would shake their heads, saying “no,” or simply whisper or type a response to their therapist (“I don’t want her here today”). In these moments, the first author would leave the therapy room and let the child participant know that she appreciated their honesty. The next day, the same children would often greet the first author with an invitation to join them. Over the course of the research, then, assent was an ongoing and reflexive process; one that was never-ending and demanded that we remain reflexive. Furthermore, the longer we engaged in the research, the better we became at interpreting the requests, desires and perspectives of the children.

Concluding Thoughts

Acquiring the assent of children who have historically been described as non-verbal is inherently challenging to researchers. This is particularly true for those researchers who have limited exposure to non-normative communication styles and alternative communication systems. Throughout this chapter, we point to the ways in which researchers can work to reflexively (Pillow 2003) and relationally (Ellis 2007) invite the assent (or dissent) of child participants. We call for researchers engaged in similar work to commit, first and foremost, to learning the varied ways in which children communicate, while assuming that communication is not inherently verbal. In doing so, we suggest that researchers will move one step closer to navigating communicative differences in ways that do not simply demand that the participant change on behalf of the researcher; rather, the researcher can work to adapt their approach in response to the needs of the child participant. In other words, we call for researchers to begin “listening” to child participants in new ways that move beyond a dependence upon verbalness. A researcher must not assume that a verbal assent is the only way to determine whether a child agrees to participate in a given study. Instead, the researcher must seek to invite the child, and those closest to them, to teach them how best to communicate. The dilemma of knowing whether a non-verbal child participant “really” gives their assent is made sense of as the researcher: (1) assumes that the child’s behaviour is communicative and meaningful, (2) finds ways to make sense of the child’s communication style, and (3) views assent as being a relational, ongoing process.

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CHAPTER FIVE

ETHICAL AND METHODOLOGICAL ISSUES IN VIOLENCE AGAINST ELDERLY PEOPLE IN PORTUGAL: AN INTERSECTION BETWEEN SOCIOLOGICAL AND EPIDEMIOLOGICAL RESEARCH

ANA PAULA GIL, ANA JOÃO SANTOS
AND CÉSAR SANTOS

Introduction

This article highlights the difficulty of balancing methodological and ethical procedures within a national regulatory ethical review system, particularly informed consent and confidentiality in a victim survey. It describes the ethical issues the researchers were confronted with during in-depth interviews in the pilot phase and the solutions encountered. Problems obtaining written informed consent and assuring confidentiality, privacy and participant safety are discussed. Access to participants through institutional and service provider professionals brought up questions regarding participant motivation and the potential misrepresentation of the research scope. Finally, we discuss how interviewing victims of domestic violence, though risking “retraumatization,” can also be perceived as cathartic and beneficial to participants.

Mainly focusing on Anglo-Saxon countries (USA, Canada and UK), some authors have criticised several aspects of current regulatory ethical systems, particularly when it comes to qualitative and social research, described as bureaucratic, formal and rigid (Haggerty 2004; Murphy & Dingall 2007; Richards & Schwartz 2002). While medical research ethical committees have difficulty in assessing ethical issues in qualitative studies (Richards & Schwartz 2002), social research may be regulated by systems

based on biomedical and clinical trials research (Murphy & Dingall 2007). Historically developed following the discovery of several questionable clinical and biomedical research practices, the current ethical review systems are mainly based on these paradigms and, therefore, are inadequate for assessing different types of research studies (Murphy & Dingall 2007; van den Hoonaard 2001).

One of the usual ethical system requirements where the movement from medical to social sciences can prove to be less feasible is informed consent (Haggerty 2004; Murphy & Dingall 2007). Autonomy as respect for people and recognition of participants' rights is one of the major ethical research principles, operationalised by informed consent (Murphy & Dingall 2007; Orb, Eisenhauer & Wynaden 2000).

The contexts of medical and social research can be very different from one another. If the former can take place as a onetime event, social research such as ethnographies, participant observation or exploratory interviews can take place over a considerable period (Murphy & Dingall 2007; Haggerty 2004). Not only is it therefore possible that initial consent does not cover all data collected or to which the researcher may be exposed (Murphy & Dingall 2007), but it can also "seem alien, unduly formal, and occasionally unworkable" (Haggerty 2004, 404). There has been increasing literature indicating the need to treat informed consent as an on-going process, rather than a onetime event (McGinn 2005; Richard & Schwartz 2002). Notwithstanding this approach to informed consent having emerged primarily within qualitative research, Katz & Fox (2004) indicate its usefulness in health research. Methods used to merely collect signed written consent are not as relevant as the process employed to guarantee participants fully understand the meaning of their participation (Katz & Fox 2004; Murphy & Dingall 2007). Consent is a relational and sequential process rather than a contractual agreement and lasts for the period of research (Katz & Fox 2004; Murphy & Dingall 2007). Nonetheless, practical and ethical drawbacks can be shown regarding informed consent as a process, such as costs and impracticability as well as the unnecessary harassment of participants (Richards & Schwartz 2002, 138).

Additionally, the anticipatory regulation system, where informed consent is given prior to research, implies that all descriptions of risks, as well as benefits, are disclosed to potential participants. This is linked to the two other well-established major ethical principles: beneficence (doing well for others and preventing harm) and justice (particularly avoiding exploitation and abuse of participants) (Orb, Eisenhauer & Wynaden 2000). However, and unlike certain clinical trials or biomedical research

where quantitative risks and benefits can be calculated, the same is not always possible within social research. The difficulty of assessing research risks and benefits is higher in social research and seems to rely on the “interpretation” of the regulatory ethical review system (Haggerty 2004; van den Hoonaard 2001).

In the case of victim studies, an ethical issue normally stressed is the potential for participant “retraumatization” (Fontes 2004; WHO 2001). It is argued that questioning individuals about stressful events or personal victimization experiences may trigger painful experiences, reawaken memories of prior traumas and therefore distress participants (Fontes 2004; Haggerty 2004; Orb, Eisenhauer & Wynaden 2000). However, it has been argued that not only is there no empirical evidence to clearly state that disclosing a traumatic experience has psychological consequences (Newman *et al.* 1997, in Fontes 2004; Straus 1981), but that there might be different consequences, given the way different individuals will experience their participation in the study (Haggerty 2004). It seems reasonable nonetheless to consider that recalling a traumatic event can be distressing even if not “retraumatic” (Fontes 2004).

Participants may also face physical harm if their inclusion in the study is known, particularly if contact with perpetrators is maintained. Hence, other key aspects of researching domestic violence are confidentiality, privacy and safety (WHO 2001).

The pilot phase identified ethical issues and enabled reflection on the next phase of the ongoing research, being a population-based survey and a victim survey.

The Portuguese study *Aging and Violence* (2011–2014) aims to estimate the prevalence and characterize situations of violence (physical, psychological, financial, sexual and that of negligence) within the family context experienced by individuals living in Portugal aged sixty and over. The prevalence of this problem will be obtained through a population-based survey on a representative sample of the Portuguese population. A structured questionnaire will be applied using telephone interviews to estimate the number of older persons that, during a given period of time (twelve months), have experienced any of the five forms of violence under consideration. The data will also reveal the characteristics of the victims in the general population and identify risk and protective factors.

Additionally, the project seeks to gain more detailed knowledge about this social problem and its origins by conducting another survey targeting victims (face-to-face interviews), identified and referred by project partner

institutions: APAV; INMLCF, IP; ISS, IP and GNR.¹⁹ Data collection considers: the family conditions in which violence occurs (behaviour patterns and frequency); particularities; extent of situations; risk factors (individual, social, behavioural, health, among others) and associated protective factors (informal and formal social network), and; the institutional trajectory of complaints within the formal network.

The exploratory pilot phase was conducted in 2011, and involved four focus groups and in-depth interviews. The focus groups carried out in the pilot phase attempted to explore the perceptions and definitions of violence within a group of people aged sixty and over, encompassing sixty participants selected differently (from the Senior University, day-shelters and local town councils) and included heterogeneous groups of men and women, of different ages and socio-professional categories. The in-depth interviews were conducted throughout the country with thirteen older adult victims of violence recruited through professional service providers.

The exploratory pilot phase	3 focus groups (60) In-depth interviews (13)	2011
Victim sample	Survey targeting victims identified and referred by project partner institutions (face-to-face interviews)	December 2011 until March 2013
Population-based sample	Population based survey to estimate national prevalence (telephone interviews)	September until November 2012
Qualitative analysis	In-depth interviews (15) after the statics analyses	2013

¹⁹ Research project commissioned and funded by *Fundação para a Ciência e a Tecnologia* (FCT) (PTDC/CS-SOC/110311/2009), a central Portuguese governmental institution responsible for financing and evaluating scientific and technological research. The applicant organization is the National Health Institute Doutor Ricardo Jorge, IP (INSA), encompassing also, as partners, the following organisations and institutions: the Portuguese Association for Victim Support (Associação Portuguesa de Apoio à Vítima (APAV)); the Portuguese Institute of Legal Medicine and Forensic Sciences (Instituto Nacional de Medicina Legal e Ciências Forenses, IP (INMLCF)); the Social Security Institute (Instituto de Segurança Social; ISS, IP); the National Republican Guard (Guarda Nacional Republicana; GNR).

Different steps in the planning and implementing of the on-going research revealed difficulties in balancing well-constructed methodological research, allowing for a high number of responses and, at the same time, set up with ethically correct principles and procedures, particularly given the inclusion of both qualitative and quantitative methods. The research documented in the present article is set within the framework of health and epidemiological research. The several institutional and legal procedures, such as the informed consent form, are therefore enclosed within criteria applied to the Portuguese health research system, even though this is a sociological research.

Portuguese ethical review systems have considered all these major ethical principles. Nonetheless, and given the ongoing research configuration of both quantitative and qualitative methods, added difficulties can be present in the regulatory system's protocol assessment. Certain ethical dilemmas may not be foreseen when designing and developing the research and even though review systems may be restricted and somewhat inflexible, the current demands of these ethical systems may still present loopholes and not encompass all the ethical issues that can arise.

To reflect on the unexpected ethical issues that arise during data collection, the present chapter firstly presents the nationally required institutional and legal procedures concerning research ethics along with the difficulties faced in terms of methodology. Specific attention is given to informed consent and its standardized regulated form, then ethical dilemmas and problems that emerged during the exploratory phase, of a qualitative nature and design, are considered and solutions/resolutions described. Finally, we consider the implications of the choices and solutions adopted for the data collection phase of both surveys.

Legal Issues: Researching Violence against Older Adults

Prevalence of domestic violence studies face a double challenge: being methodologically robust to maximize the number of identified victims among the general population and, at the same time, ensuring and safeguarding anonymity, confidentiality and safety of potential victims. Lensvelt-Mulders (2008) noted some ethical principles underlying surveys: the right to individual privacy (confidentiality, anonymity); the need for informed consent (respondent's right, prior to accepting participation, to be informed on the study's purpose, methods, benefits or potential risks), and; managing individual misrepresentations of research scope regarding the solution to the victimization and ensuring safety.

Recent prevalence studies have used two main methods: face-to-face or telephone interviews (Lowenstein, Eisikovits & Band-Winterstein 2009; Naughton *et al.* 2009). In prevalence studies about sensitive subjects, such as violence, crime and drug abuse, telephone surveys have in the last decade come to be considered as more viable and beneficial in addressing these issues (UNODC 2010).

The chosen methodology (telephone survey) raises different questions regarding confidentiality and a suitable dissemination strategy to promote the study. How to get to the respondents? Should an advance letter be initially sent or should potential informants be informed about the study during the telephone contact? Make a first telephone contact followed by a letter and a new contact? Overall, the telephone approach presents a difficult balance between effectively eliciting high response rates and guaranteeing respect for anonymity and confidentiality.

The pilot phase of the *Aging and Violence* study, involving four focus groups of sixty older adults, helped to further reflect on possible strategies in approaching potential respondents on the subject of violence. Some participants favourably perceived the possibility of an advance letter stating the study aim and identifying the coordinating organization and research team. The reference to the National Health Institute Doutor Ricardo Jorge, IP, was considered as ensuring credibility and therefore increasing the response rate. Albeit recognizing the letter's importance, other focus group participants thought it would be easily forgotten and lost among other mail. Another risk mentioned was the potential dissatisfaction in answering a survey by telephone, given the high volume of market studies to which individuals are subject nowadays. Furthermore, some participants stated that, for safety reasons, they would not answer the telephone without previously validating the caller's number. Notwithstanding the favourable arguments, the National Commission for Data Protection (NCDP) dismissed both the advance letter and the single telephone contact, given that it would imply prior knowledge of the names and addresses of potential respondents and hence undermine the confidentiality and anonymisation of the personal data.

This decision raised some methodological problems with inevitable consequences for the data collection process. In the next section, we describe the responses to the submitted scientific protocol of both the National Commission for Data Protection (NCDP) and the Ethics Committee (EC) of the coordinating institution.

Response of the NCDP and Ethics Committee

The NCDP organization represents the Portuguese National Authority for Personal Data Control and is responsible for overseeing the processing and use of personal information, and safeguarding the guarantees and Human Rights provided for in the Portuguese Constitution and Law.

Portugal has standard institutional procedures required to conduct research. Specifically in health research, and to guarantee participant protection, there are a number of juridical and legal requirements involving approval from the NCDP and the Ethics Committee (EC) of the coordinating institution. Research approval entails, along with the scientific protocol, evidence of the nonexistence of direct risks to participants and the suitable consideration of data confidentiality and anonymisation. To this end, both the NCDP and EC established a number of different items that had to be duly answered and justified when submitting the scientific protocol (see Table 5.2 below). This requires specifying information on each single item (e.g. data responsible) and, in other cases, demonstrating how the different criteria will be complied (e.g. confidentiality).

The authorisation request for approval by the NCDP depended on the compliance of two conditions: (1) Total anonymous data collection, which resulted in the rejection of an advance letter in the telephone survey; (2) Taking into consideration the sensitive topic under study and the fact that domestic violence is a public crime, the market research company to be contracted must ensure that the interviews will be conducted by health professionals. Furthermore, the NCDP recommended that when, during the interview, a victim of violence is identified the interviewer should provide contacts for competent institutions and organizations. Another suggestion was to make the coordinating researcher contact available allowing confirmation by potential participants prior to the scheduling of the interview.

In both NCDP and EC, informed consent represents the instrument which monitors and guarantees the rights and duties of all parties involved and, especially, participant dignity and autonomy.

Table 5.2. National Commission for Data Protection and Ethics Committee Conditions and Requirements	
National Commission for Data Protection	Ethics Committee
1. Data handling responsible institution	1. Study/project identification
2. Information on system features (equipment, logistic support)	2. Participant risks (envisaging how participants may be affected) and benefits (foreseeable possible gains)
3. Research goals	3. Confidentiality (measures to ensure data confidentiality)
4. Data processing responsible institution	4. Consent (informed consent form and how it will be obtained)
5. Personal data included in records	5. Financial compensation and incentives to participants
6. Data collection (direct and indirect personal data to be obtained)	6. Participant insurance
7. How data is to be updated	7. Term of responsibility (coordinating researcher statement on truthfulness of provided information)
8. Data exchange (if applicable, specify the kind of data that is to be exchanged, purposes, parties involved and security measures to be taken)	
9. Data transfers outside the EU (if applicable, specify the bases and conditions)	
10. Measures to ensure information security	
11. Deadlines to holding personal data	
12. Conditions and procedures by which the holder may know, correct or eliminate his/her data	

Informed Consent

Informed consent, a prerequisite in health research, implies informing participants about the study's purpose and scope, the coordinating institution, the questions which are likely to be asked and the use to which the results will be put, among other relevant information (Richards & Schwartz 2002). Though it can be given either verbally or in writing, the informed consent has to be registered. Oral consent will suffice when conducting telephone surveys (Haggerty 2004).

The EC recommended several key points regarding informed consent forms as well as the information to be given to study participants in a face-to-face questionnaire or its summary in the telephone interview. Some key points that must be addressed in easily comprehensible language are: research purpose; potential risks and expected benefits (including average time needed to answer the questionnaire); voluntary participation; possibility of stopping participation at any given time; guarantees of

Even though the EC has considered potential risks and benefits to participants, it did not mention safety issues regarding the research team. In socially sensitive research, there are usually potential consequences or implications directly for participants, but also for the research team. Risk of harm and physical safety, though greater to participants, can also apply to researchers and field staff if confidentiality is breached. Risks can include threats to physical safety from the abusive individuals if they find out and object to study participation. Participation may provoke further violence to participants, but also retaliatory violence towards the researcher because of disclosure (Fontes 2004; WHO 2001). This aspect is particularly relevant in the victim survey regarding the informed consent form. Since personal identification of the coordinating researcher had to be included in the form, some questions were raised regarding the most suitable procedure: include the full name of the coordinating researcher, omit or change it? Due to personal safety, the research team decided to utilize a different last name to that usually employed and hence one not so easily identifiable.

Safety of research teams is a salient question in research into elder abuse. Though issues such as safety, confidentiality, informed consent and retraumatization by participants are frequently pointed out in the relevant literature (Lensvelt-Mulders 2008; UNODOC 2010; WHO 2001), ethical problems can be specific to the nature and design of research studies.

We are going to present unexpected ethical issues that arise during the data collection that forced the team to reflect and find various solutions.

Emerging Ethical Issues in Different Phases of the Research

Ethical Issues: In-Depth Interviews

During the *Aging and Violence* project pilot phase, thirteen in-depth victims' interviews were conducted in seven APAV offices (Portuguese Association for Victim Support) and other organisations (town councils and the Public Security Police). Encompassing different victim profiles, the interviews sought to incorporate the victim's story, consisting of: acts of violence; occurrence conditions (context, extent, frequency); perpetrator characteristics (gender, age, schooling, profession, among others); relationship type (relative, friend, neighbour, paid professional), and; victimization perceptions (motivations, reasons and problems).

Some ethical issues were reasonably anticipated and safeguarded in the fieldwork, whereas others arose from the data collection procedure. Whilst

the research team tried to anticipate and foster participant safety, their right to privacy, confidentiality and informed participation, during the fieldwork some adjustment had to be made. The two main issues which arose were: potential participant identification through service provider professionals and misrepresentation of the research scope. In the present section the procedures to ensure compliance with ethical principles are described, as well as the inadequacy of such procedures to particular cases and situations. Following the ethical problems and dilemmas reported, case by case solutions are discussed and presented.

Informed Consent

The informed consent procedure applied to in-depth interviews was identical to that developed for the victim survey. After welcoming participants, the researcher explained the study and interview and in the case of agreeing to participate, the researcher requested the informed consent signature. The consent form, read either by the researcher or participant, covered the study's aims, methods and potential risks and benefits. In addition to specifying the data analysis method, and its utilization and publication, it was stressed that the interviewee could withdraw at any time, stop the interview midway or refuse to answer specific questions. However, and even though the regulatory national ethical system stresses the importance of the written consent form, in three cases, participants willing to share their story and have it recorded refused to sign. Should the researcher give up interviewing these potential participants, who actually want to share their story?

To adequately ensure participant safety, privacy and confidentiality aspects of who, how and where the interviews would be conducted required particular attention. In the present study these aspects are associated with an additional question: how to gain the trust of potential participants? Effective recruitment of participants is crucial to any research. In the case of exploratory interviews, although population representativeness was not the aim, the heterogeneity of participants was important to cover different situations and contexts of older adult victimization.

Identification through service provider professionals, already working with the victims, ensured participant safety, privacy and confidentiality. Nonetheless, the methodology adopted during the field work brought about other unforeseen ethical concerns about the participants' decision-making process to take part in the study. Some interviewees stated an automatic "trust" and acceptance of the interviews and interviewer

because of the established relationship with the privileged contact. How does someone who is vulnerable and in some cases still experiencing domestic violence on a daily basis reflect upon a proposal from a professional (sometimes the only one who knows about the victimization) directly intervening in their case?

How to guarantee participants have truly understood the context and nature of their participation and do not participate because they are afraid of penalties if they refuse to or because they expect “extra attention” in their particular case? In fact, another ethical aspect that took place during the in-depth interviews was participant expectation concerning the direct intervention in their cases by the interviewer, which sometimes revealed a misrepresentation of the research scope.

The vulnerability of individuals experiencing domestic violence and the emotional distress that could be triggered during the interviews, labelled “retraumatization,” was also anticipated by the research team which tried to develop strategies that would prevent and respond to such risks.

In most interviews, the informed consent procedure took place as intended and participants did not seem reluctant to participate. In three interviews, nonetheless, specific circumstances required adjustments to these procedures.

One participant was an English national and although had lived in Portugal for eight years did not speak or read Portuguese. The researcher proposed to translate the consent form into English but the participant dismissed the idea, stating that would not be necessary and therefore the consent was verbally translated by the researcher and signed by the participant.

The other two cases illustrate the need to always take into account the social, cultural and educational backgrounds of participants. In these cases, verbal consent (not written) was obtained. In both interviews, participants accepted to share and record their stories but categorically refused to sign the form. The researcher tried to explore the refusal reasons to understand if it derived from apprehension about participation in the study and if there was any aspect that needed to be reformulated or discussed. One participant said she had a physical condition and difficulty in holding a pen due to wrist pain. The other interviewee stated, after a while, that she did not know how to read or write. The researcher’s persistence may have “coerced” the participant into providing information the participant did not want to reveal, though at the time the researcher tried to reduce the impact of the disclosure, knowing or previously considering that the possibility of participant illiteracy could minimize the discomfort felt. In this case, the

participant's cultural and educational background should have been considered. In fact, language adaptation to the special needs of each individual has been recommended (National Research Council 2003).

Illiteracy may not be the only difficulty regarding the written informed consent form. Research aiming at sensitive or critical topics encompassing marginal, illegal and criminal behaviour may not be accessible if written informed consent is mandatory, and requiring a name and signature can undermine natural anonymity (Haggerty 2004; van den Hoonaard 2001). Demanding a participant's signature may be "unwise or tactless" (van den Hoonaard 2001, 28). What may be an informal and exploratory moment, as in-depth interviews, can become formal and legalistic obstructing the data collection (Haggerty 2004), when the more important aspect is that the nature and purpose of the interview is known to participants (Haggerty 2004; van den Hoonaard 2001). Individuals may become suspicious of the necessity of signing a document or may regard the researcher as untrustworthy when they have already agreed to participate. Though it is clear consent must be voluntary, and that participants must understand the implications of participating, this is not necessarily ensured only through a written form (Haggerty 2004). For instance, van den Hoonaard (2001, 29) exemplifies how requirement to use signed consent forms hindered the participation of individuals willing to take part in a study. In the case of older adults victimized by a family member (specifically if still experiencing domestic violence), demanding a signature might not only create embarrassment and fear for the family's reputation, but also fear of reprisals by the perpetrator. It can generate apprehensiveness, where there was none.

In the above-described cases, the interviewees wanted to participate but did not or could not sign the informed consent form. They not only agreed to share their story, but also to have their interviews recorded, which can be seen as a form of trust and tacit consent. Hence, the researcher felt that verbal consent would suffice and proceeded with the interview. This decision could be interpreted as a failure to comply with the EC requirements. However, in some cases, the requirement of using signed consent forms may also paradoxically take away the right of an individual to participate in research, as pointed out by van den Hoonaard (2001).

Participants' Safety, Privacy and Confidentiality

Participant's safety, privacy and confidentiality were regarded and considered, firstly by the method employed to identify potential participants. Initial contact was made with professionals who were working or had

worked with the person, such as victim support and social work professionals and police officers. These privileged contacts knew the victim's story and were known by the victim, given their service's intervention in their domestic violence situation.

Interviews took place in the private offices of these privileged contacts institutions, scheduled as "routine" appointments within the institutional framework and which the victim had already attended. Only in one case did the physical location not meet the desired requirements to ensure participant privacy. This interview was conducted in a private office of one of the collaborating partners; though it was an enclosed area, external conversations could be heard as well as the interview. The participant did not express any discomfort and given this was a familiar office to which she had previously attended, the researcher proceeded with the interview. Given that it is essential to establish secure and comforting conditions in which to conduct interviews on such a sensitive topic, location and space must be considered in advance.

Confidentiality was ensured through the privileged contacts, since potential participants were reached by someone aware of their victimization story and context, as well as the fact that only the interviewer (besides the privileged contact) could identify the individual. Furthermore, having only one researcher conducting and transcribing the interviews not only assured confidentiality but also enabled, with some participants, a perception of a more comfortable environment to share their story.

Gaining the Trust of Potential Participants

The research team considered that participant identification and contact with professionals with whom they were working or had worked could also minimize risks of retraumatization. The access method to participants could, in addition, foster acceptance and integration in the study.

If the preceding reliable relation between these professionals and potential participants provides added value, it also generates some ethical quandaries. For instance, given the relation already established with the professional providing a service, individuals may automatically assume the study's legitimacy and agree to participate without properly pondering the risks and benefits.

One of the interviews disclosed how implicit legitimacy can be associated with services and professionals, facilitating participant identification. An older couple, victims of violence carried out by their son who had not demonstrated any sort of ambiguity or constraint in sharing their story, seemed uncomfortable when the possibility of recording the

interview was presented. The couple's diffidence was related to a previous experience with a journalist who had published an article about their son without identifying herself when she talked to the couple in the emergency room of a hospital. In the reported case, the researcher perceived the reluctance to record the interview as being linked not so much to an unwillingness to share a private and difficult story, but foremost with fear of disclosing information associated with a previous experience. Hence, the researcher felt the need to separate the journalist and researcher roles and to explain in more depth how the data recording was going to be utilised.

Whilst the couple later agreed to record the interview, this consent seemed in part to be based on the previous relation established with the professional who had contacted them, as expressed in the following statement: "we know that the *doutor*²⁰ here he's trying to help and if he says so, we know we can trust him" (Transcript 13). This statement had the research team questioning the decision-making process of participants who were contacted by professionals directly intervening (or had intervened) in their domestic violence situation. Commonly one important ethical issue usually pointed out within health research is potential power asymmetries between researcher and participant, especially if the researcher is also the clinician (Katz and Fox 2004; Richards & Schwartz 2002). Similarly, the same could also be argued in the ongoing research, given the role and nature of the institutions contacting potential participants. Furthermore, emotional vulnerability, the desire to get help or even gratitude if help has been granted and the situation resolved, can all be factors that influence the decision-making process.

The fact that consent had been provided at the point of initial contact does not necessarily ensure that participants will be willing to maintain it. It is necessary to establish a positive and trustful relationship between researcher and subject and, therefore, adequately address needs and provide space to integrate new experiences and information and raise new doubts (Katz & Fox 2004; McGinn 2005; Murphy & Dingall 2007).

Managing Misrepresentations of the Research Scope

Despite the research team's intention to always make clear, not only among professionals but also participants, the distinction between

²⁰ In colloquial Portuguese the term *doutor*, though it can be literally translated to "doctor," is commonly employed by clients with service provided professionals (and usually associated to a college degree).

requested intervention by the victim and their participation in the study, the researcher was occasionally confronted, during the interviews, with misrepresentation about the research scope. More concretely, participants expressed expectations of direct intervention in their cases by the researcher.

This was particularly so with victims whose intervention (medical, social or legal) was just beginning or did not match what was desired (required) by the victim. This aspect, which had not previously been considered, required the researcher to manage participant expectations regarding solutions to the victimization they were experiencing.

A striking example is the following: a participant in the middle of the interview asked the researcher to contact the responsible prosecutor to ask him to return a photograph of her injuries (“Do you have the power to ask the police in Portimão to give the photograph?” Transcript 11). Even though the interviewee had apparently understood the scope of the interview and study—with expressed support for such needed research—that did not prevent her from asking for a specific form of intervention. The issue was once again the distinction of roles between researcher and professional and it was explained that such matters should be discussed with professionals working on her case. Although researchers may have an opinion about how the intervention can be conducted, they should always refrain from issuing opinions. Not only is this not the researcher’s role, but they also do not hold all the information regarding that particular situation. It can cause problems with the professional (privileged contact) and victim relation and even generates false hopes regarding possible “solutions” to an individual case. For instance, an individual victimized by their son is expecting and hoping for a solution to their situation without any criminal and legal procedures (abstaining from filing a complaint within the criminal justice system), and the victim support professional, given the assessment, considers this to be the most effective approach. Their professional opinion of how the individual should proceed may not be well received by the victim, who may want another form of resolution. In fact, it should be noted that during the interviews and in some cases of older adults victimized by descendants, the individuals often present an idealized wishful solution, such as the government paying rent for a house and providing meals to the perpetrator so that they would not be cohabitating and the episodes of violence would end.

A victim may reach for help within the scope of the interview, because the professional (privileged contact) is not able to provide the anticipated and idealized solution. If the researcher issues other alternatives without properly assessing the situation it might encourage the individual to carry

out actions that might not be the best suited or even possible in that particular case. The professional will be perceived as incompetent or unwilling and will be left with the task of re-establishing their relationship and managing the frustration that the pursuit of such action may engender.

There were several cases where the participants reached out for help. The misrepresentation of the researchers' role does not appear to be associated to the interview, but rather to emotional and psychological distress derived from the victimization experience.

Table 5.3. Exploratory phase interviews, transcript 1

<p>Entrevistadora: <i>“Estamos a terminar, não sei se há alguma coisa que a senhora queira acrescentar?”</i></p> <p>Participante: <i>“Eu queria, eu pedia o favor de me ajudarem. Que me ajudassem. Que eu não me aguento. Porque eu fico chafradinha. Que eu já tive, já tive maluquinha.”</i></p> <p>Entrevistadora: <i>“Mas sabe, já lhe tinha explicado que com esta entrevista é a senhora que me está a ajudar a mim. Estamos a fazer um estudo sobre situações, como a que a senhora está a passar. Eu não vou, nem posso, intervir diretamente no seu caso.”</i></p>	<p>Interviewer: “We’re about to finish. Is there anything you would like to add?”</p> <p>Interviewee: “I wanted, I would ask you please to help me. To help me. I can’t take it anymore. Because I’m going nuts. Cause I’ve already been, I’ve already been mad.”</p> <p>Interviewer: “As you know, I had already explained that with this interview it’s you who is helping me. We are conducting a study on situations like this one you’re going through. I will not, I cannot intervene directly in your case.”</p>
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In another interview, the researcher received the participant, accompanied by the daughter. After following the same introductory procedure, specified above, the researcher faced the daughter’s dissatisfaction and annoyance because she had “come from afar, by appointment specifically to see the mother’s problem resolved” and “not to talk” (Transcript 12).

This segment reveals not only misunderstanding of the request made by the professional who had contacted the participant, but also anxiety and expectation of a “solution.” Individuals who had understood the aim and objective of the interview (and in some cases even highlighted the study’s relevance) may find themselves so vulnerable and distressed that they will endeavour to obtain the looked-for solution in any way they can.

Although the daughter and mother actually agreed to take part in the study, this example illustrates the need for the research team to work with the partners, contacting participants to assure a suitable presentation of the study to avoid misinterpretation.

In both the previous cases, and given the need for clarification between what is expected from participation in the study (interview) and the response to victimization experience, the researcher sought to contextualize the research project. The study goals were presented in detail and the right to freely decide whether to participate or to withdraw at any time without penalty was underlined. Moreover, to avoid unfounded expectations, during the interviews the researcher emphasised, more than once, that the interview did not have any direct consequences or would enable any more rapid action in response to the violent situation. During the interviews there were situations in which the interviewed demonstrated distress and these issues were discussed among the team.

The Risk of Retraumatization

If research needs to provide in-depth understanding of the problem and help raise public awareness, it can also expose the research participants to reliving their often traumatic victimizations, with an impact on their emotional and psychological well-being. As such, it is crucial to consider in advance the victims' potential emotional and psychological frailty and develop interview strategies that can prevent or diminish possible negative outcomes when sharing traumatic experiences. How should the interviewer proceed when faced with a victim experiencing anxiety and psychological distress: should they continue, pause, change the questions or stop the administration of the questionnaire altogether?

Retraumatization is another key topic in family violence studies. The interview may trigger painful experiences and participants may become distressed throughout the discussion of or exposure to cues that cause the individual to feel as if they are experiencing the victimization again (Orb, Eisenhauer & Wynaden 2000).

Several steps were taken to prevent individuals, when sharing their personal story, from experiencing emotional distress. Prior to the interview itself, the researcher sought to establish a comfortable and relaxed atmosphere that enabled the creation of rapport between participant and researcher by engaging in diverse topics of conversation unrelated to violence, such as the city and place of residence and the weather, among other topics.

During the interview, participants were also encouraged to share other aspects of their life stories and when this was not "spontaneously" achieved the researcher introduced questions to achieve that purpose. Finally, the researcher tried to always make sure that participants were emotionally prepared to return to their daily routine and hence ended the

interview with themes or aspects commented upon in a positive view by participants or extending the post-interview conversation on matters unrelated to victimization.

However, given the sensitivity of the subject these various strategies developed in advance by the research team did not, in some cases, prevent participant emotional distress being expressed through non-verbal behaviour (crying, sobbing and shaking of hands) or verbalizations about how difficult it is “to be talking about these things” (Transcript 6). In this case, the researcher is confronted with an ethical dilemma— to continue with the interview and gain more insight about the topic under study or to interrupt it temporarily or completely. Orb, Eisenhauer & Wynaden (2000) point out that researchers have to weigh up the vulnerability and discomfort of the participants, looking for possible solutions to decrease anxiety and discomfort.

In the pilot phase, none of the interviews were completely interrupted. To reduce identified discomfort and emotional distress, the researcher momentarily stopped the interview and changed the conversation to other topics or focused it on other positively valued life experiences.

Table 5.4. Exploratory phase interviews, transcript 5

<p>Participant: “<i>Ele [o marido] não conhece a neta, que ele não conhece a neta, ele não conhece mas (choro)...</i>”</p> <p>Entrevistadora: “<i>Mas conhece a avó.</i>”</p> <p>Participant: “<i>Sim, sim. Pronto e foi a minha vida assim.</i>”</p> <p>Entrevistadora: “<i>Com dois filhos, como diz, maravilhosos</i>”</p> <p>Participant: “<i>Sim, graças a deus que sim, graças a deus que sim. E consegui dar a volta por cima.</i>”</p>	<p>Interviewee: “He [the husband] does not know his granddaughter, he does not know his granddaughter, he does not know but (crying)...”</p> <p>Interviewer: “But she knows her grandmother.”</p> <p>Interviewee: “Yes, yes. And thus was my life.</p> <p>Interviewer: “With two wonderful children, as you said ”</p> <p>Interviewee: “Yes, thank God, yes, thank God. And I still managed to bounce back. ”</p>
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Some literature has, nonetheless, pointed out the potential therapeutic benefits of participants reliving unpleasant memories. Hutchinson, Wilson & Wilson (1994, cited in Orb, Eisenhauer & Wynaden 2000) identified potential qualitative interview benefits such as: catharsis; self-acknowledgment; sense of purpose; self-awareness; empowerment; healing and providing a voice. Even some participants who, apparently, were more vulnerable and seemed to have more difficulties in talking

reported at the end of the interview that they were proud of their ability to share and others even stated the benefits of the conversation.

Table 5.5. Exploratory phase interviews, transcript 5

<p>“Eu também consigo. Custa-me estar a falar nas coisas, mas falo já mais e quando entrei aqui eu não conseguia falar, não conseguia. Mas já consigo. E pronto vou andar para a frente e a minha vida vai continuar.”</p>	<p>“I can do it. It’s hard for me to talk about these things, but I can now. When I first came in I couldn’t talk, couldn’t. But now I can. And that’s it, I will move forward and life will carry on.”</p>
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Table 5.6. Exploratory phase interviews, transcript 7

<p>“Para uma pessoa desabafar. É muito bom isto.”</p>	<p>“For a person to get this off her chest. This is very good.”</p>
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The impact of reviving traumatic experiences cannot be predicted or generalized. Different individuals may feel and react differently to the interview experience. Researchers must anticipate the worst case scenario and manage the psychological and emotional well-being case by case. In addition, as Ellsberg *et al.* (2001, cited in Fontes 2004) noted, the study-design as well as the length and nature of the interviews also has implications for the participants’ emotional and psychological well-being. Even in situations where emotional distress is present, this might not imply that individuals will relive the actual trauma and the ensuing emotional and psychological state (Newman *et al.* 1997, cited in Fontes 2004). In other words, it might be distressing to recall a traumatic event, but not necessarily retraumatization.

Batchelor & Briggs (1994) claim that it is necessary to consider ethical issues before the data collection process, because otherwise researchers are not prepared for the unpredictable nature of qualitative methods. In the present study and in relation to the in-depth interviews, some ethical issues were reasonably anticipated and safeguarded in the fieldwork while other aspects arose from the data collection procedure itself. These ethical issues detected in the pilot phase allowed for reflection on the next phase of the on-going research project, and under this light, population-based and victim surveys are discussed in the following section.

Ethical issues Within the Victim Survey

Two main issues arose during the fieldwork that also apply to the victims survey: the identification of potential participants through service provider professionals, and managing participants' expectations. The pilot phase revealed that the boundary between participation in the study and the intervention support and resources provided is not always clear. Ethically it is essential to ensure that the difference between participation and intervention is clear and transparent.

The role and nature of the victim support institutions demands careful consideration, not only regarding the methodology adopted, but also concerning the ethical quandaries that might present themselves to professionals administering the questionnaires. The established relationship between a professional who is providing a service and the receiver of it, in the case of a victim of family violence, may have implications for participants' motivations. This aspect is particularly relevant in the case of the victim survey. While in-depth interviews were conducted by a researcher outside the institution, in the victim survey the data collection will be carried out by professionals working within the institutional setting. The same professional will engage in two different roles: one as the provider of a technical service and another as collaborator to the study. The consequence of linking these two roles has to be considered, particularly for participants' motivations, which might be especially critical in the case of individuals with psychological and physical frailty.

Locher *et al.* (2006), reflecting on ethical issues in health research, highlight several factors that may compel individuals to participate in studies: the instilled trust in the professional relationship; the recommendation of participation by the entity to whom they appealed and depend on; the limited time given to the person to reflect on the costs and benefits of participating; wanting to please the professional and/or considering it will assure them better care and attention to their case; they may feel threatened concerning resources and support if they refuse to participate and experience loneliness and social isolation. Hence, the simultaneity between intervention and research can produce ambiguities and be reflected in the decision making process of older adult victims of violence.

In the victim survey, using partners who directly intervene in the scope of the domestic violence, strategies aimed at increasing the participation of the respondents (minimizing non-responses) may hinder participant free will. Will an elderly victim of domestic violence feel obliged to participate

given they are searching for a solution to the victimization situation? What strategies and solutions are to be implemented in the research regarding this ethical problem?

One of the ways the research team sought to answer these questions was through the training sessions developed with professionals who would administer the questionnaires. The training covered the data collection instrument and the approach to informed consent. The importance of this step was underlined as well as the possibility of adapting it to the individual's social and cultural background. During the training process the importance of professionals clearly explaining that inclusion or not in the study would not interfere in how the support and resources would be made available was also highlighted. In one of the training sessions carried out, one of the professionals advised about the possibility of professionals already possessing some data about participants (for instance deriving from a previous provided service). If the participant had not responded to a specific question or in the case of knowing that the response given was not true, could the professional complete those questions with known information? The research team explained and clarified that the instrument is a self-report questionnaire, such that all the questions have to be answered by participants and that it could only contain answers given by participants at the time of the administering the questionnaire. This example shows, in conclusion, that the training process does not only allow for combined reflection (methodological, theoretical and ethical) between the research team and the professionals, but is also important to clarify roles and responsibilities between service provider professionals and study collaborators.

While in institutions and organizations of this type administering questionnaires to victims can lead to the ethical dilemmas mentioned above, it may, on the other hand, contribute to minimizing the impact of revisiting the victimization experience. A reliable prior relationship between professional and victim may help minimize the stress, anxiety and discomfort caused by questions about such a sensitive subject. Professionals are already familiar with the victimization situation and questions on that subject may not be perceived as invasive. In addition, social work and victim support professionals, given their experience and fieldwork, might be more sensitized to deal with susceptible issues and working with vulnerable populations. Overall, the specific nature of such organisations could not only generate but also respond to different ethical issues that arise from administering a survey to older adult victims of violence.

In the case of the Portuguese Institute of Legal Medicine and Forensic Sciences (INMLCF, IP; Coroner's Office) other aspects have to be taken into account. Potential participants have already filed a complaint with the public prosecutor and the legal and statutory procedures are already in progress. In addition, the nature of the forensic and legal medical work with the victims raises distinct ethical and methodological aspects which have to be considered.

In order to examine the ethical problems raised in carrying out this project in the INMLCF, IP, it is important to contextualize this institution within the Portuguese Justice System, and position it as a connection between the citizen as a victim of violence, particularly physical, and the courts.

In this context, the victims of crimes against one's physical integrity or sexual crimes are submitted to a forensic examination to produce expert evidence, which is appended to the Criminal Law Procedure, allowing the magistrate, *inter alia*, to better evaluate the damage produced against the individual and the consequences of it to produce the final sentence. In some cases, such as those related to sexual crimes, the collection and preservation of biological evidence for determining the genetic profile of the assailant and comparison with possible suspects is performed, thus assisting the criminal investigation itself.

Considering the specific aspects of the forensic activity, one could begin by considering whether this is compatible with the application of a questionnaire of a predominantly sociological nature. Naturally, it was necessary to adapt its contents so that a significant amount of the questions could remain along with those already asked during the forensic interview. However, as expected, for methodological reasons it was necessary to keep a block of questions shared with the version of the questionnaire given by the other partners in this study. This required, for instance, the characterization of different types of abuse (such as financial abuse) that the victim considered to have been subjected to during the previous twelve months, not necessarily by the same individual that perpetrated the aggression under forensic investigation. This situation, for instance, poses a couple of issues, the first related to the possibility of distracting the victim from essential aspects of the forensic interview and, secondly, the victim could be reticent about talking about other types of violence not directly under investigation.

As for the former, applying the questionnaire at the end of the interview can reduce or eliminate any possibility of confusion that could be generated for the reasons stated above. As for the latter, the victim is always entitled to decide whether they wish to answer the questions or the

questionnaire itself, being assured that whatever the decision it will not influence the outcome of the forensic examination.

In practice, applying the questionnaire to victims of physical violence that accepted to participate in the study has not posed significant difficulties. As a matter of fact, a few cases have been reported in which the examinees finished the interview in a better mood, due to the fact they had additional time to talk about themselves and their socio-familiar context.

In the ethical and operational domains, the main concerns were related with the use of the questionnaire with victims of sexual crimes. This type of aggression in itself induces a feeling of helplessness combined with a sense of physical and psychic frailty heightened by the age of the victim and possible concomitant debilitating pathologies.

Therefore, dealing with this sort of case is always complex, even more so when the examination is performed shortly after the event in the context of the so-called emergency legal medical examinations. It requires, among other aspects, a careful examination of the genital area that, in itself, constitutes another anxiety factor.

Is it therefore possible to make this specific type of forensic examination compatible with the use of a questionnaire? Inevitably, a confrontation between the interest of science and the technical and ethical imperatives arises and a decision whether to apply that instrument needs to be taken. In dealing with this type of problem, it was deemed appropriate to consider two possible scenarios: forensic sexology examinations performed in the course of urgent medical legal examination and those not included in this context. In the first case, as previously stated, the victims are usually in a status of significant physical and psychic frailty, mechanisms of coping are not yet activated and, due to the violence of the act combined with the age of these individuals, there can be a state of mental confusion. In these circumstances prolonging the forensic examination more than strictly needed would contribute to extend the suffering of the victim who wishes to return to their comfort zone as soon as possible, and that was one of the reasons that justified the decision not to apply this tool in these cases. However, in the context of medical-legal examinations carried out later, in which the victims are observed days or weeks after the occurrence, it was considered that they could participate in the study as long as the professional responsible for applying the questionnaire considered this to be possible and, as always, that the examinee accepted this.

Evidently, the implementation of this project has also raised common ethical concerns shared with the other partners involved in the study and similar solutions were adopted, as discussed in previous sections.

In summary, the current research poses challenges, both in the operational and ethical domains, that require thoughtful considerations to reconcile the needs of this scientific study with the forensic activity as we firmly believe that a more profound knowledge of the phenomenon of elderly violence in Portuguese society will allow for an improvement in future preventive measures.

Conclusions

In the first part of this chapter the implementation of the first population-based prevalence study in Portugal was discussed and the legal and institutional procedures to which health research in Portugal is subjected were analysed.

The protection of personal data constitutes a central ethical issue, as well as the informed consent form. This is a binding principle with inevitable implications in the development of research projects, given that without the approved legal procedures and authorization of two institutions (NCDP and EC) the research team not only cannot initiate data collection, but is also subject to punishment and fines (financial and curricular on the part of the coordinating researcher).

However, strictly adhering to procedures oriented towards personal data protection can conflict with methodological aspects and may compromise the quality of the collected data. Strategies to increase survey response rates (e.g. the advantages and disadvantages of the data collection methods and different approaches to potential participants) established in other studies and recommended by the WHO (2001) are not compatible with the criteria established by the institutions and organisations that regulate health research in Portugal. Moreover, certain requirements, such as the fact that the telephone interviews can only be carried out by health professionals, jeopardise budgets already approved by the Portuguese research funding organization, the *Fundação para a Ciência e Tecnologia*. Finally, despite these procedures which will help researchers to reflect on ethical issues, it is still necessary to critically reflect on the proper ethical implications and possible gaps that such procedures embrace (González-López 2011). One of the paradoxes of the formal research ethics systems is that there is often a distinct but unquestioned break between following the rules and conducting ethical research (Haggerty 2004, 410).

From our perspective, informed consent should not be treated as a rigid and bureaucratic issue, incompatible with a qualitative and ethnographic approach; neither should it be regarded as a coercive mechanism or one interfering with academic freedom, as pointed out by van den Hoonaard (2001). Informed consent, as an instrument which guarantees respect for confidentiality and information, should not be treated as a simple legal instrument, bureaucratized and legalistic, reduced to a one-time event. It is crucial to treat informed consent as an ongoing process with potential ambivalences and ethical dilemmas which occur in a relational and sequential process, requiring immediate resolution and flexible action. For instance, van den Hoonaard proposes that “the researcher would provide an information sheet on which s/he would explain the research (signed by the researcher) and the verbal consent needed to continue with the interview” (2001, 33).

The first contradiction around consent is the participant signature request which contradicts the principle of anonymity. Sometimes obtaining a name and signature can generate mistrust and fear, and a strong reason for refusal. If informed consent constitutes a constraining element for non-participation, it may also not consider individual expectations regarding the resolution of their victimization situation. The wish for a faster response or a more idealized solution (more social and less criminalized), is a possible counterpart for participation in the study and these expectations must be managed by the interviewer. In this sense, the management of expectations is a crucial issue and needs to be clarified and linked to informed consent, as a full right to information. In the victim survey, the person conducting interviews performs two roles, as a professional and an interviewer. This duplicity of roles puts them in a more advantageous position given it may be easier to access victims, but can at the same time be more demanding from the ethical point of view. More than the risk of deception, advocated by Haggerty (2004), or the fact that the boundary between truth and deceit is often blurred (Murphy & Dingwall 2007), a higher risk is omission of information and therefore professional breach of trust. Hence, to minimize the risk of coercion, the following should be made clear to participants: (1) the interviewer’s professional background and role in the study; (2) the non-therapeutic purposes of their action, and; (3) that refusal to participate will in no way jeopardize their social, health or legal situation (Richards & Schwartz 2002)

Even though violence is a complex and sensitive topic, given its private and intimate context and the feelings of shame, denial and fear that this can involve, unpredictability can also characterize the survey. For

instance, some victims may, when answering the questionnaires, use this as an opportunity to verbalize, as mentioned by Keeffe *et al.* (2007), and hence become increasingly aware of victimization and the need to report it. In this regard, it is important, when this occurs, to provide them at the end of the interview (face to face or by telephone) with information on services offered. In these cases, and with the victims' agreement, they can be referred to relevant organizations and institutions, particularly to the appropriate police department and victim support organizations. This is a central aspect of the research project presented, given that under Portuguese law domestic violence constitutes a public crime. As such, the study has to establish a standard practice with the interviewers regarding the duty to inform victims of their rights.

A transversal ethical issue involving all aspects of the study is that of retraumatization. This question was clearly considered during the pilot phase of the study, when the data collection instruments were tested and strategies most suitable to dealing with participants (victims and non-victims) were considered. Interrupting, respecting silences and tears, changing the conversation topic or stopping the interview were some of the predicted and employed strategies, more easily implemented when we face an actual victim. This aspect seems more difficult to address in the telephone interview survey. Even though the telephone surveys may grant anonymity, safety and confidentiality, the unpredictability of responses can hinder the minimizing of the psychological and emotional impact deriving from sharing a personal experience of victimization, given that participants are not physically present and non-verbal communication is absent. The pilot phase, even though of a manifestly face-to-face nature (in-depth interviews and focus groups), still allowed us to consider reasonably efficient strategies to prevent retraumatization and the emotional impact of participants, and to consider how these strategies can be adjusted to the telephone interview survey. Furthermore, participation allows verbalization and not only contributes to the complaint action, but can also have a cathartic effect and does not always necessarily imply going through a process of retraumatization.

Interrupting, respect for silence and tears and the decision not to apply the questionnaire to the victims of sexual and physical abuse subjected to forensic examination were strategies that emerged through ongoing application and sometimes depended more on the ethical sensitivity and judgement of the professional than on the regulatory regimes, with fixed procedures, inappropriate to qualitative and ethnographic studies (Murphy & Dingwall 2007).

The pilot phase was also important for the victim survey, given that the ethical issues were considered previously to the fieldwork, particularly those arising during this phase. The ethical dilemmas and the methodological options found to answer these issues have shown themselves to be part of the ongoing process of research. The sensitive study topic as well as the methodologies adopted raised problems which the research team tried to answer satisfactorily, considering, nonetheless, that other issues might and probably will emerge during the rest of the study.

This chapter was an opportunity for the Portuguese team to reflect systematically on ethical issues and awakened sensitivity towards ethical practices in sociological research, even though this study is carried out within the health research system and ethical procedures.

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CHAPTER SIX

ETHICAL AND METHODOLOGICAL DILEMMAS IN RESEARCHING VULNERABLE GROUPS IN ROMANIA

GEORGIANA ANTON AND MARIAN PREDA

Introduction

This chapter examines some ethical and methodological issues that arise in social research with different vulnerable groups such as refugees, immigrants, young drug users and female sex workers in the Romanian context. It refers to two different research projects: (1) a qualitative study conducted with different groups of refugees and immigrants concerning their integration experience and motivation to become Romanian citizens; (2) a quantitative study on young injecting drug users and female sex workers. The second study was part of a broader project implemented in Romania and six other countries (Albania, Bosnia and Herzegovina, Moldova, Montenegro, Serbia and Ukraine), which was funded by the Government of Ireland (the Irish AID Fund) through UNICEF Romania. Vulnerability is seen not only from the perspective of participants' social or economic conditions and legal statuses but also from the perspective of their involvement in a research study in terms of autonomy, safety and confidentiality. We would also like to underline the fact that research participants often experience the situation of multiple vulnerabilities, decreasing their ability to protect themselves. We will focus on ethical issues that arise in research from the perspective of participants, as well as some methodological considerations related to study design, sampling and data collection. Drug addiction, prostitution and forced migration processes are considered "sensitive" topics due to their illegality, trauma and susceptibility to control and intervention by authorities.

While providing some examples of conducting research with people from the groups mentioned above, we can bring to the fore ethical issues and suggested guidelines for research practice in order to decrease the risk of harm for future research with vulnerable groups. We start by discussing some ethical and methodological issues that arose from a qualitative study with refugees and immigrants. In the second part of the chapter we present a quantitative study conducted in Romania with injecting drug users and young female sex workers.

Ethical and Methodological Issues in Social Research with Refugees and Immigrants

Refugee and immigrant research raises special methodological and ethical issues when compared to other groups of interest (see Leaning 2001; Jacobsen & Landau 2003; Birman 2005; Smith 2009). Most immigrants have a fragile legal status depending on their settlement purpose. From the perspective of their legal status in a country of destination, we can distinguish between legal and illegal migrants. Their illegality puts them in a vulnerable position mainly when migrants are settled with their family and especially when having children who are being relied upon as a family strategy designed to obtain their security: “Sensitivity and vulnerability are two notions that are crucial for understanding and addressing the ethical questions in social science research and in particular in research on irregular migration. Both concepts and the related concerns are inherently linked with the notion of risk” (Duvell, Triandafyllidou & Vollmer 2008, 8). Leaning (2001) emphasizes the vulnerability of refugees as subjects for research because of their political status (usually the country of origin stops offering protection once they leave its territory and ask for international protection) and the complex situation (e.g. war, abuses) when leaving their country.

Among refugee communities, some individuals can experience additional multiple vulnerabilities (Smith 2009, 69):

- (1) Among refugee women from patriarchal societies, interaction with the new society where women are equal with men could lead to changes in their life as ways of thinking and acting;
- (2) Refugees with a low level of education, being illiterate in their native language, being elderly, confronting their husband’s interdiction, or with medical issues face more difficulties in achieving knowledge of the host society language;
- (3) Refugees who are disabled because of war, illnesses or other kind of injuries;
- (4) Refugees whose credentials were not recognized, leading to

problems in accessing the labour market and loss of status, especially in the case of those who are well educated.

Leaning (2001, 1432) proposed guidelines for research with refugee populations, emphasizing the importance of protecting the health and welfare of the research participants and the “well-being, dignity, and autonomy of all study participants in all phases of the research study.” In selecting research participants, Leaning (2001, 1432) highlights the importance of loyalty to “scientific principles without bias introduced by issues of accessibility, cost, or malleability.” At the same time he considers it mandatory to obtain full informed consent from all participants and to carefully plan: “procedures to assess, minimize, and monitor the risks to safety and confidentiality for individual subjects, their community, and for their future security” (Leaning 2001, 1432). Refugees could be considered as a vulnerable group, in particular if their refugee status is the result of forced migration. Being forced to leave their country of origin, they often suffer different emotional, physical and/or psychological traumas. Individual and group vulnerability arises from their exposure “to risk, notably to greater risks than other groups. In this context, vulnerability is understood as the possibility that participation in research may cause the participants some harm” (Duvell, Triandafyllidou & Vollmer 2008, 12). Thus, the participation in research brings some risks for refugees and immigrants, affecting them not only at a personal level but also as a group, especially when revealing matters relating to illegality or survival strategies.

Outline of Study

Defining Refugees and Immigrants in the Romanian Context

Immigration is a complex and dynamic phenomenon influenced by factors belonging both to the country of origin (push factors) and destination (pull factors). Migration can take a voluntary or involuntary/forced form. There are, therefore, different categories of migrants as a result of the migratory process (economic migrants, asylum seekers, refugees). Membership of the European Union has transformed the notion of migration into mobility, and differentiated between “external migrants” and “internal movers” (Favell & Nebe 2009), creating differences between the legal status of a third country citizen and a citizen whose country is a part of the EU.

Romania is more a country of emigration than immigration—the number of Romanians abroad is over two million, while in 2011 Romania

had 57,211 official aliens, according to the Romanian Immigration Office (2012). The main countries of origin for aliens with temporary residence are Moldova (14,657), Turkey (6,693) and China (4,248), and the main purposes of their residence are marriage to a Romanian citizen (21,456), education (7,837), employment (5,725), and family reunification (4,356). The number of persons with a form of protection in Romania (refugees, persons with subsidiary protection) was 1,102 at the end of 2010 (Romanian Immigration Office 2011).

Refugees are those persons recognized as such under Article 1 of the 1951 Geneva Convention relating to the Status of Refugees. According to the Romanian Legislation (Law no. 122 from 4 May 2006 on Asylum in Romania):

refugee status may be granted, upon request, to an alien who, based on a well-founded fear of being persecuted for reasons of race, religion, nationality, political opinion or membership in a particular social group, is away from his country of origin and is unable, or, due to such fear, unwilling to be under the protection of that country, as well as to stateless persons who are outside their country of usual residence due to the same reasons mentioned above and who are not able or, due to such fear, are unwilling to return. (art. 23)

We conducted a research with different groups of refugees and immigrants focused on their integration experience and motivation to become Romanian citizens. We opted for a qualitative research approach, which we consider to be more appropriate to exploring the experiences of refugees and immigrants in a host society in order to understand the meaning of the realities exposed. The qualitative interview offers a better possibility of clarifying the factors involved in migrants' integration experiences and motivations to naturalize than a quantitative survey. It offers the possibility of clarifying the discussed items to achieve a deeper understanding both for the researcher and the participants. On the other hand, this type of research could point out different worldviews that may "underlie assessments of what is needed" (Berkowitz 1996, cited in Smith 2009, 65) to solve a specific problem or meet a particular need.

We conducted in-depth interviews with twenty-three refugees and immigrants from different countries of origin (non-European Union members), but mainly from Middle Eastern countries, African countries and Moldova. Moldova is a region with a historical relationship with Romania, their citizens speaking the same language and sharing a similar culture; a large number of Moldovans are eligible for a special citizenship procedure. All but two of the semi-structured interviews were conducted

in Romanian. In those two cases English was used, not because the participant had no Romanian language proficiency, but because they felt more comfortable speaking in a language that was foreign to both (thus avoiding possible embarrassment about their use of Romanian). Their level of English was advanced; one studied in this language and another was an economic migrant from a country with English as an official language. Being a female interviewer was not problematic in this case, even though previous studies revealed intrapersonal tensions during the fieldwork research, e.g. intimidating offers by the male interviewees (Vargas 1998). This positive situation could probably be explained by previous long-term interaction with participants. Interviews were conducted at a time and place that was convenient for each participant. The presence of other persons could make them feel uncomfortable and therefore we opted to avoid such situations.

Sampling

The identification of refugees and immigrants, in particular irregular migrants, as participants in social research is challenging. One aspect is access to the group of interest, this population being somehow hidden but also affected by different forms of stereotypes, prejudices or discrimination. The difficulties in identification have a direct impact on the sample size. In Romania there is a shortage of systematic and integrated studies on migration that is explained by “scarce and fragmented official statistics on migration, low interest from authorities and other potential stakeholders, lack of adequate means to approach studies of a complex phenomenon, political meanings associated with migration, etc.” (Lazaroiu 2003). Other constraints encountered are terminological confusion in the use of concepts related to the categories of migrants, scarce data collection, especially in the institutional context, and few available statistics concerning the integration process achievements among migrants (Alexe & Paunescu 2011). Furthermore, the official number of refugees and immigrants does not include irregular immigrants. None of the informants of the research was in an illegal situation at the time we conducted the interviews, but some of them experienced it during their settlement in Romania. Birman (2005) speaks about the impossibility of distinguishing immigrants from refugees arriving from the same country, a point we also agree with. However, in the Romanian context the legal status of refugees offers the same socio-economic rights as that of a host-society citizen, in comparison with most voluntary migrants whose legal status is dependent on their migration purpose (e.g. economic,

studies). Simply asking about their access to the labour market could offer the possibility of distinguishing between migrant legal statuses.

The problem of representativeness is present in refugee research due to the reasons highlighted by Jacobsen & Landau (2003, 195–196):

- (1) Lack of a clear sampling frame in the context of unknown size and distribution of the refugee population;
- (2) Problems of access due to their localization (remote areas, bad roads, hidden communities);
- (3) Security problems and lack of trust;
- (4) Snowball sampling—methodologically expressed by the fact that subjects usually represent a particular segment of the community and are likely to be similar/homogeneous in certain ways (e.g. sharing a social network, belonging to same religious group, interacting with a particular NGO);
- (5) Ethically, the sensitive information they offered to the researcher (e.g. political or religious views) can create problems within their group.

Not all migrant communities are open to sharing their settlement experience (as group resources and opportunities) in the host society. Inside some migrant communities, any participation of a member in research whose aim is to talk about the issues of integration resources, opportunities and strategies will receive high pressure from the dominant group but also create the risk of exclusion (the informant being seen as a betrayer). We learned that even though an ethnic community is seen from the outside to be united, during the interviews we discovered conflicts mainly due to the migrants' shared access to limited resources (e.g. job opportunities). Moreover, participants' fear is also justified by the fact that refugees and especially immigrants are under the control of immigration authorities during their residence in the host countries and also receive attention from mass media and civil society representatives. For example, in Romania, in the case of marriage with a Romanian citizen they receive visits/controls from the representatives of the authorities in order to verify that it is not a marriage of convenience. In the case of economic migration, the right of residence is granted according to the specific period of work authorization. Therefore, these fears could cause refugees to adapt their responses in order to change their image in the society, or to partially transmit their experience as an expression of their survival strategy (Jacobsen & Landau 2003). In relation to sensitive topics in interviews, we would like to emphasize that the same issue may provoke different emotions in different participants, because of different cultural interpretations. Culture, religion, gender or any other aspects have to be

considered alongside the research process. Being an outsider from the group you intend to study implies understanding their culture in order to know and avoid barriers along your research development. Without proper cultural competencies, the researcher could cause unintended harm to the participants.

We tried to solve the difficulty concerning access to refugees and immigrants using the snowball method through the initial channels opened by migrants and NGOs. We accepted the fact that this method can create sampling problems, but our study was exploratory and we did not intend to generalize the findings to the total group of refugees and immigrants in Romania. Besides, from the beginning our sample was considered to be the result of convenience sampling. Often the research projects' tendency is to focus on a single and large group of refugees and immigrants to collect sufficient data, but the results do not explain the peculiar situation of other smaller groups (Birman 2005). Therefore, our option was to include representatives of different communities, such as Middle Eastern countries, African countries and Moldova. The findings showed that cultural aspects could create some differences concerning their integration experience and their motivation to naturalize.

Informed Consent and Confidentiality

Informed consent is taking into account the right of individuals to make their own decision to be participants in research (i.e. the principle of autonomy) after being properly informed. Christian (2005, 144) argues that "proper respect for human freedom generally includes two necessary conditions": voluntary participation "without physical or psychological coercion," and offering "full and open information." Homan (1991) argues that real informed consent where the researcher offers participants full information is difficult because of the different levels of understanding among participants or the impossibility of predicting all consequences of participating in the study.

We agree with the definition of "minimum requirements for informed consent" aiming to ensure that the participants receive full and adequate information about "the purposes, methods, risks and benefits of the research and that agreement to participate is fully voluntary" (Mackenzie, McDowell & Pittaway 2007, 301). At the same time, it is important to take into consideration factors such as language, culture and even educational level when considering the research participant's informed consent (Smith 2009). For instance, only the knowledge of the host society language could ensure a proper understanding of the purpose of the research; or a low

level of education could impose upon the researcher the task of offering additional information to obtain a truly informed consent. Concerning cultural aspects, the researcher has to be sensitive to those participants considered to be more vulnerable (e.g. children or women from a patriarchal society, the disabled, etc.).

From our direct experience, most migrants have better oral knowledge of the Romanian language than written. At the same time, including an informed consent form to be signed by the informants could create anxiety and fear of being easily identified by a third party. Therefore, our option was to verbally inform all the participants about the research purpose and then verbally obtain their approval (which was not audio recorded). Coomber (2002, 3) argues that in the case of lack of signed and verbal recorded consent, research ethics committees may accept “the researcher's word” as sufficient. Thus, in our case, the signed consent might not necessarily be in the best interest of participant. In any case, the researchers’ national ID or documents proving their university affiliation were shown to research participants, whenever required, thus avoiding any doubts of interference with immigration authorities. Besides, we also informed the participants about their right to withdraw from the research at any time. A special situation occurred during the research when some leaders of Muslim communities were investigated by national enforcement authorities due to suspicions of their being involved in terrorism. Thus, some participants were more reluctant to take part in the study, but none of the participants already interviewed requested to withdraw even though we reiterated their right to do so if they felt threatened. Therefore, informed consent has to be perceived by researchers as a continuous process during which the participant may change his or her position concerning decision-making without feeling coerced into the research.

Participants’ approval to create digital recordings was also asked. As in the case of signing an informed consent form, asking their permission to audio record also induced fear among the informants. Even though we guaranteed that the recordings would be used only in the context of the research and that they would not be shared with third parties, some of the informants did not permit it. In one case, a participant allowed researchers to record the interview but she also recorded it with her own phone. We reiterated the aim of the research and the issue of confidentiality, highlighting the possibility of stopping if she felt insecure, and she eventually agreed to continue the interview.

By its nature, qualitative research offers the possibility of gathering detailed descriptions from research participants, including their personal views on diverse topics, thus leading to the risk of exposure and

embarrassment when their cases are reported (Stake 2000). Therefore, the researcher has to be cautious when disclosing research participants' personal data. Along these lines, a problem may arise when reporting the findings about refugees from a country of origin which in Romania registers a small number of people. Being a member of a small community can make the informers vulnerable when describing their personal experiences. Therefore, we tried to be cautious when giving the characterization of participants, e.g. not specifying precisely the country of origin but instead the geographical area.

On the other hand, as Vargas (1998, 41) stated, "an essential point to maintain is to carefully evaluate how much personal information to seek" in order to not harm the participant. For instance, in the case of refugees, asking and insisting on the reasons for leaving their country of origin can elicit an emotional reaction and harm the research participants who are subjects of forced migration. Therefore, we knew from the beginning that this issue would harm informants and we tried not to ask them to detail this subject. Moreover, they fear for their own and their relatives' security both in the host and in the origin countries, making them more suspicious about data security.

Researcher Involvement, Responding to Participants needs, Negotiating Consent

Researchers who are able to spend long periods of time (more than six months) involved in migrants' assistance may gain the trust and familiarity of their informants and their community. On the other hand, their involvement could create problems in terms of validity and research ethics (Jacobsen & Landau 2003, 191). For instance, living within a refugee community could affect the capacity of a researcher to adopt an unbiased attitude when collecting and analyzing the findings. The subjects' vulnerability could bring to the fore other ethical issues in relation to the knowledge acquired, for example, the researcher could become too empathic towards the situation of the research participants or even develop a friendship. Spending a lot of time within the migrants' community, the researcher could identify with their situation and be affected by the impossibility of offering them help. In fact, one of the ethical issues arising during the interviews we conducted was related to the impossibility of helping with all the needs expressed by informants. Some subjects asked for help with several problems they faced during their stay in Romania, thinking that we could open the door to some institutional resources in an NGO. Unfortunately, we were not able to offer them direct

support in all their claims, we tried however to refer them to the appropriate institutions, recognizing our inability to respond to all their problems. We consider this an ethical dilemma because informants could expect to rely on the researcher's help and could eventually realize that their participation in the research was not a win-win process.

The relationship between researchers and participants is of interest because the researcher may play often a dual role. In our case, the researcher also had a professional interest in the study by being involved in a NGO which offers support to migrants. The separation of these two roles had ethical implications. Therefore, we decided to conduct the interviews outside the NGO headquarters to avoid the power imbalance between researcher and participant. On the other hand, we feared that participants could consider the researcher as a trusted person due to the long-term interaction and this could make them reveal more personal information, forgetting the research aim. In this case, the researcher had to repeatedly explain her role to ensure that participants perceived her as an academic and not as an NGO professional who could intervene and provide social assistance. In order to ensure that participants are voluntarily willing to be involved in research, we described the aim of our research at the start of the process of negotiating informed consent and gave them some time to think about the participation agreement. Then we contacted them to make an appointment for the day, hour and place proposed by them. When somebody asked us to call again the next day because they were too busy, we decided to do it just once more. If at the second call, they responded that they were too busy, we decided not to call back to avoid pressuring the participants.

In this research, direct professional experience with refugees and immigrants allowed us to learn more about cultural aspects and facilitated access to interview participants. The interaction over years offered the possibility of developing a trusting relationship and helped to overcome the situation of informants not believing that the purpose of the research was only an academic one. Moreover, it stressed the fact that the researcher was acting independently of the state agencies who first interviewed them.

Translators and Data Protection

Using refugees' community representatives as translators might compromise the security of collected data. Using local researchers from the ethnic communities under research can cause confidentiality problems (Jacobsen & Landau 2003). It can produce biased results because of

“socially desirability answers,” mostly due to the face-to-face interview (Babbie 2010, 261), or can compromise the veracity of the interview and the interpretation of the research findings (Dahinden & Efnonyi-Mäder 2009). Tilbury (2006, 7–8) showed through research conducted with refugees that “socially desirability answers” appeared due to the “face-to-face nature of the interview process”, to the involvement of members of the ethnic community as research assistants and the “cultural imperatives to present a positive face.” This bias was observed concerning questions about self-assessed levels of English language proficiency, income (either underestimated to not appear too successful, or overestimated to not appear unsuccessful), and well-being. Refugees living in the Reception Centre for Asylum Seekers and Refugees were more reluctant to take part in the research. During the interview, some of them started to be critical about the difficulties they faced in accommodation there, but others described the conditions in positive terms, making us aware that fear could lead to such ambiguous positions. Even though some social researchers recommend involving cultural insiders as research assistants with the role of interviewing or assuring the translation (Birman 2005), we decided not to do it. Using key informants from the ethnic communities does not always ensure better access for the researcher, but can instead create certain ethical issues, such as difficulties in assuring data confidentiality and participants’ anonymity. In Romania, only a small population of refugees and immigrants are settled. Therefore involving a member of the migrants’ communities in research could create a high probability of respondents being able to identify each other (assuring confidentiality is problematic when the researchers’ selection is reduced to a small number of subjects in institutions or organizations offering their services to refugees as possible providers of research subjects). They could also be harmed, even unintentionally, through the sensitive information they offered to researchers (e.g. access to resources, socio-economic situations, political or religious views) or through the lack of cultural competencies of the researcher. Thus, researching issues relating to migration and integration could be considered a sensitive topic, posing an “intrusive threat, dealing with areas which are private, stressful and sacred” (Lee 1993, 4). This sensitivity results from the high level of personal emotions evoked by participants and also from the risk they face when describing the integration experience of the ethnic communities they belong to (e.g. matters related to illegality, such as working in the hidden economy, or strategies to surviving in periods without legal residence permits).

In order to avoid harm, but also to ensure anonymity, we encouraged participants to talk about cases with similar experiences instead of

revealing their own. In addition, we tried to erase from the interview all of the topics irrelevant to our research, especially those comprising many personal details, and those that participants required us to take out. Similar ethical problems were found in the second research, a quantitative study on injecting drug users and young female sex workers that we are going to discuss in the second part of the chapter.

Ethical and Methodological Issues in Social Research with Young Injecting Drug Users (IDU) and Female Sex Workers (FSW)

These two groups—young injecting drug users and female sex workers—are considered hard-to-reach people or a hidden population, which creates difficulty for researchers in getting in contact with them or estimating their real number in order to base their study on a relevant sample. As Shaver (2005, 296) stated, because “membership in hidden populations often involves stigmatized or illegal behaviour, concerns regarding privacy and confidentiality are paramount and difficult to resolve.” The risk is very serious with both of these phenomena, if we are taking into account the consequences in terms of associated diseases (e.g. HIV/AIDS), the age of drug users/sex workers, and other social problems (e.g. exclusion, delinquency, family dysfunction). Thus, the subject of research is an extremely sensitive issue. Concerning vulnerability, Preda *et al.* (2010) showed the dependent relation between commercial sex and injecting drug use, emphasizing the high probability of female sex workers joining the ranks of drug users and vice versa. Moreover, both drug users and prostitutes usually experience double or multiple vulnerabilities being in more than one situation (e.g. diseases, unwanted pregnancy, abuse or even human trafficking exposure, stigmatization, being minors, being involved in illegal activities other than drug using or commercial sex, being vulnerable to police raids or in a relationship of complicity/resignation with the police).

Both drug consumption and prostitution are incriminated through specific legislation in the Romanian context according to the Romanian Criminal Code. Therefore, fear of control and punishment is present among potential research subjects that are not just hard-to-reach but also hard to persuade to answer questions and to be sincere. Distrust transforms this research topic into a sensitive issue. Lee (1993, 4) defines sensitive research as being “research which potentially poses a substantial threat to those who are or have been involved in it.” Moreover, the potential harm affects not only research subjects but also researchers, who may be

incriminated and involved in illegal practices and criminal networks. The information given by participants could create fear among dealers or “pimps” who could threaten the researcher in order to avoid a possible incrimination due to the information revealed by the research.

Outline of Study

Data Concerning Young Injecting Drug Users and Female Sex Workers in Romania

In Romania, drug abuse and commercial sex increased rapidly after the fall of the communist regime in 1989. In 2009, statistics show around 24,000 drug users in Bucharest alone (Preda *et al.* 2010), and between 23,000 to 47,000 women and men practicing commercial sex at the national level (WHO 2003, cited in Preda 2009).

Concerning the characteristics of commercial sex in Romania, one study conducted in 2005 (ARAS, UNAIDS 2005) underlined the major problems of this population as health problems, low access to specialized services, high exposure to HIV, STDs, association with drug use, and being victims of human trafficking.

This study was part of a broader project implemented in six other countries (Albania, Bosnia and Herzegovina, Moldova, Montenegro, Serbia and Ukraine). Among the research objectives were: “to identify the behaviours of young people at higher risk of HIV infection, to identify and evaluate existing services addressing to them, to supply different stakeholders with knowledge and working tools to enable them to effectively address the needs of these groups” (Preda *et al.* 2010).

A quantitative study was conducted in Romania between November 2007 and March 2008 with injecting drug users and young female sex workers, up to 24 years of age, with the focus on the subpopulation of minors (under 18 years old). The sample for the first group, injecting drug users (three hundred subjects), was comprised of people settled in Bucharest (this city registered the highest number of drug users, 24,000 from the total number of 28,000 of IDUs estimated at the national level). For the second group, young female sex workers, the sample was selected from Bucharest (150 subjects), Constanta (75 subjects) and Timisoara (75 subjects). The cities included in this study are relevant with regard to the prostitution phenomenon—Bucharest, the capital, is the largest and the richest city, Constanta is the largest harbour and a tourist destination and Timisoara is a cosmopolitan city of transit, close to Romania’s borders with Hungary and Serbia.

Concerning the research methodology, in the case of female sex workers snowball methods were used; in the case of drug users the choice was the respondent-driven sampling method (RDS) which also relies on the respondents' social network in order to get to hard-to-reach people. To ensure the respondents' participation, an incentive was delivered after the questionnaire was completed (cosmetics for FSWs and phone cards for IDUs). Additional incentives were offered to those already interviewed to contribute to the selection of other people from their group.

The RDS methods applied to this research consisted of the following steps (Preda *et al.* 2010):

- (1) As starting points (hubs) for local IDU networks, seven individuals eligible for the survey (16–23 years old) were selected from different areas of Bucharest.
- (2) Each of them completed the questionnaire, receiving an incentive for being interviewed.
- (3) Each of them received two participant's coupons in order to distribute them to two eligible persons and two incentive-coupons for secondary inducement (a remuneration coupon for participant-driven recruitment) which enabled them to receive an additional incentive for each of the two persons they recruited after they were interviewed.
- (4) The recruited persons who participated in the research in the second wave received in turn two recruitment coupons in order to expand the network with the third wave of respondents.
- (5) The process continued until the desired sample size was reached (three hundred questionnaires). For one of the seven "hub-subjects" the recruitment process stopped at the beginning, for the other six between three and seven waves of recruited IDU were registered before reaching the designed sample size.

To increase the trust of participants, research subjects were completely anonymous; no names, nicknames nor addresses were registered in regular sample lists for quantitative field researches. To examine the structure of each drug use network and to assess whether the individuals fulfilled the recruitment criteria, the researchers used a coding system: a specific code was printed on coupons and noted on each respondent's questionnaire, allowing us to later identify in the database every individual questionnaire within the network. The questionnaires contained similar items for respondents, either in the IDUs group or in the FSWs group, but included a special section for drug users in order to ensure the possibility of assessing the scale of the network to which the respondent belonged. The quantitative study has been completed along with a qualitative one: seven interviews were conducted with drug users (17–24 years old) and ten

interviews with persons who had provided commercial sex in the last month (16–22 years old).

Some measures were taken to prevent the risk of coercion when using RDS methods in participants' selection through participant-driven recruitment. Besides the in-kind incentive, the number of recruitment vouchers was limited to two, and therefore the rewards for participants could not be transformed into a source of income using coercion. The research field team obtained the recruits' informed consent to verify that participation to study was voluntary. To prevent the inclusion of non-users in the study, their injection marks were checked; it was also verified if participants had been interviewed in the last three months on the same issue, to avoid pressure on them.

The interviews were conducted by social workers from an NGO (ARAS-Romanian Anti-AIDS Association: a Romanian NGO dedicated to addressing the concerns of the health and social needs of HIV-infected people) in order to be accepted by the IDUs' and FSWs' communities. To ensure high confidentiality, we organized field teams of two social workers, one dispensing syringes and condoms as regular activities, while the other conducted interviews in a safe compartment of the van. We assumed that trust is "an important social value in its own right ... provides the sense of security and predictability" (Kelman 1982, 63).

Ethical and Regulatory Requirements

The methodology was designed in accordance with the agreement of ethics commission of the Ministry of Public Health, thus following the regulations and ethical codes related to human subjects, at the national level. The ethical requirements from the ethics commission involved providing information about the research team, the provider of the funds, the research methodology, the informed consent form and a specification of all of the ethical issues included in the research protocol. The agreement of the ethics commission guided the entire research activity and encompassed requirements at all the stages of the research process. Being the first research protocol approved by the ethics commission of the Ministry of Public Health for sociological field research, the process of drafting it involved the commission's representative, the research coordinator, the field research coordinator (from ARAS, a NGO), and a representative from UNICEF Romania (the main beneficiary of the research). One example of a contribution from this joint drafting process was the UNICEF staff requirement to avoid money as an incentive for research subjects and to instead use goods such as mobile phone cards,

shampoo, condoms, etc. Representatives of institutions and NGOs addressing the concerns of the IDU and young FSWs were involved in the questionnaire design process in addition to their participation in drafting the research protocol.

Informed Consent and Confidentiality

The research participants were informed throughout the course of the research about the purpose, benefits and possible consequences of their participation in the study. A consent form was used without asking for the name of the IDU/FSW research participant, only for their signature. The research team assumed that this form of consent was the best way to protect the IDU/FSW privacy due to their illegal practices. As an alternative, verbal consent (possibly recorded) could be a better option. The inclusion of professionals working with IDU/FSW in the research team helped to adapt the consent form to the situation of these groups, thus ensuring an appropriate and voluntary consent process.

Some of the participants—both drug users and females practicing commercial sex—were minors, which brings to the fore their decision-making capacity. In this regard, some researchers consider that adolescents' participation in any type of research generally requires parental permission as well as the minor's assent (Anderson & DuBois 2007). In our case, consent was given solely by the adolescent participants due to the fact that their family could have no information about the practices which were the subject of our research and also their living conditions (in spite of their age, the IDU minors were living on their own). In the case of drug users, an ethical issue of interest was related to participants' autonomy when giving their consent to participate in the research—the possibility that consent may be compromised by their being under the influence of a substance. Nevertheless, none of the members of the research team reported such a situation, their professional experience enabling them to confirm the influence of a substance.

Incentives and Providing Information to Participants

Incentives offered to participants were seen as a way to compensate them for their efforts in taking part in this research, even though some researchers (Homan 1991, for example) consider that incentives could act as coercion, affecting voluntary participation. Offering incentives for research participation could decrease the likelihood of autonomous decision making, but we took into consideration the fact that incentives are

necessary to recruit hard-to-reach substance users and to motivate them to participate in the study (Festinger *et al.* 2005). On the other hand, there are studies that underline the fact that incentives do not affect the consent of taking part in research (Festinger *et al.* 2005). Fry & Dwyer (2001) argue that IDU motivation for research participation is multi-dimensional and not necessarily associated only with personal benefits. At the same time, Fry *et al.* (2006, 31) state that, in the case of drug users who participate in research, there are other factors that influence the decision to participate beside the monetary gain, factors such as “expected direct benefits to self” (e.g. access to information, personal satisfaction, and therapeutic benefit) as well as benefits to others.

In relation to incentives, Semaan *et al.* (2009, 20) consider that “providing cash payment highlights the importance of respecting IDUs and their autonomy in deciding how to use their remuneration,” thus considering it more appropriate to provide monetary incentives, in compliance to the principle of respect for human dignity. As we already mentioned, the incentives in our case were non-monetary as we tried to avoid a situation in which they could use money to buy drugs, thus avoiding encouragement of their illegal practices.

In the case of participants practicing commercial sex, we would like to point out the often associated phenomenon of human trafficking (Preda *et al.* 2010). Some of the participants confessed that they had been victims of human trafficking and that the “procurer” was, in some cases, their partner. The research team also asked about the social and health services accessed in the last year by IDUs and FSWs. The findings emphasized that most of the subjects had accessed services only in extreme cases (e.g. severe illness or unwanted pregnancy). Moreover, access to methadone as a substitute-drug for IDU involved many barriers and risks, being a poorly developed service.

Trying to improve the situation of these at-risk-groups, the researcher made some recommendations based on experiences revealed by participants; recommendations that were included by UNICEF Romania in their publicly disseminated reports. The field interviewers, experienced social workers from ARAS, also discussed available social services with the interviewed sex workers or drug users who were not aware of them.

Conclusions

The two research projects described in this chapter, targeting migrants, young drug users and female sex workers, could illustrate possible answers to the many challenges one faces in terms of methodology and

ethics. We showed respect for the vulnerability of participants (considered as a hidden population or hard-to-reach people) and tried to avoid or to minimize harm by adopting appropriate strategies. The fear of control and possible persecution, given their uncertain legal status (the migrant population) or involvement in illegal activities (young drug users and female sex workers) speaks to the necessity of offering guarantees to the participants that data confidentiality will be respected. The involvement of professionals (e.g. social workers, social counsellors and therapists) or long-term volunteers in activities with these groups could reduce the harm, because of their knowledge and experience. It could also increase the research-participation rate based on the trustful relations already built.

Concerning informed consent, researchers have to consider a broad range of aspects. In the case of refugees, to sign a consent form could create the fear of being easily identified. In addition, proficiency in the Romanian language is very relative among refugees and immigrants, some of them even being illiterate in their native language. In these cases, a verbal consent could be sufficient to include them as research participants and to avoid doing harm.

The incentives offered to participants could create biased and socially desirable responses. In our research, the incentives offered to young injecting drug users and female sex workers were thought of as a reward (offering goods, not money) for their efforts in taking part in this research.

The presence of data-recording devices was perceived as uncomfortable for participants even though it offers the possibility of registering more research details. In this case, an alternative could be the involvement of a research assistant in order to register the information offered by the research participants. In the case of immigrants and refugees, as already mentioned, the involvement of a member of their community could create “socially desirability answers” (Babbie 2010) and problems in ensuring confidentiality and anonymity because of the small number of refugees and immigrants in Romania.

Research studies should take into account the benefits of the research to the participants or to the larger group they represent. The beneficiary’s perspective offers the possibility of evaluating public policies dealing with the groups being studied and adapting these policies to their real needs. Empirical research could contribute to the development of evidence-based ethics, at least with regard to research conducted with the aforementioned groups.

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CHAPTER SEVEN

THE RESEARCHER IN THE FIELD: NAVIGATING NETWORKS OF RELATIONSHIPS

LARISA KOSYGINA

Introduction

Upon entering the field, the researcher encounters a complex network of relationships among social actors. Being in the locality and interacting with social actors, they become a part of this network. In this chapter, I address the effects of such involvement on my decisions with regard to interactions between two groups of the research participants and myself—people working for some non-governmental organisations (NGO) assisting migrants in Russia and migrants themselves. The chapter is based on notes made during fieldwork conducted within the research project “The Russian migration regime and migrants' experiences: the case of non-Russian nationals from former Soviet republics.” The fieldwork took place in Russia—in Moscow and the Moscow region—in 2004, and lasted for four months.

The feedback given by the reviewers for the first variant of this article revealed some level of disagreement about whether or not my text had managed to focus on ethics in research practice. That difference in opinion has made me think once more about the methodology-ethics nexus in the context of sociological research, namely about the question of whether methodological issues and ethics can be separated from each other in such a way that we can say that this particular issue is purely methodological and there is nothing ethical to be discussed.

Research methodology can be defined as the logic which guides the organisation and implementation of a research project and which is informed by the researcher's ontological and epistemological positionalities (Patton 2002). While ontological and epistemological positionalities can be respectively expressed through answers to the questions “What is the form and nature of reality and, therefore, what is there that can be known

about it?” and “What is the nature of the relationship between the knower or would-be knower and what can be known?”, methodology is what constitutes the answers to the question “How can the inquirer (would-be knower) go about finding out whatever he or she believes can be known?” (Guba and Lincoln 2004, 21–22). However, if we acknowledge that research activities are social activities, meaning that they are undertaken by people and have implications for the lives of others, then we need to realise that research methodology cannot be defined solely by a researcher’s epistemological and ontological positionalities. The answer to the above-mentioned “how” question is also shaped by their ethical positionalities, in other words by moral principles which define what (non)action is right or wrong. Personally, I agree with those social scientists who believe that all methodological issues which arise in the course of the research process have ethical aspects (Kvale 1996). In this article, discussing how I navigated the network of relationships which I encountered in the field, I show that this navigation was informed not only by practical reasoning, such as the aim of acquiring more data, but also by my considerations of what would be right or wrong in relation to the research participants and myself as human subjects.

The first part of the chapter provides information about my research project—its aims, objectives, methods, etc. The second part is devoted to reflection on the methodological and ethical issues raised by my interaction with the heads and staff of two Russian NGOs. These issues include my decision to maintain an “outsider” position within the field and to avoid vocalising any negative evaluation of activities conducted by social actors in the field. I also discuss the influence of my migration history on the development of the relationships. The third part of the chapter focuses on my interactions with the migrant respondents. I show how the involvement of the researcher in a wider and complex network of relationships could negatively affect her/his communication with the social actors and handicap the research process. This part includes my reflections on the decision to refuse one of the respondent's requests linked to our participation in one wider social network. It also includes the discussion of my decisions about the presentation of research findings.

A Few Words about the Research Project

The issues discussed in this article stem from my work on a sociological research project, undertaken at the intersection of two multidisciplinary fields (Russian studies and Migration studies). It covered the period 2002–2009 and aimed to explore how the Russian migration

regime—legislation and discourses—constructed as a response to immigration from other former republics of the USSR was intertwined with the experiences of migrants as well as the construction of their identities.

Designed within the framework of the theory of structuration, which holds that analyses of both institutions and the strategic conduct of social actors are important in studying social issues (Giddens 1984, 288), my research project encompassed two objectives: to analyse changes in the structures constituting the national migration regime of the Russian Federation and the present composition of this regime, and to collect and analyse migrants' stories about their lives in Russia. The analysis of the Russian migration regime was guided by the questions: What trends can be discerned in the transformations taking place? What limitations/opportunities are imposed on non-Russian nationals by the current migration regime? Questions posed by the study in relation to migrants' stories were: What limitations/opportunities are experienced by migrants in the receiving society? How do migrants access resources allocated in the receiving society? What meanings are attached by migrants to the limitations/opportunities that they encounter in the receiving society? How do experiences of limitations/opportunities in accessing resources affect migrants' identities?

In order to reach the above-mentioned research objectives, the empirical study contained what might be termed “desk-based research” and a fieldwork component. This article draws on my research experiences which took place in the framework of four months of fieldwork conducted in 2004 in Moscow and in two small towns in the Moscow region which I regularly visited during this time.

The aim of the fieldwork was to investigate the immediate experiences of knowledgeable social actors who have participated in the construction/reproduction of the Russian migration regime, as well as their understandings of this regime. Expert interviews with members and leaders of NGOs, officials, academics and journalists, and informal observations and conversations which took place in the field provided a great deal of data for the analysis. However, from the start, the migrants' stories generated via semi-structured interviews were considered to be the main sources of information. There were three criteria for selecting research participants among migrants: they should be former citizens of the USSR, should have been permanent residents in another former Soviet republic before moving to Russia and, at the time of the interview, should have been living without Russian citizenship in post-Soviet Russia for more than one year.

One of the first questions I had to ask myself during my work on the research design was, “How am I going to find migrants to participate in my research?” This question was not easy to answer. Even though I knew places where I could find non-Russian nationals from the former Soviet republics (for example, building sites, markets, etc.), I could not simply go to such places and ask people to give me an interview without being introduced to them by some intermediary whom they knew and trusted. First, I was not sure whether people would be willing to spend their time talking to a stranger for no other reason than helping with a piece of research. Second, I was interested not only in the experiences of those migrants who managed to secure their legal status in Russia, but also in the experiences of those who violated migration regulations imposed by the Russian authorities. I assumed that these people, in their vulnerable situation of “illegality” in a country from which they could be deported at any time, would not be eager to speak to a complete stranger. All these factors encouraged me to approach migrants through mutual social connections. One of the ways to reach my migrant respondents was to ask for assistance from NGOs helping migrants in Russia. Some methodological issues (including their ethical aspects) that I faced during my interaction with these organisations are discussed below.

Experiences of Constructing and Navigating Relationships within NGOs

Russian NGOs which deal with issues of migration may be subdivided into two groups. The first group includes organisations which operate at the federal level. The second group consists of organisations which operate locally (at the regional, city or village level). The local organisations, in turn, may be further subdivided into formal organisations and informal self-support groups. Research on the Russian migration regime has shown that NGOs operating at the federal level and the local level perform different functions. While the first group tends to concentrate their efforts on protecting the human rights of migrants and influencing the Russian migration regime through active interaction with the state bodies involved in the construction and implementation of Russian migration policy, the second group of NGOs has focused on socio-economic provision for migrants (Flynn 2006).

For me, as an outsider, it was much easier to identify NGOs operating on the federal level since information about them and their activities were relatively well presented in mass media. At the time that this research was conducted, there were three NGOs operating at the federal level: the

Forum of Migrants' Associations, the Civic Assistance Committee, and the "Memorial" Human Rights Centre. They all had their headquarters in Moscow.

Since 1996, the "Memorial" Human Rights Centre, established in 1991, had been running the "Migration Rights" programme, aimed at protecting the rights of migrants in Russia through the creation of a national network of legal consultation services. The programme also conducted seminars which provided an arena for academics, human rights activists, parliamentarians and state officials to discuss problems of migration regulation and legislation in Russia.

The Civic Assistance Committee was created in 1990 with the aim of providing assistance to forced migrants. Although its functions were similar to the local NGOs—it provided migrants medical and social assistance (including educational programmes for children)—its activity also had influence on the federal level through its efforts to protect migrants' rights. The leader of the Civic Assistance Committee—a well-known human rights activist in Russia who actively participates in the construction of migration policy in Russia—was the creator and head of the above-mentioned "Migration Rights" programme.

The Forum of Migrants' Associations, established in 1996, unites migrants' associations located in forty-three regions of the Russian Federation. The main tasks of this association are lobbying on behalf of migrants' interests, protecting migrants' rights, and influencing state bodies to create a welcoming migration regime and construct a positive image of migrants. The leader of this organisation is a professional journalist with good connections which are quite helpful in achieving the aims of her organisation.

I initially approached the leader of the Forum of Migrants' Associations and the leader of the Civic Assistance Committee, who is also the head of "Migration Rights" programme, by telephone. It is worth noting that I contacted them not only because they could introduce me to their clients among migrants, but also because I considered them to be experts who could provide valuable insights into migrants' experiences and ongoing changes in the Russian migration regime. I wanted to interview them; however, because they were extremely busy people whose schedules made it very difficult for them to allocate time for an interview whose practical outcome was not immediately clear, there were some difficulties in arranging expert interviews with them. Consequently, the head of the Civic Assistance Committee, for example, elected to give her interview in the form of a press conference (that is, she collected several researchers together and answered their questions in a single interview

session). The head of the Forum of Migrants' Associations, on the other hand, postponed her appointment for an interview several times before finally arranging to be interviewed simultaneously by me and another researcher. At the same time, both NGO leaders helped me a great deal by sharing printed information, introducing me to the field and to the social actors (officials, academics and journalists, as well as the leaders and members of some other NGOs based in Moscow) operating there. The head of the Forum of Migrants' Associations and the leader of the Civic Assistance Committee also allowed me to work on the premises of these organisations, so I had the opportunity to communicate with employees, partners and clients of these NGOs.

Researchers have pointed out that living in the field gives a valuable opportunity to gain insider knowledge about the places, cultures and societies of their research subjects (Round 2002; Popov 2005). According to my experience, such knowledge comes to us first of all through informal conversations and observations, which are unavoidable since a researcher cannot formalise every communication and observation occurring during their prolonged presence in the field. I think that those of us who choose to use ethnography or at least some of its elements in research projects are actually looking for non-formalised ways of gaining knowledge. However, these ways generate ethical questions. Situations of informal communications and observations are unplanned, and it is not always possible to inform people that they become part of the research. Does this involvement violate people's privacy? What ethical principles should guide a researcher in the situation of informal observation or conversation?

Visiting the NGOs' premises for interviews with experts and to work with printed materials, I witnessed interactions among social actors within these settings. While the NGOs' workers were aware that I was a researcher and were informed about my research project, I did not always have the opportunity to introduce myself to each of visitors at the NGOs' venues. Since the NGOs' venues were a public space, I did not feel that I violated the privacy of anybody by being there. At the same time, I took into consideration that people who were observed by me informally did not realise that their words and actions constituted data for my research. In the situation of informal observation when informed consent was absent, the central ethical criterion for me as a researcher was the "guarding against harm" principle—in other words, participation in the research must not cause harm to the person (Hollway & Jefferson 2002, 88). The same principle was applied for informal conversations occurring in the field.

The literature on research methodology and methods shows that there is no single answer to the question “what could be considered as harmful for the research participant?” (Bryman 2008, 118). In my research, I defined harm as the worsening of a respondent’s wellbeing, including the worsening of their relations with other people. Taking into consideration the interconnectedness of my research participants to one another and the fact that I could not fully control the outcomes of my writing, I could not directly use data received via informal observations and conversations in my texts. I used these data only to develop designs of formal methods (semi-structured interviews, expert interviews, analysis of legislation) and to verify data obtained through these formal methods. It goes without saying that throughout my research I also followed the principle of confidentiality; in other words, I paid careful attention to preserving the anonymity of data sources (experts who provide interviews were the one exception in this regard) and to avoid spreading any personal information revealed by the research participants in the course of my research (including the opinions of research participants about other research participants).

Because I was aware of the inevitability of my involvement in the networks of relationships in the field, I paid attention to my positioning within these networks and to the influence of this positioning on the research process. I recognised that my positioning in these networks would stem from how I presented my position in the wider society (for example, my profession, educational background, nationality etc.) to the social actors whom I encountered during the fieldwork. Wolf has pointed out that if the researcher is a newcomer to the field, then they have opportunities to play with their positionalities during the construction of their self-presentation in the dialogues with people rooted in the field (Wolf 1996, 11). Being away from their home setting, the researcher, for example, has the opportunity to alter and conceal different aspects of their position in the society to access more information or for other reasons (Rollins 1985; Thapar-Bjorkert & Henry 2002). However, such altering and concealment can lead to serious consequences in terms of ethics. At the very least, a researcher could be accused of deceiving people (Stein 2010). I myself preferred to be honest about my positionalities, but with the aim of developing a rapport with the research participants I emphasised those aspects which I supposed could help me in communicating with them.

From the start, my position within the network of relationships, which involved people working in the approached NGOs and other social actors interacting with these NGOs, was constructed as a “researcher.” This was how I introduced myself to the social actors with whom I communicated

within my work on the research project. The introduction also included the indication of my affiliation with a foreign university and information about the aims of my research.

Through communication with NGO staff, I felt that my position as a researcher made them think that I could provide expertise about what was going on in the field, although I constantly pointed out that I was there to learn from them about this. During my fieldwork, from time to time I was occasionally asked to express my opinion on this or that matter. Judging from the academic literature on fieldwork undertaken within organisations, this is quite a common phenomenon (Okumus, Altinay & Roper 2007, 19). It was rather surprising for me, however, that the social actors who asked for my opinion were not so interested in learning about my evaluation of their activities. Instead, they expressed curiosity about my attitude towards the activities of other social actors. I was very cautious in expressing my point of view in this regard. The principle I followed for such situations was to express a positive attitude toward the discussed social actors if there was ground for this, and otherwise kept my position neutral.

There were at least two reasons for adopting the above-mentioned rule. First, I acknowledged the possibility that my words could be used out of context by those with whom I spoke, as it could spoil relationships with those who were discussed and negatively affect my access to the field. The danger of such a scenario, in the case of people working for the NGOs whom I approached, was increased by the rivalry between these organisations. They co-operated a great deal, but at the same time they also competed for different resources (social, symbolic and financial capital). However, in addition to the practical reasoning behind the principle just discussed, there was also that originating from my answer to the question “what could be considered as harmful for the research participant?” I could not express my negative evaluations of social actors because I included the worsening of relations between a research participant and others in my concept of harm. I assumed that such evaluations could provoke or support the deterioration of relations between those who asked my opinion and those who evaluated.

From the start, I was also aware of my positioning as an “outsider” in the field. The literature contains discussions of the advantages and pitfalls facing social scientists who are considered by their research subjects to be “outsiders” or “insiders” (Newton *et al.* 2012). As the experiences of these researchers show, this status is re-negotiable (Pitts and Miller-Day 2007; Sultana 2007). However, in my case, I admitted that having the opportunity to be in the field for only four months I would not have the chance to re-negotiate my status as “outsider” with NGO workers and others. I also felt

that, in this particular research project, my “outsider” position would be ethically correct. After all, I was a person from the outside who was entering the field in pursuit of aims which were not necessarily shared by the research participants living there, and I would be leaving the area after some time. Besides this ethical consideration, I also had a practical reason for maintaining my “outsider” position. As an “outsider” I could avoid being perceived as a person affiliated with any particular interest group within the existing net of relationships in the field. This was extremely useful for accessing different points of view on what was going on there.

I agree with those who state that the “outsider” is neither a discrete nor a fixed position, and who rather see it as fluctuating between “distance and nearness” (Newton *et al.* 2012, 589). My experience shows that the researcher can construct quite close relationships with research participants even when they are perceived by them as an “outsider.” There could be some aspects of their social positionalities or experiences that may connect them with some social actors in the field or that simply could be interesting for them. For example, one of the main factors that helped me in developing close relations with research participants was my migration history—the fact that I came to the field from the UK where I had lived and studied for some years.

I felt that my migration history was interpreted by some of my interlocutors as an indicator that I had some knowledge that might be shared. This was manifested not only in the simple curiosity which they expressed about my life “in the West” (“*zhizn’ na zapade*”), but also in the interest which they showed in more practical matters. For example, since I had received a scholarship to study in the UK, some assumed I knew how to find funding and how to write successful grant proposals. Different people sought different types of information from me. While some of the social actors involved with NGOs asked me to design research projects and write grant proposals to support the activities of their organisations, others were interested in ways of organising the continuation of their education or the education of their children in the West. There were people who simply asked me for advice on how to change their lives for the better because somehow they considered my movement to “the West” as an indication that I had been successful in improving my own situation. I also need to point out that some of my respondents among migrants obviously related their stories about their lives in Russia to their imagination of my experience in the UK. They assumed that I would understand them because I was also a migrant residing in a country other than the country of my citizenship.

Undoubtedly, better relations with research participants provided me with better access to information. However, my work on relationships was not all about gaining data. By assisting NGO workers with writing grant proposals, I also wanted to give something back to them in return for their assistance, as well as to contribute to improving the situation of migrants in Russia. There was also the simple pleasure of sharing stories about my own experiences with people.

Researcher-Researched Interactions— Mind the Wider Network of Relationships

In the framework of my research, the NGO workers assisted me with access to the potential interviewees among migrants and as such could be considered as “gatekeepers.” Understanding of the term “gatekeeper,” as a person who controls and provides access to resources and opportunities for research activity, could be rather wide (Punch 1994, 86). However, in the literature this term is mainly used to signify people who are in a position to provide the researcher with access to respondents (Bryman 2008, 407). In this chapter, I also employ this meaning of the term. In this section, I would like to discuss the influence of gatekeepers on the relationships between researchers and respondents, as well as the dilemmas confronting me as a result of my involvement in the complex net of relationships which included the NGO workers and migrants whom I approached via these NGOs.

In my experience, gatekeepers not only provide information which allows the researcher to get to know the field better and to find their subjects for research, but they also influence the interactions between the researcher and the researched. I had the impression that one of the most important factors influencing my relationships with the migrants was the way in which I approached them for an interview (in other words, through which people and where I got in touch with them). Apparently, they tended to associate me with these people and/or places. Interpretations by my respondents concerning who and what I was—a relative or a friend of a friend, a friend of a manager or teacher, a person involved in the activity of an NGO, etc.—played a crucial role in the construction of our relations from the outset.

The association of a researcher with a person trusted by the potential respondents and with whom they have good and/or profitable relationships can prompt people to do this person a favour by agreeing to participate in the study, while the association of a researcher with a person who is mistrusted can prompt people to refuse to participate. In fact, the latter is

hardly a gatekeeper, but researchers can be taken in by such a person's self-presentation and perceive them as a gatekeeper until the truth is revealed through meeting other social actors in the field. By this time, the initial misperception may already have caused harm to the research process.

At one point in my research I almost lost access to a group of respondents because I unwittingly approached them through someone they did not trust. This person was a leader of one of the NGOs which constituted the Forum of Migrants' Associations. I met her at the headquarters of this umbrella organisation and she gave me information about where I could find my potential respondents. She presented herself as a person fighting for migrants' rights and someone trusted by them. However, when I came to the small town in the Moscow region where these migrants lived and met with them, I perceived a negative attitude as soon as I mentioned her name. Apparently, they considered her a person who did not really care about them and did not do anything for them. They believed she had used them to make her own career in politics. Associating me with her, they refused to be interviewed. Only a stroke of good luck saved the situation. I approached my potential respondents during one of their meetings where they were discussing their problems and trying to find solutions. Some local people trying to help them were also participating in the meeting. One of the locals expressed interest in another aspect of my identity—my migration history, which I had mentioned during my introduction. Through interaction with this local person, I managed to renegotiate my identity to decouple myself from the person who was mistrusted, showing that I had my own agenda. Later, I was reintroduced by this local person to the group of respondents who had initially rejected me, and this time they agreed to participate in my research.

In the course of communication with this group of respondents, I had the opportunity to learn some details about the reasons for their negative attitude toward my initial "gatekeeper." Members of this group were those non-Russian nationals who had arrived in Russia from other former soviet republics long before 2002—the year that the law "On the legal position of foreign citizens in the Russian Federation" was issued, as well as the new law "On citizenship of the Russian Federation." The new regulations, however, treated these people as though they had only just arrived. Experiencing difficulty in meeting the requirements imposed by the new legislation, these once legal residents of the country were now trapped in a situation of "illegality." Sometime before I initiated my fieldwork, my initial "gatekeeper" attracted media attention to the situation of these

migrants. To address this situation, she also organised a conference attended by both the local authorities and representatives of civil society. As a result of this conference, a civil council was set up to assist non-Russian nationals in applying for Russian citizenship. It was planned that this council, consisting of migrants and locals, would work in co-operation with local authorities. However, that co-operation never happened. Furthermore, the “gatekeeper” failed to assist my respondents with the promised consultancies. As a result, the council lacked the necessary mechanisms to fulfil its aims, and thus my respondents did not improve their situation by agreeing to participate in the activities which my “gatekeeper” had initiated. Moreover, the respondents pointed out that the local authorities had been angered by the public attention caused by all of these activities and had started to treat them much worse than before. All of these factors made my respondents feel that they had been used and abandoned by my “gatekeeper.”

Knowing that I worked on the premises of the Forum of Migrants’ Associations and that I had had the opportunity to meet the head of this organisation, members of the above-mentioned group of respondents wondered whether I could inform her about their dissatisfaction with the leader of the local NGO. I asked them why they did not approach the head of the association themselves, as the town in which they lived was near Moscow and they constantly visited the capital for business and private matters. In answering this question, they pointed out that they did not know her personally and, more importantly, they did not know a lot about the relationship between her and my “gatekeeper.” Thus they could not predict what the outcome would be if they made a complaint in person. The migrants’ fear of being forthright about their complaints, even with the representatives of NGOs that stated assistance to migrants as their mission, illustrates their vulnerability. They felt that in their struggle for the right to live in Russia, and that in order to enjoy social, economic and political rights in Russia, they were dependent on the good will of the Russian authorities, locals and representatives of civil society.

In my opinion, a person who believes that they can sort out the interpersonal problems of others is highly conceited, especially if they have not had the opportunity to observe first-hand the development of the conflict and therefore must base their actions solely on the interpretations made by the other parties involved. Despite the fact that all my sympathy was with the respondents, I nevertheless could not complain on their behalf. However, I offered to introduce them to the head of the association so that they could express their points of view on the matter to her personally, or to pass a letter or note to her with their description of the

situation. They did not agree. Although I could understand their reasons for refusing (see paragraph above), it still left me with the uneasy feeling that they had tried to use me as a safe way to express their frustrations. Ultimately, they could just say that I had misinterpreted them. That would leave me in quite an unpleasant situation. At the very least, I would look like a gossip.

The net of relationships existing in the field should be taken into consideration by the researcher not only during their interactions with research participants, but also while presenting results of the research, especially in written form. The researcher, analysing data and writing the text, follows an agenda and presents their perspectives on the situation in the field. However, whatever the agenda, they must bear in mind that the dissemination of the research results has the potential to influence those who remain in the field, so they have to think how best to avoid causing harm to the participants of the research.

Protecting the anonymity of the research participants was one of my priorities in reporting the results of my research. Some of the migrants who gave me interviews had not managed to secure legal status in Russia and were thus under constant threat of deportation. Among those respondents who had secured legal status in Russia, there were also people who could still be in danger if their anonymity was not preserved. The reason for this was that in order to receive legal status and to retain it, they occasionally had to find ways of overcoming loopholes created by the incoherence of migration regulations in the Russian Federation. Thus, when reporting the results of my research, I identified all my interviewees only by letter-codes. While in the case of Moscow this measure could be considered to be enough to protect my respondents from unwanted interactions with law enforcement agencies, in the case of the two small towns near Moscow its efficiency was problematic. Although in my writings I also changed the names of these two towns, the literature contains examples of research projects which took place in such settings and yet failed to preserve the anonymity of the research participants simply by giving them pseudonyms (Stein 2010; Vidich & Bensman 1958). Acknowledging the likelihood that research participants from small towns might become visible due to their participation in a research project is higher than that of respondents living in Moscow, I still decided to employ data from all of my interviews. This decision was based on the fact that the respondents from small towns were already public figures there and the local officials knew them very well. However, the already-existing visibility of these respondents did not mean that I could use all the information provided by them in their interviews. I assumed that publishing some data

might harm respondents who could be so easily identified. For example, I left unreported their activities in overcoming the social exclusion they experienced as a result of Russian migration legislation, since this could reveal some of the law-bending practices which they employed and thus could increase their vulnerability.

I should admit that even if my respondents remain anonymous for those readers who do not know them well, the manner of sampling used in this research makes total anonymity impossible. My respondents will recognise themselves, as will, possibly, people who know them (and those who put them in touch with me). Sometimes, as my previous experience has shown, people can be recognised even through their way of speaking. Taking this into consideration I did not reveal any information which my respondents viewed as confidential. I did not report any personal secrets and used the information received from my respondents only to discuss general topics in the focus of my research, such as social exclusion and the “territorialisation” of identity.

The literature highlights that the researcher should think not only about what they can do to avoid negative consequences for the research participants, but also about how to present research participants in their writings (Currier 2011). I do not support those who think that the so-called “bland fashion” of portraying research participants is damaging for the readability of publications (Stein 2010, 566). There were people among the research participants whom I did not like, however, and I did not feel it possible to express this in my writings since this could damage their position within the existing network of relationships in the field. I believe that a researcher can be critical in analysing social issues without being personal.

Taking into consideration the paragraph above, this chapter creates an ethical dilemma for me. I have been concerned about the rather delicate matter of the discussion of interpersonal relationships which sometimes show the participants in not necessarily the most favourable light and could negatively affect their future relationships in the field. At the same time, I believe that it is crucial for researchers to share their field experiences with their colleagues to highlight the issues they themselves may face. Thus, I chose to wait a considerable amount of time after my fieldwork to publish this text. As far as I know, those migrants who are discussed here have solved the various problems with the legalisation of their status in Russia, so at least I am sure that my work will not cause them any difficulties in this regard.

Conclusion

Any research has ethical aspects since science is achieved by people and has implications for their lives. In the case of sociological inquiry, these aspects can be found throughout all research processes. The most ethically charged stage of this inquiry is perhaps the fieldwork where the researcher directly interacts with the research participants. Although relationships between the researcher and research participants are the focus of many publications on methodological issues and ethical aspects of research, very often discussions presented in these publications omit the fact that the interactions between the researcher and each of their interlocutors are intertwined in a wider network of relationships within which different actors may pursue different interests. Upon entering the field, the researcher inevitably becomes a part of this network, and they should take this into consideration when constructing their relations with other social actors. The necessity for the researcher to be conscious of this role is increased by their limited ability to sort out possible misunderstandings between themselves and the other social actors in the field. As a newcomer and “outsider,” the researcher could easily be cut off from relationships that they have carefully constructed during the fieldwork. This is especially true for those who, like me, have the opportunity to be in the field for only a relatively short period of time, and who therefore do not have the time to renegotiate their “outsider” position.

Discussing my methodological decisions about the issues generated from my involvement in the networks of relationships already existing in the field, this article, however, shows that my navigation through these networks was informed not only by practical considerations, but also by my understanding of what is right and wrong. Although philosophers have developed various ethical frameworks, each of which provides a different perspective on “what is right and what is wrong,” the perspective prevailing among social scientists nowadays considers the “guarding against harm” principle as pivotal for defining what decision and action in the course of the research is right or wrong (Bakker 2007). In other words, participation in the research must not cause harm to any person. This principle guided my actions as a researcher. I defined harm as a worsening of a research participant’s wellbeing (including worsening of their relations with other people).

It is widely acknowledged that dissemination of the research findings has the potential to influence those who remain in the field, so a researcher has to think how best to avoid causing harm to research participants. The general problem here is that although the researcher may have the aim of

improving the lives of their respondents, they do not know how the information presented in the written results will be used by the readers. Those who do qualitative sociological enquiry or ethnography should acknowledge that preserving the complete anonymity of research participants could be very problematic in some cases. Thus, in my opinion, decisions should be taken not only about what data can be published, but also about how research participants will be represented/depicted in the publications.

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CHAPTER EIGHT

WORKING WITH ADOLESCENTS: IDENTITY, POWER AND RESPONSIBILITY IN SOCIOLINGUISTIC ETHNOGRAPHY

DOMINIKA BARAN

Introduction

In the first months of my ethnographic research with high schoolers in the Taipei City area, I spoke to a senior colleague experienced in work with adolescents. She gave me invaluable advice regarding my project, but at one point she asked a puzzling question. I was explaining that much as I may try to be my participants' friend, and be like them or one of them, there are certain things I cannot do.

"I smoke," I said, "and so do these guys in the vocational classes. But I can't have a cigarette with them."

"Why not?" asked my colleague.

"Because they are seventeen," I responded, somewhat taken aback.

As I have revisited this exchange over the years, I am not sure whether my colleague was asking a genuine question, or trying to provoke me to reflect on my research practice. What would it have meant in my specific context, as a 29-year-old Caucasian American female doctoral candidate and researcher, to smoke cigarettes in front of 16 to 18-year-old Taiwanese boys studying electronics repair in a low-ranking high school in the industrial suburbs of a busy Asian metropolis? And more specifically, what would this have meant not for my research project, but for the boys? Taiwanese society does not favourably view women who smoke in public. "Talking and smoking at the same time" is how one of my adult interviewees described "problem girls" likely to be rebels and high school dropouts. While, as a foreigner, I may have risked this stigmatized behaviour in the company of my adult friends or strangers on the street, I felt less comfortable engaging in it with my underage research participants.

Realistically, I doubt that my smoking would have in any way encouraged these boys to smoke, as the practice was determined by their participation in local friendship networks. Nevertheless, I wondered whether it would compromise my complex relationship with them—undermine their respect for me, cast into question my respect for them, be seen as a sign of low moral standards in general and thus sexualize my identity, or reinforce problematic images of Western females as “too free” and thus likely promiscuous.

The impact of the researcher’s everyday choices and actions on research participants is an inescapable component of fieldwork activity, and it gains additional weight when the participants are children or young people. In addition, how the researcher’s behaviour is read and interpreted depends on how the researched envision and situate the researcher’s identity within their group. Meanwhile, the researcher’s identity in the field extends far beyond, to take my own example, “the sociolinguist.” Indeed, as a sociolinguist I was especially ill-prepared to deal with ethical dilemmas of power and responsibility in the field. Sociolinguistic and linguistic-anthropological literature, including sociolinguistic ethnographies of young people, is noticeably silent on the subject of ethical management of researcher roles (e.g. Eckert 1989, 2000; Mendoza-Denton 2008; Bucholtz 2011; Lawson 2011).

To be sure, ethics has been an important topic in this literature for some time, but the discussion typically focuses on the research dynamic itself, including issues of consent, confidentiality, the research agenda (Duranti 1997; Swann 1994; Cameron 2001), as well as access, authorship, advocacy (Labov 1982) and empowerment and knowledge-sharing (Cameron *et al.* 1992). However, although sociolinguists frequently work with children, introspective analysis of how the researcher impacts their attitudes or values beyond the research project itself is missing from key texts in sociolinguistic ethnography. Yet I argue that it is essential for linguists to be aware of and reflect on these issues precisely because the very subject matter that they study appears on the surface to lend itself to objectivity and scientific detachment. Sociolinguists are interested in *how* people talk and not *what* they say. Even when linguistic anthropologists record comprehensive ethnographic data, its purpose is to situate linguistic practice within its socio-cultural context. If I am interested in your vowels and consonants or in the social meanings of your use of “like,” then I am less likely to question why you are choosing to tell me that you have been depressed or that you and your classmates deal drugs. This chapter brings these questions to the foreground, asking linguists who enter adolescent

communities to reflect on how their perceived social roles influence young lives.

Fieldwork at Sunrise Senior High School in Taipei

Between 2003 and 2004, I spent three semesters conducting fieldwork in a small, private high school in the greater metropolitan area of Taipei City, Taiwan. My project was a sociolinguistic ethnography focused on language use and the construction of identity within the school institution (Baran 2007). The school, which I call Sunrise Senior High School (Sunrise SHS), ranks relatively low in terms of academic prestige. It draws its students from the surrounding industrial area; most of them are from working-class families and choose Sunrise partly because they have low high school entrance exam scores, and partly because of its proximity to home. The school has a large vocational division, including programs in car mechanics, electronics repair and office administration, as well as a college-preparatory division focusing on general education and preparation for college entrance exams. Students in the college-preparatory track are considered better behaved and more serious about their studies than vocational students. They mostly adhere to this stereotype, and they view vocational students as immature and uncouth. Students training for blue-collar occupations are often seen as troublemakers. Because students are placed in groups (in Chinese *banji*) or classes numbering twenty to forty students, and each class shares the same classroom, curriculum and schedule throughout their three years of study, both group stereotypes and a strong sense of class identity emerge and are constantly reinforced through daily practices.

During my fieldwork, I worked with a college-preparatory class, an office administration class, and an electronics repair class. My work entailed spending time in the school and in the classrooms, recording student conversations and one-on-one interviews, and participating in school and out-of-school activities. From the beginning, following Eckert (1989), I distanced myself from the identity of “teacher” or other authority figure. I asked to be seated at a student desk in the back of the classroom, and to be addressed by my Chinese first name, Xiao-lan, which is an extremely informal practice. However, my Caucasian appearance placed me in the category of “English teacher”; moreover, teachers sometimes invited me to “encourage” students to work hard, or made comments such as “The foreign lady came here to observe you students, not to listen to your silly jokes.” Consequently, I stepped up my efforts to befriend the students and become “one of them,” different in ethnicity but otherwise

their equal. My age worked to my advantage: at 29, dressed casually and with no make-up, I looked only slightly older than the students, which compensated somewhat for the power imbalance implied in my “English teacher” ethnicity (cf. Mendoza-Denton 2008; Morris-Roberts 2001, 149). However, as I will demonstrate in later sections, my status as a foreign adult re-emerged as visible and salient throughout my fieldwork.

Researcher Roles and Identities

Qualitative fieldwork, and especially ethnography, necessarily produces a multiplicity of researcher roles. Textbooks on qualitative research typically deal with this issue in terms of prescriptive advice on how to best maintain the research focus and the primacy of one’s role as researcher (as opposed to friend, co-worker, etc.), and how to navigate issues of access and objectivity in light of potentially conflicting roles in the field (de Laine 2000; LeCompte 1999; Duranti 1997). An example might be Adler & Adler’s caution against the researcher “going native” and becoming over-involved with the participants, thus compromising the scientific integrity of the research project (1987, 17). In other words, the focus of most guides to fieldwork that deal with researcher roles is the research objective, and not research participants or even the researcher. Ethical concerns discussed in such texts tend to address informed consent and the transparency of one’s activities.

But the reality of multiple researcher roles in the field brings up other ethical questions—those of responsibility towards the participants for the relationships one has formed with them, as well as for the different identities that the participants may ascribe to the researcher in a given fieldwork context. As more recent approaches to fieldwork coming from poststructuralism, critical fieldwork and feminism emphasize, the researcher’s identity is never uniform; furthermore, attempts to “minimize” the impact of this identity on the data-gathering process are missing the point. England (1994) argues that the researcher’s biography does not simply affect the data, but is part of it, rendering the scientific objectivity of the ethnographer “completely mythical” (England 1994, 85). The researcher’s gender, ethnic and social background, and personality are part of the research setting; they determine how we interact with the participants, what data is available to us and how we interpret it (England 1994; LeCompte 1999; Finch 1993; Preissle 2006).

Poststructuralist thought has further implications for the researcher’s identity. The notion that an individual inhabits a multiplicity of complex, hybrid and contradictory identities (Hall 1992) has been influential in the

humanities and social sciences, as has the idea that identity is a social construct, that it emerges in and through social interaction, and that it is not something we have and subsequently “project” or “signal,” but rather something we “do” every time we enter a social encounter (Bucholtz and Hall 2004). This social situatedness of identities implies that the definition of one’s identity depends equally on the actor and on the audience; identities are not only constructed, but also negotiated.

All social interactions, including ethnographic fieldwork, entail negotiation of identities. De Laine (2000) describes cases where the fieldworker’s attempts at establishing a particular role within the studied community are redirected according to the community members’ own agenda. Similarly, LeCompte (1999) outlines potential scenarios where the researcher’s “fieldwork identity” is not understood or not welcomed by the researched. Like Adler & Adler (1987), she warns against “going native,” but for a different reason—her concern is with the participants’ interpretation of the researcher’s intentions and assumptions, citing examples where overzealous imitation of the participants’ behaviour is seen as mocking, disrespectful, and otherizing. Here, while the researcher seeks to position herself as “participant,” she is read as “outsider.” During my work in Taiwan my identity was likewise constantly negotiated. As I will discuss in more detail below, teenagers variously positioned me as an English teacher, a confidant, a friend, a role model, a foreign Other representing America or the West, or a visitor to impress or to look after. These different readings of my identity were often performed simultaneously or by the same people, and had as much to do with the students’ prior assumptions and knowledge as with my efforts at self-presentation.

What is crucial is that such different readings of researcher identity have implications for how the participants interpret the researcher’s behaviour, and how they envision their relationship with them. Feminist scholars in particular challenge the idea that the researcher’s involvement with the researched can or should be limited to its data-gathering dimension, or that it is possible to separate this dimension from other aspects of the researcher-researched relationship. The feminist approach criticizes traditional research methods as objectifying research participants and excluding the female voice and experience in the name of the “fiction” of neutrality (Preissle 2006). Instead, feminists propose the “ethic of care” (Noddings 2003; Denzin 1997), where the researcher seeks to develop friendships in the field, and pays attention to the participants’ needs, interests and concerns. Critics of this approach claim that friendships developed in the field are short-lived and misleading (because the researcher’s ultimate objective is data-gathering), and that they expose

participants to the risk of divulging highly personal information that falls outside the scope of the research (de Laine 2000).

However, Oakley (1981) and Finch (1993), among others, argue persuasively for engaging with the multiple roles one performs in the field. Oakley discusses her work with women transitioning to motherhood, where her interviewees positioned her in the role of a female friend and source of valuable information. She asks how one could reject these roles when interviewees ask questions such as “Which hole does the baby come out of?” (Oakley 1981, 48). She also reports that 73% of the women found participating in the research beneficial, stating that it was “therapeutic” and reassuring to talk, and that it led them to reflect more on their experience (50). Finch (1993) similarly finds that her female interviewees accepted her as “one of them,” an insider and thus a friend, rather than just a researcher, and that they found it valuable “to have someone to talk to” (Finch 1993, 168). These identities of friend, confidant or counsellor emerge in response to how the participants perceive us (Finch 1993; de Laine 2000), and how they prioritize the different relationships they see us as offering them. We as researchers, in turn, face the ethical and moral dilemma of taking appropriate responsibility for our interactions in the field, and prioritizing our goals as researchers vis-à-vis our human relationships with the participants (de Laine 2000, 100–101).

Working with Children and Young People

Oakley (1994) describes parallels between women and children as subjects of research, arguing that both are social minorities whose voices are excluded from traditional scholarship. Correspondingly, contemporary child and youth research in geography, social work and education challenges existing definitions of childhood (Holland *et al.* 2010; Orellana 2009), urging researchers to treat children as persons and respect their rights and competencies (Morrow & Richards 1996; Alderson & Morrow 2004), including their right “to participate in decisions that affect them” (Holland *et al.* 2010, 361). Fieldworkers are further advised to scrutinize and address the unequal status and power relationships between the adult researcher and the child (Holland 2010; Morrow & Richards 1996; Matthews 2001; Barker & Smith 2001), and to reflect on issues such as the meaning of children’s informed consent (Alderson & Morrow 2004; Morrow & Richards 1996), recruitment and inclusion of child participants (Maguire 2005, 1999; Alderson & Morrow 2004), inviting children to co-produce the research agenda, and involving them actively in data-collection and analysis (Holland *et al.* 2010; Morrow & Richards 1996).

With the focus on “agency, empowerment and voice” (Holland *et al.* 2010, 362), researcher roles in work with children and young people are only occasionally discussed. Morrow & Roberts (2010) briefly point out that “researchers need to be aware that as adults dealing day to day with children, their *responsibilities* as adults to children must be fulfilled and they must ensure that children do not suffer harm at any stage in the research process” (100). Morris-Roberts (2001) describes her fieldwork dilemma when witnessing verbal abuse and friendship exclusion among teenage girls, unsure whether and how to intervene. Not intervening made her feel “complicit in the ‘bullying’” (150), and the situation itself made her realize that her assumption of having been accepted into the girls’ friendship groups was “naïve and problematic” (150). Barker & Smith (2001) stress the centrality of power negotiation and researcher positionality in fieldwork, demonstrating that aspects of the researcher’s identity such as gender have a crucial impact on how the research process evolves, but do not discuss the ethical implications of their argument. For example, they report that the female fieldworker had greater access to the children, and “in extreme cases, children disclosed information to her about abuse they were suffering at home” (143), but they do not say how this situation was dealt with.

Not only is discussion of researcher roles and the responsibilities they entail rare in childhood studies, but there is also little cross-disciplinary dialogue about these issues. Scholars in other fields that rely on children as research participants are equally silent on the topic, including sociolinguistic ethnographies of adolescents that have become essential reading in the field, most notably Penny Eckert’s (1989, 2000) seminal study of a Detroit area high school, and Norma Mendoza-Denton’s (1997, 2008) work with Latina youth gangs in California. Since these researchers were interested in how young people’s social networks and identity categories structure language use, they each sought to develop friendly, comfortable and long-term relationships with the participants. Eckert (1989) details her efforts at distancing herself from the role of an authority figure, and Mendoza-Denton (2008) describes activities through which the gang girls included her in their groups. She talks about “becoming friends” with the girls (Mendoza-Denton 2008, 54), and about being “taught” by them how to dress and wear make-up. Mendoza-Denton reflects on the effect of her own Latina background on how the girls treated her, including their disapproval of her European-American boyfriend (Mendoza-Denton 2008, 39), and complains about the paucity of self-reflexive work in the field (39). The most direct comments concerning ethics come from Eckert (1989), who raises the question of the adult’s

responsibility in the friendly researcher-teenager relationship: for her, the problem “was not how to gain people’s trust, but how to deal with it when it came” (34). She does not explore this issue further, however. More recent work with young people such as Bucholtz (2011) or Lawson (2011) does not address researcher roles and ethics.

In the rest of this chapter, I describe the ethical dilemmas that I encountered in my own sociolinguistic research with adolescents, and that centred around the question of researcher identity in the field. With this discussion, I hope to draw attention to this important element of sociolinguistic and linguistic-anthropological fieldwork.

Identity, Power and Responsibility—Research Dilemmas

As a sociolinguistics doctoral candidate embarking on ethnographic fieldwork among high school students, I felt inspired by my predecessors’ dedication to understanding adolescents on their own terms by becoming their friend. However, as my fieldwork unfolded I found that the adult researcher is never just another friend. In this section, I discuss three contexts in which I faced ethical dilemmas posed by the complex social roles I inhabited in my relationships with students at Sunrise SHS.

Researcher as Confidant

One of the common roles in which a fieldworker might find herself is that of a confidant or even therapist (de Laine 2000). The case of 17-year-old Fay forced me to interrogate my assumptions about the neutrality of my “confidant” role, and the responsibility associated with being the adult in the friendship.

I interviewed Fay in December 2004. She was a student in the college-preparatory class who had transferred from the class next door in September. When I asked her why she moved, she shared a personal story about her experience (all interviews were in Chinese and translated by me):

D: Why did you move to this class?

Fay: Mmm ... well in year two some things happened ... I sort had a fight with someone in the class. And then there were some, some romantic issues, and then I just wanted to transfer to another school. But our vice-principal kept on telling me to stay. She said “Your studies are going pretty well now, stay here, continue to study here, that will be better for your academic performance.” She said, “Actually your grades are good enough to be in the *jia-ban* class,” and she suggested I move to *jia-ban*. And then

my mom said the same thing. And so in the end I decided to just transfer to their class. Yeah.

D: And how would you compare the two classes?

Until this point, Fay's story remains fairly general, and I choose not to probe further. Instead, I ask her a seemingly unrelated question—"How would you compare the two classes?" What follows is a much more detailed, emotionally intense account of Fay's painful experiences from the year before, including the end of a friendship and a difficult break-up. The story continues for about twenty minutes. At one point, Fay describes being depressed and having suicidal thoughts:

Fay: I was very upset, extremely upset. I was terribly upset, really like, I just cried all the time, and then I encountered some romantic problems that didn't go well. And it just became like being beaten up from both sides, my friendship and my love relationship. And then I just felt worse and worse, and in fact at that time I thought about killing myself. I just felt, I just kept on crying every day, I didn't know what to do with myself. I felt ...

D: Did you really have such thoughts?

Fay: Really

Treated purely as sociolinguistic data, this narrative exemplifies a passage likely to contain the least careful and most vernacular speech style, such as can be elicited with the "Danger of Death" questions proposed by Labov as one way of mitigating the Observer's Paradox (Labov 1972, 209). But clearly, rejoicing that one now has excellent casual-speech-style data would be a rather cynical response to Fay's story, and indeed some authors have questioned the ethics of involving participants in "Danger of Death" stories with the ulterior motive of getting "natural" data (Mendoza-Denton 2008). The central problem in situations such as my interview with Fay, however, is that the researcher is suddenly entrusted with information in light of which resolving methodological dilemmas such as the Observer's Paradox takes a back seat.

Significantly, I did not elicit Fay's narrative intentionally. I began our conversation with the same questions that I brought to each of my semi-structured interviews, concerning her family, the school and her feelings about language. Fay volunteered her story in response to my question "And how would you compare the two classes?" This question appears as my attempt to redirect the conversation after the previous one, "Why did you move to this class?", opened a potentially sensitive topic. However, Fay continues with her narrative until, after she mentions suicidal thoughts, I interrupt with "Did you really have such thoughts?"

Although Fay knew that I was a researcher, and that my objective was to learn about students' lives and language, her unprompted personal story completely changed our role relationship. Fay rejects, or at least ignores, my role as a researcher, and instead positions me in the role of a confidant. I am not just any confidant, however: I am older and foreign. It is likely that Fay saw me in the role of "a nonjudgmental and confidential adult" (Eckert 1989, 34): someone clearly removed from her own day-to-day life and thus non-threatening, and at the same time explicitly interested in listening to her and thus easy to confide in. However, in the United States at least, assumptions of confidentiality in most mentoring relationships become void upon mention of suicidal thoughts. This holds true, for example, for advisor-advisee or professor-student relationships in universities. The issue has also been raised, albeit seldom and vaguely, by some childhood researchers. Morrow & Richards (1996) write: "Children should be entitled to the same degree of confidentiality and privacy as adult research subjects, with added proviso that researchers will have to deal with cases of disclosure of potential harm as and when they arise" (95).

It was clear to me that once Fay began to talk about what resembled depression, and mentioned suicide, the role of confidant that she positioned me in took primacy over my role as researcher; it was not a role I could reject. The first decision I immediately made, therefore, was to stop thinking about the interview as data collection. My subsequent responses to Fay were thus guided by an attempt to be a caring and responsible listener. However, as de Laine (2000) points out, assuming the role of therapist is dangerous business for fieldworkers who have no relevant training (117). This, in fact, is precisely why advisors and professors whose mentees share information about serious mental health issues are obligated to inform the appropriate professional. But are the rules the same in Taiwan? Was I supposed to tell someone?

These questions went through my head as I continued listening to Fay. I occasionally interrupted with questions such as "Did you have anyone to talk to?", "Did your teachers have any idea?" and "Did your mom know about this?" Her affirmative answers reassured me that at least I was not the only one with the knowledge of her problems, and that those close to her were presumably looking after her. In addition, Fay's story dealt with the previous semester and was therefore not immediate cause for alarm. Consequently, I refrained from contacting anyone about Fay, but I also never used her interview in my sociolinguistic work.

I will never know if I made the right decision. Only a few months had passed since the difficult events Fay described, and she admitted that she

was still upset. In addition, she told me that at the time she considered seeing a psychologist, but did not: "I had no one to come along with me, so in the end I didn't go." This in turn begs the question of how much her friends and family actually knew about her mental health. The very fact that she chose to confide in me suggested that the matter still preoccupied her thoughts. Yet, if I wanted to seek some help for Fay, where would I go? I had no knowledge of the local norms and procedures for such situations. I had never been trained to find out about them, even though I would work with children. Sociolinguist Penny Eckert (1989) similarly reflects that where she was least prepared for her work with adolescents was "in knowing where to send people ... the full range of resources available to adolescents, in particular, the adolescents in this school" (Eckert 1989, 34). It seems ironic that university ethics boards apply stringent criteria for securing informed consent from children, including elaborate forms whose detail sometimes looks scarier than the prospect of being recorded, but graduate students receive no training in how to handle situations where they may suddenly find themselves responsible for a child's mental health.

Researcher as Mentor

Helen also studied in the college-preparatory class. I met her at the very beginning of my fieldwork when she heard about me and approached me herself, surprising me with her fluent North American English. It turned out that she had just returned to Taiwan after living for several years in North America. This was her first year at Sunrise, and she was experiencing culture shock.

Taiwanese high schools are far more rigidly structured than North American ones. Student life is micromanaged, and in-school activities are constantly monitored. Uniforms and rules regarding make-up, hair length, jewellery and even acceptable socks and shoes are enforced, especially at less prestigious schools that see themselves as managing "problem" students. Sunrise SHS imposed a daily twelve-hour study regime on its college-preparatory classes, composed of lectures and mandatory study periods. Extracurricular activities such as sports or drama, a staple of student life in North American high schools, were discouraged as distracting from schoolwork. Helen, who had been used to wearing T-shirts and make-up, moving freely around her school and going out with friends, suddenly found her life strictly controlled, and many of her regular activities were not open to her. Teachers saw her as too outspoken and her new classmates as a "foreigner." She did form friendships in her class, but

she felt out of place, and found that she had to substantially alter her personal style to fit in.

What Helen did not know when she came to me was that I, too, immigrated, and at age 15 joined an American high school whose academic and social structure alienated and confused me. When I shared my experience with her, she began to confide in me. I was someone who had struggled through a similar experience to hers, and appeared to have adjusted and succeeded both socially and academically. This was a complicated field relationship because Helen reminded me of myself 15 years earlier, so I immediately felt close to her. I also remembered feeling very lost at that time in my life, and wanted to offer her reassurance. Moreover, our similar experiences and Helen's North American upbringing and fluency in English positioned her as a source of familiarity and, by extension, comfort, amidst the foreignness of my field environment. The relationship thus fulfilled a mutual need: for Helen, I was a source of advice and reassurance, and for me, she was a cultural bridge of sorts. However, this did not make the relationship equal: I was the adult who had already grappled with and resolved the issues that she was now facing. I became her mentor, and this meant that I had to behave appropriately to that role.

Helen's background meant that she could place me in the North American context, which made it easier for me to evaluate my own behaviour in front of her. At the same time, however, I had to be careful not to allow this shared knowledge to inadvertently misguide me into treating our friendship as one between peers. I was constantly asking myself how much of my personal life it is appropriate to reveal to her, especially since, seeing me as a friend, she often asked me personal questions. I also had to remember that Helen was now living in Taiwan again, and I could not simply assume that all her cultural points of reference paralleled mine.

I also worried that my reliance on Helen as a "translator" of local culture undermined my ethnographic project, and created problematic allegiances (Morris-Roberts 2001). I did not want to be seen as the foreign researcher who hangs out with the "foreign" student, and who perhaps does not value other students as much. This problem resolved itself when Helen transferred to another school, and our friendship continued. In her last year of high school, Helen began to think seriously about applying to colleges in North America. She asked me for advice, simultaneously telling me that her mother was not thrilled about the idea. I encouraged Helen's plans, advised her to do what was right for her, and proofread her applications. But I wondered if giving advice that contradicted that of her

mother's was appropriate in the Taiwanese context. I also worried that I was making assumptions about Helen's needs based on what I saw as our shared adolescent experience.

My relationship with Helen illustrates a number of points about researcher roles in the field. It is an example of an enduring friendship that can emerge out of a fieldwork encounter. As such, it offers evidence that fieldwork relationships do not have to be temporary and "friend-like" (de Laine 2000, 114), but it nonetheless highlights the potential conflict between research goals and friendship. De Laine raises the question of "whether probing is ethical among friends," emphasizing the importance of reminding one's friends in the field "that you are actually performing fieldwork" (115). In Helen's case, I accepted my mentoring relationship with her and prioritized it above my researcher role, and she was not included as a participant in my study. I have not regretted this trade-off. I believe that when we enter adolescent communities, we cannot be single-mindedly committed to our research goals at the expense of our participants' needs. The concern with participant-focused research and responding to the research communities' actual needs that has been increasingly voiced by scholars including sociolinguists (Cameron *et al.* 1992) needs to extend to those needs that may fall outside the research project itself. My friendship with Helen highlighted to me the all-encompassing scope of our ethical responsibilities to the young people whose lives we set out to study.

Hanging out with "Gangster Types"

Yet another dimension of researcher roles and responsibilities emerged in my work with the all-male electronics repair class at Sunrise SHS. Both teachers and other students described this class as "different" and "lively," using these as euphemisms for "troublemakers." One female student even warned me to "be careful" in the electronics classroom, wondering how I was not afraid to be among "those gangster types." In my fieldwork notes from my third day with this group I wrote the following:

3/4/04. Zheng-yi and Shu-ming together speak some Taiwanese, teasing each other. Shu-ming gets the class leader to come and agree [to be interviewed], says "you're the class leader, you first!" Then someone else keeps teasing the class leader, pinching his butt and pulling down his pants. Meanwhile, as soon as class leader walks off, Shu-ming says "He takes ecstasy" "How do you know?" [I ask] "I know." "What about you?" I ask. "Me? No!" Then to me: "You?" "Me neither." Then he points to—not

sure, class leader or Zheng-yi, and says, “He sells it!” Clearly this is different from the other classes where people don’t even smoke.

The topics of illegal drugs and illegal pubs, motorcycle racing (an illegal activity), and temple gangs came up frequently in this class as the boys simultaneously teased each other, competed with each other for the wittiest comments and quickest retorts, and performed a kind of hyper-schooligian group identity. On the very first day with them, I was greeted with endless accounts of the boys’ exploits—getting into fights, smoking in the classroom—all summed up with statements such as “the teachers just cannot handle our class,” or “we are the scariest class in the school.” In the exchange reported in my field notes above, I had to decide quickly how to respond to Shu-ming’s announcement that his classmate takes drugs, and my questions “How do you know?” and “What about you?” were intended to fit with the joking, teasing tone of the entire interaction. I certainly did not expect honest answers; rather, I wanted to present myself as someone on the guys’ level, someone they could hang out with. It was only in retrospect that I wondered whether the ease with which I engaged in banter on the topic of drug use was appropriate to my status as an adult among adolescents. Eckert (1989) mentions that while she never brought up the topics of drugs and sex with her interviewees, she maintained a non-judgmental attitude if the teenagers chose to discuss them (Eckert 1989, 35). However, participating in jokes and banter is not the same as a non-judgmental attitude in an interview; it can suggest familiarity with the topic or even sympathizing with the activities, which is not a message I wanted to send out. Again, this was the case of allowing the sense of friendliness and ease of interaction to obscure the fact that I was not interacting with my peers.

This was made apparent to me by the contrast in the boys’ interactions with me in a group and in a one-on-one interview. As a group, they seemed to accept my efforts to be “one of them.” They made fun of each other in a sort of double performance, positioning me as the audience for their witty remarks but also constantly seeking to outdo each other, thus negotiating their status within the group. As a result of this dynamic, I also became the target of teasing and jokes, some of which capitalized on my being the only female in the group. An excerpt from one conversation, recorded in May 2004, begins as J. R. and Wen-hua are looking at a copy of a local English-language newspaper I lent them, examining a photograph:

- J. R.: Do you know who this is?
 WH: Chen Shui-Bian [Taiwan’s president at the time]

- J. R.: And this?
 WH: Who?
 J. R.: The foreigner. Do you know who it is?
 WH: How would I know?
 J. R.: Do-mi-ni-ka [my name]
 WH: (*laughs loudly*) No it's not! (*gasps*) Oh yeah looks kind of like her!
 J. R.: No, no, no, no
 WH: And who is this, Bin-Laden's older brother?
 J. R.: (*laughs*) Bin-Laden's brother!
 (*they continue looking at the paper*)
 J. R.: I can't understand this here
 D: No, this is ...
 WH: Lunar calendar
 D: I understand it—this here?
 J. R.: Let me tell you about this, this one here (*serious tone*)
 D: mhm
 J. R.: This, this here, right? June twenty-seventh, right?
 D: Yeah
 J. R.: (*continues in serious tone*) This one, really
 D: Why?
 J. R.: Because that day is my birthday! (*everyone laughs loudly*)
 J. R.: (*laughing*) Really, it's pretty good [the date]
 D: Pretty good, huh?
 J. R.: Really
 D: I have one, too
 J. R.: You do?
 D: (*quietly*) September twenty-ninth
 J. R.: That, that is my death date! (*everyone laughs*)
 J. R.: September twenty-ninth?
 WH: September twenty-ninth
 D: It's the best
 (*everyone continues discussing birthdays, more boys join*)
 D: So how old are you?
 J. R.: mmm ... now? (*starts counting*)
 WH: You have to count?
 D: You don't know how old you are?
 J. R.: Twenty, I think
 D: Twenty? (*surprised tone*)
 J. R.: Yeah. You know? I'm of age. [implying: old enough for me]
 B: That's gross! (*everyone laughs loudly*)
 J. R.: So I have more **power** (*uses English word "power"*)
 D: You have more **power**, eh? (*also uses English word "power"*)
 J. R.: Yeah

In this exchange, as I get pulled into the banter, the boys position me as a peer, as “fair game” for chaffing, which is underscored by the sexual innuendo that works because I am the only female among them, but that would not be possible with an available local female their age whom they saw as a romantic interest. At another occasion, while planning the upcoming graduation trip, much merriment ensued as the boys began to discuss my sleeping arrangements. “You’ll have to sleep together with our [male] teacher,” they insisted, while others shouted, “She can just sleep with us!” (Field notes, May 18, 2004).

However, in one-on-one interactions, the same boys became soft-spoken and serious, often talking about their passions or future dreams in a way that would likely elicit mocking and teasing if witnessed by their classmates. Whether it was the relative formality of the “interview,” the privacy of the conversation, or the need that these boys, just like other students, felt to have “an adult to talk to” (Eckert 1989, 34), within this context they seemed to treat me primarily as a friendly, trustworthy adult. Their demeanour was respectful, as noted in my field notes:

4/29/04. Interview Shu-ming/electronics. At lunch. He was completely different from when he sits in class. Polite, spoke slowly, didn’t eat while talking, then when finished, sat with his hands on his lap, pretty formal.

Similarly, J. R., the main participant in the conversation cited above, spent his interview in serious conversation. At one point, he told me that he had been recruited from junior high school by a prestigious high school to play baseball, but ended up transferring to Sunrise because of bullying:

J. R.: The others also had to pay tuition, and I didn’t. So they were upset, and they beat me up. So in the end I just quit.

D: And how long did you study there for?

J. R.: Only two weeks, and then I came here. I had no choice.

D: So they beat you up every day?

J. R.: Yeah

D: And why did you come to Sunrise? You could have gone to a sports school?

J. R.: At the time I wasn’t thinking very clearly, you know. I just didn’t like to fight.

It seems that in the classroom, the boys treated me as a peer as part of performing a group identity that centred around masculinity, unrestrained behaviour, toughness, mutual chaffing, and the use of profanity. The successful assertion of this identity required that no exceptions be made for me, especially since I presented myself as “one of them.” However,

individual interviews revealed that my status as an older, foreign researcher was not permanently erased by our group interaction, and in these one-on-one contexts emerged as primary. Here the boys were no longer performing the group identity and co-opting me into that performance. Instead, they presented themselves as young men with worries and dreams. Our relationship dynamic shifted completely.

In light of these observations, I began to ponder the implications of joining the boys in activities that involved risky or socially stigmatized behaviour. I was never witness to anything illegal such as drug use, but our outings included cigarette smoking and drinking. In addition, on each occasion I was the only female present. While this was self-explanatory in the classroom context, I was very aware of the questioning stares I received from passers-by, or even from male participants from outside the Sunrise community. The latter would sometimes want to take pictures with me on their phones, or ask me for my phone number. My gender became the most salient aspect of my identity, especially since I did not look much older than twenty. This sexualized role contradicted the in-group status I had with the boys, and had the potential to undermine their trust in me as an adult to talk to. At the very least, I felt that my reaction to being positioned as a “girl” one can “hit on” was crucial in maintaining my legitimacy as both a “peer” and an adult. Therefore, in these out-of-school contexts I did not engage in any provocative exchanges, and sought to interact mainly with the boys from Sunrise.

For similar reasons, I did not feel comfortable when Sunrise students from other classes saw me with the electronics boys outside of school. The boys were considered the “gangsters” of the school, and being seen in a posse of ten scooters, seated on the back of one of them, with the boys swearing, spitting and smoking, associated me with this group much more intimately than simply “observing” their classroom did. As a result, when challenged with “I saw you with those guys from over there, the electronics class, the other day” by a college-preparatory student, I always explained that for my research I had to gather all kinds of data. This was the best response I could think of, although it also prompts ethical question marks. On one hand, it calls into question my loyalties—if I am indeed in the electronics boys’ in-group, then my implicit acceptance of other students’ negative stereotypes of them constitutes a betrayal. It also reinforces negative stereotypes of vocational students. On the other hand, however, according to local norms espoused by non-vocational students, an educated foreign woman would not actively socialize with the electronics boys outside the remit of her research. Openly challenging these norms with adolescents seemed inappropriate, given my status as an

outsider. I never found a satisfactory resolution to these contradictions, and uneasily accepted that I had to live with them. My work with the electronics students illustrates, however, that the totality of the researcher's behaviour—her dress, her choice of words and jokes, who she hangs out with—has an impact on the researched. It will be interpreted differently by different participants, and requires numerous management strategies. In addition, when the researched are adolescents, old enough to be friends with the researcher and to engage in adult activities, but not yet adults themselves, the researcher has an increased responsibility to reflect on the implications of her actions and everyday choices.

Conclusion

As the above account of my fieldwork experiences demonstrates, there are no easy answers to dilemmas concerning researcher identity and positionality, and the resulting power relationships between the adult fieldworker and young participants. Because of the many possible forms that such field relationships may take, and because of the variability of the specific socio-cultural contexts in which they develop, most researchers are likely to encounter situations they could not have predicted. On-the-spot judgments about ethical conduct are thus unavoidable, and greater access to accounts of other scholars' experiences and dilemmas may be the best preparation for making such judgment calls. Existing literature in sociolinguistics and linguistic anthropology does not venture into researchers' impact on child and adolescent participants beyond the scope of the research project, even though some authors have noted that such impact can be significant and should not be ignored (Eckert 1989; Mendoza-Denton 2008).

Sociolinguists and linguistic anthropologists who choose to study adolescent language use, identity and culture are likely to find themselves encouraged into befriending their participants, becoming part of their group or at least accepted as its "honorary" members. This is seen as necessary if one is to gain access to the shared knowledge produced by adolescent communities, and it is not much different from how an anthropologist approaches any community to be studied. Power imbalances also exist in contexts that are not focused on children; for example, between researchers and indigenous communities speaking endangered languages, or bilingual immigrant communities. Rectifying these imbalances through empowering research and knowledge-sharing has been discussed extensively in the literature (e.g. Labov 1982; Cameron *et al.* 1992; Paulston 1997). However, not much is said about power

imbalances between researchers and young participants, even though children and adolescents present a unique population, because as an adult the researcher always has a certain moral responsibility towards children that they do not have towards other adults. This responsibility unquestionably demands ensuring children's safety, but beyond that it also encompasses being accountable for the influence that one may have on a child more broadly. For example, "friending" young research participants on Facebook if our Facebook page featured photos of us inebriated (or worse) at a questionable establishment would likely be judged as inappropriate by our colleagues, even if it could render fascinating data on teenage computer-mediated communication. This example may seem relatively clear-cut, but many more situations in the field are riddled with nuances and contradictions that turn ethical decision-making into a moral struggle. It is, however, a struggle that cannot be escaped, because our status as adults always takes precedence over our goals as researchers when we become involved in the lives of children. In this chapter, I have sought to emphasize the need for awareness and self-reflection when working with children and adolescents, and argued for the importance of including this aspect of fieldwork in linguistic literature.

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CHAPTER NINE

EXPLOITATION VERSUS “GOING BACK”
TO THE FIELD:
THE ETHICS OF DOING PARTICIPATORY
RESEARCH IN INDIA’S URBAN SLUMS

YUTAKA SATO

Introduction

Participatory research, or participatory action research, has been consolidated as an applied method of enquiry in much of the anthropological and sociological practice in international development. It has emerged as a critique to the established methods of social research which are scientific but devoid of the sensitivity to look at how fieldwork as power of knowledge can exploit the researched and fashion exclusive authority over their representation from the eyes of Western researchers (Mohan 2001, 155). The starting point of participatory research is to therefore reject the assumption that experts know best what creates the space for assessment of local knowledge accessed (Mohan & Stokke 2000, 252).

Although the methodology is tailored to access detailed information on the day-to-day hardship that the poor face, as well as enable them to take over their own development, participatory research has been under attack by its critics (Mohan & Stokke 2000; Mosse 2005). One such criticism points out that participatory research is so lauded that policymakers and practitioners take it as a functional necessity to document their “success stories” and attract funding that can improve their project management (Moss 2005). Juxtaposing the purported mission of participatory research as a tool for empowering local people with a means of organisational management is fundamentally at odds with research ethics, which are “determined by the extent to which the research takes the participants’

needs and concerns into account” (Scheyvens, Nowak & Scheyvens 2003, 140). Ethical turbulence of this sort also applies to researchers who, regardless of geographical fields, investigate issues of social injustice with the marginalised but that are in need of funding to continue doing fieldwork (Cloke *et al.* 2000).

In this chapter, I aim to explore the ethical dilemmas of doing participatory research by drawing on my own experience in working with a local non-governmental organisation (NGO) in the slums of Ahmedabad, India. In particular, I focus on decisions that not only the researcher and researched, but also a range of collaborating agencies such as NGOs and funding bodies make in negotiating field research. It is my contention that the ethical codes of conduct for participatory research are shaped by the institutional hierarchy of international development. Since our methods of enquiry were designed by the World Bank, this makes a good case study to test how ostensibly a reflexive practice of participatory research has been re-authorised not only by aid agencies that influence the action of Southern NGOs, but by Northern academia that frames the ethical conduct of researchers. How such re-authorisation determines the nature of fieldwork on or with the poor and whether or not their participation in the research meets their expectation is a crucial ethical question (Mosse 2005). More importantly, how we respond to the claims that informants make in contesting the authority we create in the name of participatory fieldwork must be carefully analysed (Cloke *et al.* 2000). I claim that “going back” to the field has some limited potential of transforming the balance of power between the researchers and researched into a more equitable relationship (Rupp & Taylor 2011, 484).

The organisation of this chapter is as follows. Firstly, I explore the background of how participatory research has been popularised among practitioners and scholars in international development, considering the growing requirement for research ethics in both the development sector and Northern academia. Secondly, I analyse the process by which participatory research that aid agencies tailored for assessment and evaluation of poverty across the global South took shape in my collaborating NGO. Thirdly, I examine the ethical limitations of our participatory research to shunning exploitation by the researcher. Fourthly, I identify the agency which the participants exercised in the course of our research in a way that was highly critical of our “empowering” missions. Fifthly, I describe how I opted for “going back” to overcome the ethical constraints of participatory research.

The Transnational Production of Instrumental Ethics in Development Research

Ethnography under the conditions of globalisation, or “global ethnography” (Burawoy 2000; Gille & Ó Riain 2002), requires an analysis of the multilayered relations between the researcher and the researched, which are conditioned by the effects of major events and structured in the large systems of political economy (Marcus 1995). Global ethnography is not merely a method of fieldwork; it seeks to analyse the social by locating the researcher in the transnational space of the social relations being analysed (Gille & Ó Riain 2002; Chong 2007). Not only do these relations connect between the sites of the researcher and researched, but are constantly shaped by external forces under the global processes (Burawoy 2000, 5). Such external forces include academia and aid agencies in the global North which often determine what constitutes “the ethical” in ethnographical practice in the global South.

In this regard, David Mosse (2005, 8) asserts that ethnography concerning development needs to explore not “whether” but “how” development projects work, and not whether a project succeeds, but how “success” is produced. Success in a development project depends on the stabilisation of a particular interpretation but such a policy model fails to examine the way in which policy interpretations are produced and sustained socially. Development projects need what Mosse calls “interpretive communities,” which are obliged to enrol a range of supporting actors with reasons to “participate in the established order as if its representations were reality” (*Ibid.*, 8).

For the success of a development project to be interpreted, some dominant methods of social research become essential for evaluation. Participatory research, which was popularised by applied anthropologist Robert Chambers (1992) in the field of development studies, has been adopted by many Southern NGOs and aid agencies because of its egalitarian orientation. Its main thrust is that the mode of these methods is of sharing with the information owned, analysed and used by the local people which would empower them, while the outsiders’ role remains as being facilitators (*Ibid.*, pp.13–15).

Significant in the function of participatory research is the transnationalisation of knowledge pertaining to the methods and ethics of fieldwork, mediated through the growing coalition between aid agencies and grassroots NGOs. Localities in the global south have become sites of global ethnography (Gille & Ó Riain 2002). Similarly, they are now the objects of social reform in which multifaceted power is entangled across

actors and their audiences, who translate the keywords of development into public policies for their pragmatic purposes. Hence, it becomes clear that participatory research now constitutes an “instrument” of programme evaluation. It in turns entails the risk of reproducing power imbalances between researchers and informants, a key ethical concern of development research (Scheyvens, Nowak & Scheyvens 2003, 149).

It is not aid agencies and NGOs alone that constitute the interpretive community by virtue of participatory research. Fieldworkers from the global North, who often rely on grassroots NGOs as their gatekeepers, equally reproduce the authority of participatory research. They are increasingly under pressure to produce data for publication within a short period of time, while simultaneously meeting the requirement for research ethics. According to the Economic and Social Research Council (ESRC 2010, 40), research ethics refer to the “moral principles guiding research, from its inception through to completion and publication of results and beyond.” Since the publication of *Research Ethics Framework* (ESRC2005), the ESRC, a principal funding body of the British government, has made it mandatory for any research it funds to abide by a number of rules, such as proxy consent, that are intended to secure the best interests of vulnerable populations (*Ibid.*, 24). During peer review, referees and other assessors are asked to comment on the ethics assessment in the proposal; if they disagree with the proposed approach to ethics issues, this could lead to the rejection of a proposal (*Ibid.*, 11). As with Sriram (2009, 58), I treat the ESRC framework as the baseline ethical requirement not simply because I began my academic career in the UK, but because it has more elaborated guidelines for data collection, analysis and write-up than those of other funding bodies. For example it was only in 2005 that the Japan Society for the Promotion of Science (JSPS) made it mandatory for applicants of its doctoral and postdoctoral fellowships as well as grants-in-aid to fill in the research ethics checklist.

Fieldwork aided by participatory methods and visual methods is thus favoured when one applies for a research grant (Cancian 1993). My postdoctoral research at a British university convinced me of the merit of including participatory and visual methods in a research proposal to be in an advanced position to bid for funding. Not only are these considered “reflexive” but they also ensure rapidity and effectiveness in doing fieldwork. The latter is particularly important for doctoral research scholars if they submit their thesis within three to four years (Cloke *et al.* 2000). It is of no surprise, then, that the teaching of participatory research is now commonplace in development studies in the UK. The use of visual methodology is a rather recent trend. The practice of visual research to

include the subjects in a research process not only has the potential to subvert the researcher–researched relationship (Sato 2010); its moral sensitivity also gives credential to the researcher when they apply for research grants.

The political economy of global ethnography thus presents a picture of the dominance of the development industry and Northern academia over the poor in the name of participation. However, there are a number of cases in which the poor have contested the dominant mode of fieldwork in development research (Philips & Edwards 2000; Pottier 2003; Rossi 2004). The poor are not puppets of researchers whose decisions are constrained by the structure of society and culture, but those who often tactically contest the dominant codes of rules that external actors bring in. Hence, participatory research should be seen as a battlefield of knowledge (Long 2001), where the ideas and interests of aid agencies, NGOs and researchers are imposed upon local people, while they are equally subject to local people’s contestation by virtue of their aspiration for recognition and well-being (Appadurai 2004). In this context, research ethics can neither take on a universal form nor are they followed regardless of the place and circumstances in which the researcher finds themselves (May 1993, 42). It is possible to reassess the ethical conduct of ethnography by closely looking at the meaning of research participants’ contestations.

In what follows, I explore how the participatory research that I conducted with an NGO in India, which also intended to empower the informants, faced repercussions from them and what choices I made to overcome such constraints.

Instilling “Globally Standardised” Participatory Methods in NGO-led Fieldwork

As part of my PhD fieldwork, I conducted six focus group discussions with women and interviews with 32 individuals in six slums during March–May 2004. These investigations were undertaken as part of the NGO’s research project “Moving out of Poverty” (MOP). For reasons of confidentiality, I have disguised the identities of the NGO and all informants. The research aimed to understand slum dwellers’ experiences in moving into/out of poverty over the span of five to ten years as well as their subjective understanding of poverty, power and freedom. I played a role as an observer in identifying the power relations among the participants and in adding questions during the investigations. We particularly focused on the social consequences of the downward mobility among the households with retrenched workers from textile mills,

Ahmedabad's premier industry until the 1980s (Sato & Chhatrapati 2004), and the how NGOs had built the capacity of women leaders in the slums, which might mitigated their social and economic vulnerability to some degree (Sato 2008).

Beginning in December 2003, the MOP research project aimed to publish its first annual *Urban Community Report* (hereafter the *Report*). I was not directly concerned with the documentation of the *Report*, nor does my analysis represent the views expressed in it. However, explanation of the context of the MOP research project helps to understand not only the focus of these methods but, more importantly, the growing partnership between Southern NGOs and aid agencies in the production of knowledge through poverty research. The MOP research project was developed by the World Bank for its qualitative database of the *World Development Report 2000/01* (World Bank 1999, 2000) and subsequent publications (Narayan *et al.* 2000). It can be discerned from these publications that many Southern NGOs have participated in the World Bank's "pro-poor" country case studies and organised local research teams to conduct focus groups and individual interviews.

My collaborating NGO was not part of the above research projects. However, the fact that it adopted the World Bank's methodology demonstrates that the ideas and knowledge of aid agencies, which were originally the property of local people, have travelled back to the global South and underpin the approach of grassroots NGOs in working for the poor. The descriptions below are based on the NGO's project proposal and an instruction on the methodology by two programme co-ordinators in February 2004.

The NGO held a two-day training programme where a few practitioners from the Aga Khan Foundation in the UK provided training on participatory development to some of the NGO's staff. The aim of the *Report* was to bring the voices of the slums to the advocacy level and to disseminate the publication to concerned authorities, NGOs and slums for replication. While the topic of the 2004 *Report* was the MOP, it dealt with issues revolving around experiences of the neighbourhoods whose amenities had been upgraded by the city-wide slum upgrading scheme, the updated news, experiences and improvements of the slums and the efforts of municipal authorities and NGOs. The NGO sought to replicate examples of the "best practices" across the globe and the *Report* expected to:

- (1) raise greater awareness among slums, NGOs, municipal corporations and municipalities

- (2) encourage partnerships between the slums and government authorities as well as between slums, NGOs and other concerned organisations such as international donor agencies
- (3) foster sharing of the NGO’s activities
- (4) bring the voices of the slum communities to the advocacy level, and integrate lessons from other examples of slums and municipalities for replication.

The MOP project disseminated the *Report* to other NGOs and aid agencies. It was then anticipated to generate data for the partnering NGOs, which ultimately won them the Dubai International Award for Best Practices in the field of urban governance from the United Nations Human Settlement Programme (UN-Habitat) in 2006. While unravelling ongoing problems of marginality, discrimination and dependency, the project proposal focused on the “success stories” of the urban poor and emphasised the role of NGOs:

So far, there have been number [*sic*] of reports and efforts talking about poverty and the people suffering from poverty ... there seem to exist examples and case-studies of people, families and communities that have risen out of poverty ... Therefore, an attempt has been made, in this publication to not write about the people in poverty as the focal theme but instead to write about those who have been in poverty, faced the challenge of living in slums and have eventually with efforts, moved out of poverty.

Although the research has its roots in the MOP research project by the World Bank, which seeks “pro-poor economic growth” (Narayan & Petesch 2007, 32), it proved to be a useful source of data for my sociological enquiry. The focus group and individual interviews generated ample evidence of the inequalities between gender and status groups in the slums. The quasi-sociological variables such as power and social cohesion considered by the project identified a number of crucial issues on the politics of participatory development and research in the slums. In this case, my study identified some institutional constraints that reproduced the poverty and exclusion among the slum dwellers. Therefore, they were fundamentally at odds with the intentions of the MOP research project to find cases of upward mobility among them (Narayan & Petesch 2007).

It must be noted that the director of the NGO appreciated these findings from his commitment to social justice. Even more so, the NGO was compelled to terminate its programme in the slums of Ahmedabad by 2008 because it attempted to reconcile Hindus and Muslims in some slums after the communal violence which broke out in 2002. The government of Gujarat, ruled by the right-wing, Hindu-dominated Bharatya Janata Party, suspended its funds to the NGO.

Nevertheless, my day-to-day observation of work at the NGO suggests that it identified the MOP research project as an opportunity to disseminate its achievement to aid agencies, local government bodies and other concerned NGOs. In this context, the NGO had to comply with the programmatic need to write up the research and findings (Mehta 2008, 242). The following sections describe the repercussions that I faced in the course of my fieldwork with the NGO, and the ways in which I tried to overcome the uneasy relationship with the informants.

Dynamics of Power and the Ethical Limitations of Participatory Research

My fieldwork posed two methodological issues relating to my position as a young, foreign researcher. First, textbook views suggest that qualitative research, participatory research in particular, is an organised event where the researcher can attempt the restructuring of power of the informants (Scheyvens, Scheyvens & Murray 2003). Second, the political economy of local knowledge situates the researched–researcher relations in the context of institutional hierarchies in development (Thapar-Björkert & Henry 2004). Not only did my status as a Japanese PhD research scholar at a premier Indian university indicate the structured inequality, but the mainstream development discourse and practice that the NGO and I adopted for investigation might lead to the exclusion of certain sections within the slums. In this regard, the ethnography of development has long since called for an understanding of the “positionality” of the researcher by situating their production of knowledge about other people, placing it within the framework of international relations, and analysing the political and historical relations of power and systems of values which shape representations (Mosse 2005, 11). These multilayered relationships of knowledge, I found, were critical to understanding how research data were generated, collected and analysed.

The central challenge in this regard was to ensure that the methods employed in our research were sensitive to the voices of the researched. Proponents have stressed the potential of such tools in collectivising the poor that revolve around rights of access to housing, municipal health and educational facilities, subsidised food and so on (Chatterji 2005, 198–9). Appadurai (2001, 35), for example, emphasises this point by drawing on the experience of the Housing Alliance, a federation of grassroots NGOs that work with slum dwellers in Mumbai:

[t]he creation and use of self-surveys are a powerful tool in the internal practice of democracy, since the principal form of evidence used by the Alliance to support slum dwellers’ claims to space is the testimony of neighbours, as opposed to forms of documentation such as rent receipts, ration cards, electricity meters and other civic insignia of occupancy that can be used by the more securely housed classes in the city.

He sees censuses as the most salient modern technology to govern the citizens, and they exclude “invisible citizens,” i.e. the urban poor. These self-surveys have generated the internal practice of democracy against the politics of “numeration” as a modern technology of the nation state (*Ibid.*, 34–35).

Participatory research can thus become a tool of social movements. It represents local knowledge as a means of generating reliable data on local subjects and neighbourhoods, within which they can be recognised and organised. Appadurai (1996, 181) asserts that by virtue of its local teleology and ethos, local knowledge is not only local in itself but for itself. However, he does not fully examine the internal dynamics of power in the course of research. My research areas, like many other urban slums in India, are sharply divided along the lines of gender, caste and regional origin. Without appraising such a multi-layered social order of the slums, the term “community” was frequently used among the NGO staff to refer to a slum settlement or, even worse, a single focus group. Similarly, assembling focus group participants was insurmountable without the help of the leaders of each settlement. However, although my study focused on the gendered dimensions of urban poverty, two of the six research areas had only male leaders. Our dependence on those “gatekeepers” never encouraged women who belonged to less influential groups within the slum. Some of them appeared less articulate or confident (Gibbs 1997) and remained silent during the discussions.

Unintended Consequences of Participatory Research— Repercussions from Slum Dwellers

The hindrances to the participatory research led me to clarify the relationship between the slum dwellers and the NGOs during personal visits. My visits revealed significant discrepancies between the data that we expected the informants to provide and the realities they avoided expressing during our formal investigations. These ethical dilemmas point to “reflexivity” in doing ethnography. Reflexivity, which refers to the monitoring, contestation and revision of expert knowledge, has become

central to conducting research in “late” modernity, where authority in professional knowledge and conduct is losing ground (Cant & Sharma 1998, 245). In development research, the authority of expert knowledge is especially contested when the intimacy between the researcher and researched allows the latter to express their scepticism of the fieldwork in view of what material gains it ensures. Reflexivity in this sense calls for a conscious analytical scrutiny of the self of those who were previously constructed as the researcher (Cloke *et al.* 2000, 136). Following this fashion, I consider the social relations of participatory research and its impact on the data collected.

Indeed, in some cases, eliciting sensitive information on the difficulty in communicating with NGOs was insurmountable in the presence of research assistants. We were rather expected to collect data on the positive aspects of the activities by the NGO and its partnering organisations. Similarly, I was constantly encouraged to describe the positive impact of the NGOs on slum dwellers in a fieldwork report which I was to submit to the NGO (cf. Aldred 2008, 896). The focus groups in three slums where the NGOs had principally been engaged in community development work were all aware of this. During discussions on the evaluation of institutions in these areas, they unanimously ranked the NGO as the best by cynically appraising it. The scenes were in conformity with what James Scott (1985, 245) called “avoidance protest,” i.e. the cautious resistance for which the poor opt in everyday life, avoiding the risk of direct confrontation. Thus, with my wife I made frequent visits to these areas with which we had become familiar, owing to my work with the NGO. Her presence was crucial in the light of the advantages of a married foreign female researcher in getting access to both women and men (Panini 1991, 5–6; Wolf 1996, 9). The challenge that we faced was rather institutional. My participation in the NGO’s research project was often viewed unfavourably by some informants. Our personal visits made us sensitive to the artful strategies that poor people use to construct their responses to researchers and demonstrated the importance of reflexivity in data gathering.

My encounter with the leader of the Ashapuri Nagar slum offers an important insight into the institutional positionality of development research and how a reflexive approach ensured that its consequences on the data collected could be analysed and assessed. It must be mentioned that the NGO has endowed him with skills and confidence. It was even more so because he has stayed unemployed. He was made redundant from the textile mill where he had served many years. Hence, aside from the loss of income, the loss of honour and prestige also characterised his

poverty. On one occasion, I had the opportunity to arrange a site visit of Japanese students to Ashapuri Nagar with the NGO. They were visiting Ahmedabad on an exposure programme organised by a Japanese human rights group in July 2004. Both the NGO and I hoped that their visit would enhance the leader’s achievement in building solidarity among the residents and in tackling their problems through negotiations with local government officials. That is to say, I was anxious that their replication of my role as a “story gatherer” with a morbid curiosity might hurt the residents (Cloke *et al.* 2000, 146). Fortunately, the leader stated that they: “felt honoured to show them the development of our area. Those Japanese students were taking photos and shooting with a video camera around this area.”

However, he was sceptical about using translators for conducting interviews:

Those who visit us interview in English, but who else here can communicate with them? ... They understand whatever problems we have through what the staff [of the NGO] translate. Ultimately, they don’t understand what our problems actually are ... What kind of information do they get through the NGO staff after all? Isn’t it something that the NGO has offered us excellent schemes? ... Don’t you think we deserve return from the NGO rather than offering them a lot? Whenever the NGO runs any programme, we get a long interview and have to offer them a lot [water, tea and snacks], even if we know we’re not going to benefit. Why do we have to do all this? Those researchers say they’ve come to improve this area but nothing has happened!

During our informal talk, his wife came out of the house and shouted at him: “Your chapattis have gone cold! What on earth are you wasting time here without having dinner?” Apparently, she was equally tired of her slum being showcased. However, it is wrong to say that their sense of being exploited makes them indifferent to fieldwork by outsiders. The leader told me that he would provide different answers had we visited with the NGO: “My answers are always the same to everyone—that the NGO has provided a lot to us and that the area has improved.” However, he does not like to see the NGO’s staff change the answers that he has given to the researcher. For this reason, he once told a member of staff that he would stop the NGO from visiting his area even if the NGO were to introduce a new scheme. An impact assessment of the programmes of the NGO and its partnering organisations was part of the focus group discussions. However, it was fundamentally at odds to an objective and critical appraisal of the social relations of poverty in the slums (Phillips & Edwards 2000, 64).

It was inevitable for the NGO's staff to produce data for their work performance. For this, effective organisation of the focus groups was their prime concern. The focus group of this area had a woman who was notorious among them for her participation in tea and snacks, and not for discussions. In fact, she enjoyed conversation with my wife together with other female neighbours. On one occasion, she was deeply disappointed with us as we did not notice her talking to my wife during heated discussions. She suddenly left the venue and refused to speak to us. We broke the ice after the group discussion by approaching her and picking up the dry fruits from her unwashed hands. Our efforts were appreciated among some residents of this area. After the completion of my research, two girls—one of whom later joined my fieldwork as an assistant—invited us to their joint wedding held in May 2004, which we were unable to attend. It disappointed them and their neighbours. These cases exemplify how researched–researcher relationships remain fragile. Being sensitive to the way in which informants perceive their relationship to the researcher is critical if negative consequences are to be avoided.

In other areas I observed deep-rooted scepticism among slum dwellers in their views towards fieldwork, both covertly and overtly. There were three instances of ethical turbulence worth mentioning here, though not all of them arose from my participatory research. The first instance occurred in February 2003 when I was conducting a survey with my collaborating NGO in a slum called Ghanshyam Nagar. The moment a male resident saw us take interviews, he scolded me. He was a volunteer worker of a charitable Hindu organisation who played a part in distributing leftovers from wedding ceremonies to children of the area. Offering me the leftovers, he lamented that no researcher and activist had brought any benefits to the area, whereas his contribution was immense.

The second and the third instances of ethical turbulence occurred in a slum called Babalavlavi Nagar. The slum had already been studied by some researchers and social activists who concerned the possible displacement of the entire neighbourhood due to the Sabarmati Riverfront Development, which is one of the flagship schemes in Ahmedabad. A women's NGO arranged a group interview with around ten female residents for me in September 2010. My wife accompanied me during this visit. As individual interviewers we faced some ethical difficulties in explaining the purpose and value of our research accurately and unambiguously (Cloke 2000, 139). At the end of the interview, one of them asked us: “Sir, Madam, now that we've described our problems to you, tell us how you can support us.” The rest of them followed her, saying that they had joined our group interview bearing the hot weather

after their day’s hard labour. The whole group turned out to be aggressive. We feared that we would be thwarted in our attempt to press for narratives unless we provided them with well thought-out answers. We answered honestly: “We’re not politicians but academics only and our responsibility is to let people concerned your experience and situation. We understand that they’re ill-informed of your current problems. We want to record what problems you’ve faced and share our findings with them.” Our claim seemed to have convinced them. We left the venue wondering how we might revisit the area without damaging the “thin” trust that we had managed to build on our first visit.

After this visit, I took further group interviews with men and women in March 2011 and a questionnaire survey in March 2012 with a team of researchers and students from a local university. I faced no outright repercussions during these visits, probably because they were accompanied by local élites and not my wife. It does not mean, however, that the residents were comfortable with collecting data from them. For instance, during the questionnaire survey, one female respondent recounted: “Immediately after that survey [on the transport mobility of slum dwellers which my Indian colleagues conducted in October 2011] was done here, the bus fare hiked double. If I respond to your questions, the fare might rise again.”

It is important to note that the aforementioned incidences occurred in the slums where NGOs had been intervened on a more substantial scale than other areas. To be sure, their external intervention either through development work or participatory research has inculcated some slum dwellers with the “capacity to aspire” (Appadurai 2004), but it is not the kind of empowerment that those NGOs intended to build.

“Going Back” as a Partial Solution to Overcome Ethical Dilemmas of NGO-Led Research

“Can you imagine you will keep coming back to the same slums and
the same community after 20 or 30 years?
Are you confident of maintaining your friendship with the residents here?”
(Rutul Joshi, CEPT University)

The episodes above suggest that the urban poor would normally expect not only material changes but also recognition from outsiders. Although my collaborating NGO stressed the pedagogical potential of the MOP research project, the “one-off” event that we created in each slum was far less effective in inculcating our informants with the sense of “participating”

in our project. There were two major constraints in dismantling the balance of power among us.

One is the institutional hierarchy of many NGOs in India. It is generally believed that work experience at an NGO, especially when it is renowned globally, can enhance one's own career. In this respect, I came across some staff at a few NGOs in Ahmedabad who aspired to work in developed countries and identified their current job as a "stepping stone." With fluency in English and higher educational qualifications, they tended to occupy higher ranks in their NGOs with fewer duties to visit their project sites. On the other hand, those who are assigned work in the field occupy the lowest status in their NGO's rank-and-file. In the course of my stay in Ahmedabad during 1997, 2003–5 and 2010–12, I witnessed the increasing number of such "field staff" at these NGOs. In some cases, they hold a Bachelor's degree but have little command of English, partly due to their lower-class background. In effect, they are normally assigned the "manual" work of visiting slums for government-contracted surveys, organising the residents for community development, and so on. They are at the forefront of scaling up their NGOs which seek to build further collaboration with aid agencies and the local government. Foreign researchers working with such an NGO, as I did, rely on those field staff's help. Ironically, they tend to exchange ideas and build friendship more with higher-ranked staff who have fewer duties to visit the field.

The other is the creation of rapport with the researched. As demonstrated earlier on, my interaction with the slum residents remained formal so long as I was collecting data with my collaborating NGO. While my assistants from the NGO were extremely motivated in organising the focus groups, with note taking and translating as their duties, they had little interest in the topics that we were investigating during the MOP research project. They were either secondary school or college graduates. In the latter case, all of them had studied commerce, which is the most popular subject in the region that has historically been dominated by entrepreneurs. Therefore, I decided to revisit a few of my research areas with my wife. Her fluency in Hindi made it easy for us to access both middle-aged and younger women with whom I could have never had any conversation had I visited alone. Moreover, as Srinivas (2002, 26) stresses, the husband–wife team of ethnographers is likely to be more successful than single ethnographers. Indeed, many women asked us where we met each other, how we got married and what type of family we wanted to establish.

These two cases suggest the need to combine participatory research with other methods, particularly participant observation. More importantly, my personal visits to a few slums helped me unravel the unmet desire and

failed negotiation of the poor with external agencies such as NGOs. I found that the slum dwellers did not normally expect intimacy with NGO workers with whom they have a vertical “donor–recipient” relationship. Recalling the ESRC’s (2010) *Framework for Research Ethics*, securing the best interests of vulnerable populations calls for recognising the need to establish one-to-one relationships of equality and mutual respect with the poor, and to treat them as individuals rather than merely research “subjects.” It was only towards the end of my doctoral fieldwork in 2005 that I acquired a working command of spoken Hindi for carrying out participant observation. I was already at the write-up stage of my thesis by that time and I was set to embark on my postdoctoral research outside India thereafter.

After a long halt, I returned to Ahmedabad in 2010 on a grant-in-aid that I had obtained from the JSPS and launched a new research project which still continues. My grant and my status as a university lecturer still position me as an “embedded” outsider in the light of the difference between my powerful and affluent lifestyle and the plight of my informants (Cloke *et al.* 2000, 144). However, my new status has allowed me to step out of the institutional hierarchies that existed between the NGO and my informants during our MOP research in many ways.

Firstly, it has enabled me to seek affiliation to a local university. As a visiting fellow, I enjoy assistance from young, esteemed researchers in urban planning and housing studies. Nevertheless, no matter how they are trained to be “neutral” observers, informants’ perceptions of assistants’ bias, or associations of assistants with the middle-class, might hinder the development of cognitive and emotional trust (Norman 2009, 81).

Secondly, to reduce such a cognitive divide, I employed one of the daughters of the aforementioned leaders in Ashapuri Nagar for participatory research in March 2011 and a questionnaire survey in March 2012. Employing only one of many in the slums may not be in tandem with the spirit of ethical concerns of participatory research, which stress the involvement of the “local community” (Scheyvens, Nowak & Scheyvens 2003, 141). My “experiment” was indeed my conscious performance of “giving back” to my informants (Rupp & Taylor 2011). Nevertheless, it did solidify my friendship with her family and some other informants. For example, as Rupp & Taylor (*ibid.*, 493) maintain, my frequent returns to the field after employing her have raised some awareness among the researched of their vulnerability. Upon my personal visit to her family in December 2011, her mother and elder sister appreciated my equal partnership with my wife, saying: “Men think that their wife is a servant. She’s supposed to do all the work in our culture which should be

improved.” They then quickly added: “Not all men are the same, but most men get married because they want someone to do all their work.”

Aside from fieldwork with my assistants, I have continued revisiting my research areas on my own, so as to avoid ending up as a mere “story gatherer.” My effort has borne fruit to the extent that some informants have invited me for lunch and dinner, and a few of them are now willing to accommodate me on my next visit. However, the web of my intimate relationship has not extended beyond the gatekeepers and their close neighbours. Regrettably, I am unlikely to do so, due to the time constraints of my fieldwork. One possible solution in this regard is to present a summary of my research findings in each research area. Only by doing so shall I be able to “give back” to the majority of my informants, and thus avoid exploitation (Cloke *et al.* 2000, 135).

Conclusions

The main point of this chapter has been to emphasise that participatory research, despite its moral sensitivity in the process of data collection and its potential to subvert the researcher–researched relations, is not free from ethical dilemmas due to the clash of stakes between the various actors involved. It has identified the following issues.

Firstly, there is a growing pressure on the part of young researchers in the global North for both meeting ethical requirements at the stage of fieldwork and data analysis, and for publication in a time-bound manner. With their proximity to the poor, grassroots NGOs play a vital role in assisting researchers who are to meet both the requirement of research ethics and the target of publication plans. The emerging transnational coalition of fieldwork between aid agencies, grassroots NGOs and researchers has contributed to re-authorising participatory research for their own gains.

Secondly, my collaboration with the NGO revealed some weaknesses in doing fieldwork with strong NGO involvement and thus raises some important issues for future research. This reminds us of the need to be aware of our positionality vis-à-vis the collaborating NGOs. As Mehta (2008, 249) points out, responding to NGOs’ requests for “success stories” and “policy impact” do not encourage us to appraise the nuanced versions of change. As some of my informants demonstrated, participatory research is not merely an effective technique to empower the researched through their participation in the research process. It rather offers an arena in which the participants address their problems, express their unmet desires from external agencies and negotiate with the researcher and NGOs. By

this token, participatory research as an organised social event may offer ample evidence of the hope and despair of the researched. It thus has the potential to empower the researched but normally not in a way that NGOs want them to be.

Thirdly, my short-term research with the NGO resulted in our reliance on the gatekeepers in each slum and further created some discomfort among our informants. Despite such an uneasy relationship, some informants showed awareness of the issue of truth and deception as a component of ethical responsibilities (Scheyvens, Nowak & Scheyvens 2003, 158–61). This “bottom-up” appraisal of the ethical practice of fieldwork by the researched, I would argue, deserves more attention in the study of research ethics. My frequent “going back” to the field and the employment of a slum-woman as my assistant was a critical choice that I made to understand the agency that the slum dwellers exercise in responding to outsiders’ fieldwork. However, such attempts have not been enough for me to step out of my role of a “story gatherer”. I currently plan to disseminate the data through holding workshops in my research areas so as to “give back” to my informants and avoid the risk of creating over rapport with the gate keepers.

Briefly, the short-term commitment of researchers has become the norm and knowledge on development is exploited for their career. As a consequence, fieldwork as a “professional” conduct becomes meaningless to the research subjects due to the lack of regular machinery in both academic and development organisations for a review of possible “complaints” from vulnerable research subjects (Cant & Sharma 1998, 260). It is my contention that one should focus on developing an individual rapport and a less exploitative relationship with the informants when conducting research. Establishing such a mutual relationship is so time-consuming that it calls for greater commitment by the researcher to the researched through frequent visits and participant observation.

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EPILOGUE

PROMOTING AWARENESS ON ETHICAL ISSUES IN SOCIAL SCIENCES RESEARCH

ISABELLA PAOLETTI

The studies presented in this collection document practices related to procedural ethics in a variety of countries, but are primarily focussed on actual ethical problems researchers have encountered during research activities (Blee & Currier 2011; Guillemin & Gillam 2004) in the course of data collection, in the implementation of ethical procedures and during transcription and analysis of data. With a wealth of details, some studies articulate the complexities involved in complying with procedures of legislation on research participants' protection, obtaining informed consent from research participants and in anonymizing data. But, in fact, many ethical problems described in these essays unexpectedly emerged during research work and were left unaddressed by procedural ethics (Guillemin & Gillam 2004). The researcher's responsibilities towards informants were discussed by various authors, such as: the difficulties in responding to the request of help from informants, the risk of retraumatization, the necessity felt by researchers of giving something back to participants, etc. All the chapters in this collection include the descriptions of researchers' moral reasoning about a great variety of ethical issues emerging in actual situations, in relation to the conduct of research in different disciplinary areas, such as: sociology, gerontology, sociolinguistics, communication studies and anthropology. Here are some of the main questions the researchers asked themselves:

Costa: "would a simple name replacement be enough to safeguard the subject anonymity in a middle-sized town like the one where we collected the data? Which side to choose? And how to decide?" (p. 36)

São José and Teixeira: “Should we obtain an initial informed consent only from the elders or also from their caregivers?” (p. 52)

“Should we report negligence against an elder, or should we preserve his/her autonomy?” (p. 57)

Lester & Barouch: “Was it sufficient to simply ask her [the child] one time whether I could make observations and record her therapy sessions or did I need to continue to ask her each time I saw her? I was troubled and questioned whether ‘mm-hm’ or a single ‘Y-E-S’ truly indicated assent to participate. What indicated ‘true’ assent?” (p. 70)

Gil *et al.*: “How should the interviewer proceed when faced with a victim experiencing anxiety and psychological distress: should s/he continue, pause, change the questions or stop the administration of the questionnaire altogether?” (p. 102)

Anton: “An ethical issue arising during the interviews we conducted was related to the impossibility to respond with help to all the needs addressed by informants” (p. 123).

Kosygina: “Situations of informal communications and observations are unplanned, and it is not always possible to inform people that they become part of the research. Does this involvement violate people’s privacy? What ethical principles should guide a researcher in the situation of informal observation or conversation?” (p. 142)

Baran: “What would it have meant in my specific context, as a 29-year-old Caucasian American female doctoral candidate and researcher, to smoke cigarettes in front of 16-to-18-year-old Taiwanese boys studying electronic repairs in a low-ranking high school in the industrial suburbs of a busy Asian metropolis? And more specifically, what would this have meant not for my research project, but for the boys?” (p. 155)

Sato: “In development research, the authority of expert knowledge is especially contested when the intimacy between the researcher and researched allows the latter to express their scepticism of the fieldwork in view of what material gains it ensures” (p. 186). In other words, how to be loyal to participants’ knowledge? How to give them something back and not be exploitative towards them?

Personally, I can endorse most of the decisions that were made by the different authors in relation to the ethical problems they faced; nevertheless I have problems with some of them and probably some of the readers may disagree as well. But should we necessarily find an agreement? I think the main point emerging from the studies in this collection, as a whole, is that the ethical dimension is intrinsically an individual dimension, a personal, social and moral responsibility within one's own research profession. Moral reasoning belongs to the individual and cannot be extrinsically defined. What is right or wrong ethically is established within one's consciousness; it cannot be defined by law, decided by a democratic consultation, nor can "objective" criteria be found to reach an agreement. Above all, ethical issues are complex and ingrained in specific situations (Kohler Riessman & Mattingly 2005), in networks of relationships (Etherington 2007) with power imbalance (Sultana 2007), in the universe of meanings and values, and in cultural forms (Cannella & Lincoln 2007; Christians 2007). These essays document researchers' practical moral reasoning in carrying out their research activities and in complying with the relevant legislation in relation to protecting research participants. Practices of ethics are identified and made describable; they are made the object of empirical documentation.

The recent literature documenting ethical issues in research (Barton 2011; Blee & Currier 2011; Clark & Sharf 2007; Cloke *et al.* 2000; Conrad 2006; Currier 2011; Czymoniewicz-Klippel *et al.* 2010; Dougherty & Atkinson 2006; Einwohner 2011; Ellis 2007; Etherington 2007; González-López 2011; Goodwin *et al.* 2003; Guillemin & Gillan 2004; Hurdley 2010; Irwin 2006; Kohler Riessman & Mattingly 2005; Medford 2006; Poulos 2008; Rupp & Taylor 2011; Stein 2010; Sultana 2007; Wood 2006; Wyatt 2006) and the studies in this collection have highlighted an insufficiency, a gap, in relation to procedural ethics. Procedural ethics involves the process of seeking formal approval for human subject research from an ethical and scientific oversight group (Guillemin & Gillam 2004) prior to the beginning of research activities. Above all, these studies appear as an act of resistance towards bureaucratizing ethics. They highlight an irresistible uneasiness. They spell out an awkwardness, a discomfort, a thorn in relation to aspects of one's own research practices. This is what ethics is about—questions asked to one's own consciousness. It is important to point out that the ethical dimension of research activities should be clearly discerned from procedural ethics and the legislation on protection of research participants. It should be clear that complying with the law, protecting research participants, is different from dealing with ethical issues in research. The two dimensions are certainly related, but

they are not the same thing. It should also be said that ethicality of research depends inescapably on researchers' integrity. Procedural ethics, ethics committees and legislation on protection of research participants can contribute to oversight prior to the start of a project, but provide limited instruments to control what actually goes on in the field (Guillemim & Gillam 2004, 269). In the end, the ethicality of research depends on the personal integrity of researchers.

In many countries, a specific legislation aimed at protecting human participants in research has been established, together with Ethic Research Committees. In the debate recently developed on ethics committees (Boser 2007; Connolly & Reid 2007; Ells & Gutfreund 2006; Fogel, 2007; Gunsalus *et al.* 2007; Haggerty, 2004; Halse & Honey 2007; Hedgecoe 2008; Koro-Ljungberg *et al.* 2007; Lewis 2008; Lincoln 2005; Lincoln & Tierney, 2004; Mueller 2004; Patterson 2008; Pritchard 2002; Rambo 2007; Stark 2007; Swauger 2011; Taylor & Patterson 2010; Tierney & Blumberg-Corwin 2007; Tilley & Gormley 2007; Tilley *et al.* 2009; van den Hoonaard 2002), both opponents and defenders miss an important point—discerning ethics in research from legislation on the protection of research participants. It is reasonable that universities and research institutions make sure that their staff obey these laws. It is a matter of institutional self-protection, as was pointed out in the literature (Lieberman 1999, 60; Cloke *et al.* 2000, 138), but there is nothing objectionable about it. One may consider it hypocritical that some research institutions may be more worried about institutional self-defence than about actual research participants' protection, but it is certainly an institutional right and duty to ensure that the staff comply with legislation. The main problem resides in confusing ethical issues with law enforcement. The very name "Research Ethics Committees" or "Research Ethics Boards" appears problematic. For example, "Research Participants' Protection Law Committees" appears to be a more appropriate term to name these types of institutional bodies. Whatever one wants to call them, the term "ethics" should be avoided. The present review bodies should be unambiguously identified as institutional instruments organized to ensure researchers' knowledge and respect of the relevant legislation on research participants' protection. However, the functioning of such committees should be clearly discerned from researchers' awareness towards the ethical dimension of their work. For research institutions and universities involved in social sciences research, making sure that such a law is observed is an obligation, but different attention should be given to the ethical dimension of research activities.

A different type of committee could be organized, for example research ethics committees as consulting bodies, actually supporting and sustaining researchers during the development of research activities. This type of ethics committee could constitute an open space of discussion on ethical issues among colleagues. Researchers could freely consult those committees when facing ethical dilemmas during their work. Those committees could also promote empirical documentation of ethical issues, as illustrated in the chapters of this collection. In fact, if ethical decisions are ultimately established in one's own consciousness, the importance of joint reflection and discussion on ethical issues is nevertheless undeniable. Individual alertness and sensitivity towards ethical matters are unlikely to be achieved in isolation. If the ethical dimension is intrinsically subjective, in the sense that we ultimately have the responsibility to subjectively determine what is ethically right and wrong, it is nevertheless through shared reflection and discussion that we improve our ability to perceive and decide on this matter.

Empirically documenting ethical reasoning certainly has value at the personal level as a systematic process of self-reflection. The importance of the personal process of self-reflection on ethical matters on one's own work has been highlighted in the literature (Ackerly & True 2008). González-López (2011, 449), for example, points out:

Through this process, I have become an introspective and critical observer of my own fieldwork experiences, which has helped me become more conscientious and alert to the emotional, physical and political safety and well-being of people participating in my research.

Moreover, Ellis (2007, 5) points out the importance of reflection in relation to broadening the spectrum of possible solutions to be adopted:

The conflicts I have experienced have taught me a great deal. By repeatedly questioning and reflecting on my ethical decisions, I have gained a greater understanding of the range of choices and the kind of researcher I want to be with my participants.

Some of the authors in this collection, such as Gil (personal communication), have testified how the writing of the chapter made them reflect systematically on issues that they had noticed in their work, but that were otherwise left unaddressed. The different chapters in this collection are exercises in self-reflection that were certainly useful to the authors, providing them with an occasion to systematically ponder ethical issues that generally risk being overlooked in the busy schedule of research work.

They describe the various ethical problems and the solutions that the researchers adopted in different situations. But how can these studies be useful to other researchers? If the ethical dimension is a subjective dimension, what is the use of sharing the description of the ethical problems and methodological solutions adopted? These studies, as texts, are a means to develop sensitivity towards ethical matters in research. Reading this type of literature may help researchers to widen their perception of ethical nuances of research relationships. It may increase their level of awareness and alertness towards ethical problems; it will raise their level of discussion and sensitivity towards ethical matters. Shared reflection and discussion promotes a kind of literacy in ethical matters—the ability to identify, to critically understand, interpret and take decision on ethical problems in relation to research activities.

The documentation of practices of ethics could also inform procedural ethics and relevant legislation. Could the systematic documentation of moral reasoning provide a base for improving ethical guidelines in social sciences research? Could these empirical studies allow for the development of a more effective legislation on research participants' protection? Could they result in the development of more flexible and effective procedures? This has yet to be seen. These studies can certainly contribute to an understanding of research activities as social activities, that is the importance that issues such as politeness and face, as well as appropriateness and cultural relevance, have in research interactions. Ethical procedures are often standardized, ignoring the complexity of the actual circumstances of specific research settings. The documentation of practices of ethics allows us to precisely highlight these features in the implementation of procedures for the protection of research participants. For example, the negotiation of informed consent is often described as problematic in the literature (Barrett & Parker 2003; Czymoniewicz-Klippel, Brijnath & Crockett 2010; Katz & Fox 2004; Bhattacharya 2007; Janocek 2006; Lugosi 2006; Marzan 2007; Murphy & Dingwall 2007; Ness, Kiesling & Lidz 2009; Thorne 1980) and various chapters in this collection. Informed consent has to be negotiated in terms of material circumstances. The actual situation creates specific constraints within which the consent has to be negotiated there and then. An understanding of the variety of situations and conditions could allow for the definition of more effective procedures.

A word of caution is in order at this point. The documentation of practices of ethics can imply some risks, such as: letting ethical decision be “diluted,” weakened and lost in details. A clear and sound sense of direction in ethical terms may be lost in considering the “particulars,” and

ethical decisions may be accommodated to suit other orders of priorities. The special case becomes opportunistically shaped by extrinsic matters that have nothing to do with the ethical order of relevance. If we say that the ethical dimension is intrinsically subjective and that which is ethically right and wrong is ultimately established in one's own consciousness, this does not mean that it could suit any whim, any passing and fanciful idea. The documentation of practices of ethics implies a serious search for what is ultimately good—the search Wittgenstein (1929/1965, 12) refers to. It is important to be clear in this respect. Through the description of practices of ethics this personal search is documented and made public.

Last but not least, the documentation of practices of ethics in social science research has relevant implications for ethics as a discipline. The authors in this collection, together with the authors describing recent practices of ethics in their research work (Barton 2011; Blue & Currier 2011; Czymoniewicz-Klippel *et al.* 2010; Clark & Sharf 2007; Cloke *et al.* 2000; Conrad 2006; Currier 2011; Dougherty & Atkinson 2006; Einwohner 2011; Ellis 2007; Etherington 2007; González-López 2011; Goodwin *et al.* 2003; Guillemin and Gillan 2004; Hurdley 2010; Irwin 2006; Kohler Riessman & Mattingly 2005; Medford 2006; Poulos 2008; Rupp & Taylor 2011; Stein 2010; Sultana 2007; Wood 2006; Wyatt 2006) created a disciplinary space with ethical practices in social science research as an object of study and empirical documentation as its specific approach. Moral reasoning in relation to research activities is identified as a relevant practice on its own that can be empirically documented. A new methodological approach to ethics as a discipline is emerging, having practices of ethics as its specific object of study. It is an empirical approach to ethics in social sciences research. But what is the scope and meaning of an empirical approach to ethics? What kind of knowledge could such documentation entail? This documentation process is still at its beginning. It is significant, though, to link this kind of empirical documentation of moral reasoning to the ethnomethodological project. Ethnomethodological studies have highlighted the centrality of moral reasoning for understanding social order (Garfinkel 1967; Jayyusi 1984). The actual documentation of moral reasoning as practical moral judgment is a central matter of this endeavour. As Jayyusi (1984, 18) points out:

... the very point is that if we wish to understand the organization of the moral order it is precisely the question of how, in what way, and for what practical purposes are circumstances made out to be relevantly different or relevantly similar that are of analytic interest. It is that that reveals the nature of moral organization and interaction, and it is the practices by

which that is accomplished that inform us of the logic and properties of the moral order of which we are member.

Practical moral judgement is a social practice that can be studied by itself, and such a study can shed substantial light on the understanding of the interaction-produced social orderliness.

To conclude, with this book we aimed to take up and develop what we identified as a very fruitful and useful approach to the study of ethics in social science research. The different chapters discuss in detail a variety of ethical problems and the reasoning the researchers developed in relation to them, together with specific methodological solutions. The implications of this approach to ethics in relation to the recent debate on ethics committees and procedural ethics was highlighted, pointing out the necessity to discern ethics from the relevant legislation on the protection of research participants. Ethics belongs to the individual, and cannot be bureaucratically administrated. What is ethically right or wrong is subjectively determined. This stand does not imply any criticism to legislation on the protection of research participants, and such legislation should be complied with. We stress the importance of differentiating the two dimensions. Ultimately, procedural ethics is not “enough.” These studies are a claim towards making individual moral reasoning visible and shareable.

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