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When people matter: The ethics of qualitative research in the health and social sciences

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Abstract

When research involves people, ethics are fundamental. In the health and sciences, when qualitative methodologies are used, in addition to ensuring an ethical process approved by the ethics review board, it is also necessary to guarantee an ethical practice capable of responding adequately to the complex questions and dilemmas which arise as the study progresses. This theoretical article analyses some of the most sensitive issues involved in qualitative research and discusses the following questions: (a) How should ethics be approached when working with vulnerable groups? (b) Is informed consent enough? (c) Should we rethink anonymity? (d) What is the difference between confidentiality and anonymity? (e) What exactly do we mean by relational ethics? (f) How can we avoid hurting people, yet remain honest? In the conclusions, we discuss some basic aspects for ensuring ethical studies. This paper, therefore, may be of interest to all health and social researchers concerned about ensuring that their studies comply with ethical principles which recognise, protect and respect participants' rights.

KEYWORDS
ethics in practice, health and social sciences, qualitative research, research ethics

1 | INTRODUCTION

In any piece of research involving people, ethics are fundamental. The most common procedure for guaranteeing an ethical study is to submit it to an ethics review board. The purpose of these review boards is to ensure that all research is carried out in such a way as to respect and safeguard participants (Busher & James, 2015; Wijngaarden et al., 2018). In general terms, review boards and codes for ethical research with human beings are based on four principles and obligations, which in turn are derived from the 'Nuremberg Code' and the 'Helsinki Declaration' (Halse & Honey, 2007): respect for autonomy, non-maleficence, beneficence and justice.

Nevertheless, in the health and social sciences, the way in which ethics review boards function has been called into question, on the basis that their biomedical model may not be apt for some research carried out in this field, particularly in the case of studies using a qualitative approach (Vermeylen & Clark, 2017). The boards charged with reviewing qualitative research proposals still tend to assume

that projects should emulate quantitative research conducted in accordance with the medical model (Connor et al., 2018; Giraud et al., 2019). The problem with this approach is that the decisions taken by an ethics review board at the start of a research project are far removed from actually happens during the study. Biomedical or experimental models view research as a constant, sequential process. However, this is a far cry from the realities of the qualitative research carried out in the health and social sciences. In such qualitative studies, the majority of research designs change and develop over time, and different dilemmas arise as the work progresses (Hewitt, 2007; Sabar & Sabar, 2017).

Guillemin and Gillam (2004) distinguish between procedural ethics and ethics in practice. The first of these is linked to gaining the approval of an ethics review board in order to undertake a research project. Indeed, one of the first stages of any research process, at least in the majority of countries which have ethics review boards, is to complete and submit a form to said body. For many researchers this is a mere formality, a hurdle to surmount in

order to obtain funding and/or gain the authorisation required to proceed with the study. In qualitative studies, however, another kind of ethics is also required. Ethics in practice refer to ethical issues which arise in the everyday context of conducting a research study. They may be viewed as a code of ethics or a professional code of conduct, determining such questions as how to access the sample and how to present information in such a way as to preserve participants' anonymity. From this perspective, ethical research is much more than ensuring that an ethics review board has approved the study. This approval may serve as a guideline for practice, but cannot, in itself, guarantee an ethical research process (Tangen, 2014).

As Simons (2009) points out, in many cases, the normal conventions of informed consent are, along with the validation and impartiality of the informant and accurate, relevant reports, sufficient to indicate ethical practice. But this alone is not always enough. As Sabar and Sabar (2017) argue, qualitative researchers should, above all, ensure respect for the participants in their studies. In the world of research, ethical practice implies that the relationship we establish with participants should respect human dignity and integrity, and should be one in which people feel safe, comfortable and among friends (Simons, 2009). To this end, research projects should not only ensure a high degree of quality and scientific rigor (Bryan & Burstow, 2018), they should also respect a basic set of ethical principles: the principle of informed consent, the right to withdraw at any moment, confidentiality, privacy, non-coercion and protection against possible harm (Josselson, 2007; Wijngaarden et al., 2018).

Ethical questions are therefore often complex (Hammersley, 2015; Stutchbury & Fox, 2009). Guillemin and Gillam (2004) acknowledge that ethical dilemmas and concerns are part of the everyday practice of doing research. In this article, we explore some of the most sensitive issues which may arise during the course of qualitative research and which should be taken into consideration by anyone wishing to design an ethical research process. Specifically, we will strive to answer six questions: (a) How should ethics be approached when working with vulnerable groups? (b) Is informed consent enough? (c) Should we rethink anonymity? (d) What is the difference between confidentiality and anonymity? (e) What exactly do we mean by relational ethics? (f) How can we avoid hurting people, yet remain honest?

To answer these questions we have carried out a theoretical review. The literature search was conducted in ERIC, Scopus and Web of Science. The keywords applied for the search were 'ethic' and 'ethical' and the combination of 'qualitative research' or 'qualitative methodology' or 'health sciences' or 'social sciences'. Our review included these keywords, with no restrictions in terms of date of publication. We also included other works which, although not included in these databases, were known to the author for their contributions to ethics in qualitative research (e.g. Josselson, 2007). We also searched specific journals on qualitative research, such as Health and Social Care in the community, Qualitative Health Research, or Qualitative Inquiry.

2 | ETHICS IN RESEARCH WITH VULNERABLE GROUPS

Thapliyal and Baker (2018) argue the necessity of doing research that is sensitive to people. These authors view all participants as potentially vulnerable, since this situation depends on the interactions between their characteristics and the nature of the study itself. Thus, ethical issues serve to guarantee protection for the most vulnerable participants. This becomes even more relevant in light of the fact that one of the characteristics of qualitative research in the health and social sciences is subjectivity, which is both recognised and valued (Moriña, 2020) and often prompts participants to reveal intimate personal and sometimes even painful information. This is the case, for example, in research involving refugees or victims of abuse or bullying (Benezer & Zetter, 2014). As such, one concern that may arise is linked to how to avoid harming or traumatizing participants with our research, an ethical consideration that is particularly important in sensitive studies involving vulnerable groups (Isham et al., 2019; Shaw et al., 2020).

One truly complex type of research is that conducted with children. Indeed, Salamon (2015) introduces the concept of ethical symmetry in participatory research with infants, arguing that researchers should adopt a methodological attitude that recognises, respects and incorporates the active involvement of infants in research processes. The idea is based on the concept of responsible participation which respects 'other' minority groups in research by involving them in dialogs that seek to recognise commonalities and address potential power imbalances between researchers and those being researched. Indeed, the way in which researchers introduce themselves, their verbal and body language, clothes, how they interact with minors and the research context itself may all have a positive or negative influence on the power balance. In order to avoid imbalances, Colliver (2017) advocates being sensitive to young children's signs of dissent to participate. Researchers need to obtain children's true consent to participate in the research project, rather than just the consent of their parents or guardians, as some studies do.

The choice of research method can also help minimise power imbalances, with more participatory methods being more positive in this sense. Indeed, one way of resolving this ethical dilemma is to adopt participatory or collaborative approaches (Goodson & Gill, 2011). Some authors suggest that inclusive research methods could be used, in which research is carried out *with* rather than *on* participants (Hammersley, 2014; Nind, 2017; Walmsley et al., 2018). With the idea of working with rather than on participants, biographical-narrative research (Josselson, 2007) or action research (Elliot, 1991) are suitable methodologies that allow involving changing the traditional power structure and developing more democratic research processes (Porter, 2016). Likewise, in-depth interviews, photo-elicitation or lifelines are instruments that involve the participants in the studies by giving them a voice and making them co-protagonists of the research processes. Therefore, these types of methodologies and instruments are appropriate for research with vulnerable groups, understood as groups that have traditionally

been silenced in academic discourse, such as people with disabilities, children, women, and immigrants, among others.

3 | NEGOTIATING THE STUDY: IS INFORMED CONSENT ENOUGH?

The process of obtaining informed consent is a critical element for protecting participants from possible risks and harm. Specifically, informed consent helps ensure that those participating do so of their own free will. Standard processes recommend that researchers ask participants to sign an official consent form, often accompanied by a written explanation outlining the details of the study (Thapliyal & Baker, 2018).

By giving their informed consent, participants declare that they have been informed of the purpose, intent and method of the research project and how they were selected, and confirm that they have not been coerced or pressured into participating (Ngozwane, 2018). Consent forms enable participants to formally decide whether or not they want to participate voluntarily in the study, and oblige researchers to ensure that everyone involved fully understands the process.

Normally, informed consent is obtained only at the start of the study and is taken into consideration by ethics review boards when granting (or denying) approval (Vermeylen & Clark, 2017). Nevertheless, this process is particularly complex in qualitative research undertakings, which are mostly emergent in nature. This means that the work evolves as the process develops, with new topics for study arising, along with new participants and instruments. In such processes, the initial document soon becomes obsolete and a new type of consent is required. This new type of consent has been given many different names, including process consent by Ramcharan and Cutleffe (2001), rolling informed consent by Piper and Simons (2005) and provisional consent by Flewitt (2005). It is an informed consent that is given once the study is underway and new, unexpected issues that were not foreseen in the initial document arise and need to be negotiated. In addition, this consent helps to ensure that participants review the conclusions of the study and the research report that will be published.

Informed consent is also particularly sensitive and delicate in studies involving minors or vulnerable groups, such as people with disabilities. For example, in the case of research with minors, in order to respect children's dignity, it is important to gain not only the informed consent of their families, but also of the participants themselves. Researchers should explain to them both the aim of the study and their role in it and minors should be given the opportunity to refuse to participate, even if their parents have already given their consent. Consequently, it is worth considering that the document signed by minors should perhaps be different from that signed by adults, rather than just the same format couched in simplified terms (Moriña, 2020). Nevertheless, although no uniform standard has yet been established, the general trend for involving young children in the informed consent process is indeed based on the model used with adults, simplifying and adapting the language and delivery method to participants' age and capacities (Mayne et al., 2016).

It is therefore necessary to design age and capacity-appropriate consent mechanisms. In the case of research with children, depending on their age, these mechanisms could be more graphic and present the information in such a way as to guarantee that the child in question understands what they are committing to by agreeing to participate in the process. For example, Mayne et al. (2016) propose an 'interactive narrative' approach as a means of informing children about what their participation would involve and helping them to understand and respond as research participants.

4 | SHOULD WE RETHINK ANONYMITY?

It is not always easy to respect participants' anonymity. This gives rise to a new ethical dilemma: to what extent does a study remain believable when numerous changes are required in participants' identity in order to respect their anonymity?

Josselson (2007) calls attention to small communities or family units, pointing out that care should be taken in these contexts since privacy and confidentiality cannot be guaranteed (Mauthner, 2000). This author also highlights situations in which other people are named in studies. When people who may be recognised are mentioned, they may be harmed as a result of what others have said about them. In such a situation, the ethical problem lies in how to protect those featured in qualitative reports.

It is common practice in research reports to respect the anonymity of those featured and provide them with a certain degree of protection or privacy through the use of pseudonyms, changes in the name of the institutions involved and the introduction of fictitious elements. For example, in a study by Ngozwana (2018), participants were assigned numbers when their data were transcribed in order to protect their anonymity.

However, the principle of anonymity has been called into question by Walford (2005), who holds that there are good reasons why it should not be applied to small-scale studies, since it is easy to determine who is speaking and it is often useful to know the context in which certain things are said, particularly in order to enable those reading the history to verify their veracity. Kushner (2000) also questions the principle of anonymity, claiming that it is not ethical to deny someone's identity. According to this author, anonymity is as potentially harmful for the individuals concerned as giving their true names in the report. It is a complex issue that cannot be reduced merely to the question of maintaining (or not) someone's anonymity. It depends on to whom it is and is not applied, the reporting method used and how readers receive the reports themselves.

Other colleagues in the field adopt a radically different approach, arguing that anonymity should always be guaranteed (Josselson, 2007; Mauthner, 2000). Some of the reasons given for this stance are related to the idea that while some people may not mind their real name being used, others who may be mentioned by that person may find it embarrassing to be identified. Another reason is that identification may

limit the explanations given and the comments made by participants. Finally, researchers cannot guarantee that those reading the study will react with sensitivity and impartiality. In this context, many believe that it is necessary to guarantee anonymity. Moreover when the study is finally published, this anonymity will help protect against any unjustified or unjustifiable judgment from unexpected parties. It may also help protect against possible lawsuits.

5 | IS CONFIDENTIALITY THE SAME AS ANONYMITY?

It is often taken for granted that anonymity refers to the need to protect people's privacy and identity and to guarantee confidentiality (Simons, 2009). However, it is important to distinguish between the two concepts and consider them separately. When a study is published, protecting participants' privacy through anonymity is different from ensuring confidentiality during the research process.

Josselson (2007) argues that it is impossible to conduct qualitative research without ensuring confidentiality. Assuring confidentiality is common practice at the start of any research project as a means of gaining participants' trust and encouraging them to speak openly and honestly. Indeed, protecting participants' confidentiality is often one of the researcher's primary obligations. We must assure them that any sensitive, personal or problematic information they may share will, if they so desire, be kept confidential and the source of said information will not be revealed. In democratic procedures, negotiation is the process by which confidential data are checked and approved by those involved prior to publication. This analysis, which can be carried out at any time, is particularly important when drafting the report.

As Sandín (2003) states, the confidential nature of the information gathered is the main procedure for guaranteeing participants' privacy and intimacy. Nevertheless, it is also important to ensure that no one is harmed or made to feel uncomfortable as the result of the research process at any point in its development, from initial contact to the drafting of reports and possible publications.

Kaiser (2009) claims that by giving detailed descriptions of participants, researchers often violate the principle of confidentiality through deductive divulgence. As a result, qualitative researchers face a dilemma: how to convey detailed and accurate information about the social world they are exploring, while at the same time protecting participants' identities? People sometimes feel identified and hurt by research reports. Pseudonyms and 'camouflaged' descriptions are often recognised by participants, their family members or those outside the process who read the study (Shaw, 2003).

6 | RELATIONAL ETHICS IN HEALTH AND SOCIAL SCIENCES RESEARCH

The ethics of relationships are linked to the implicit and explicit contracts established between researchers and research participants.

As Josselson (2007) explains, the explicit contract establishes the relationship between researcher and participant (this is who I am, this is the aim of my study, you are free to participate or not, etc.). The implicit contract, on the other hand, is linked to the personal relationship between the two parties, which develops as the study progresses. Within this relationship, the following questions need to be considered: How does the participant feel? Is the research relationship characterised by mutual respect, care and interdependence, as opposed to distance or hierarchy?

In this sense, Simons (2009) and Suarez (2020) adds that it is important to generate and maintain relationships based on trust. Once in the field, the first thing a researcher should do is establish relationships and lay the groundwork for winning participants' trust. Measor and Sikes (1992) recognise the importance of the relationship established between the two parties involved, which should be based on trust and should offer different levels of access.

The relationship deepens as the research progresses and the ideal scenario would be one in which, towards the end, the researcher no longer needs to ask questions, since the information flows fluently and naturally, as the trust established makes the participant feel free to talk openly about their experiences. At this stage of research it is essential that researchers are trained in how to conduct in-depth interviews or any other qualitative instrument that trains them in collecting information as neutrally as possible.

For their part, Mietola et al. (2017) explore the idea of 'asymmetrical reciprocity'. This means not only establishing trust-based relationships, but also making a commitment to acknowledging participants and taking their perspective into account. For these authors, 'asymmetrical reciprocity' is particularly important when working with people with profound intellectual disabilities, with whom (in the majority of cases) communication is non-verbal. In such circumstances, researchers must take their time and make an effort to understand participants' individual, non-verbal communication methods.

7 | BEING HONEST BUT NOT CRUEL

Over 20 years have passed since Taylor and Bogdan (1998) first introduced the idea of being 'honest but not cruel'. Doing no harm is a basic ethical principle (McDonand et al., 2017; Sabar & Sabar, 2017). However, this concept is not as simple as it may at first appear. Different people interpret the meaning of 'harm' differently, and may also perceive it differently at different moments in time. During the research process, when, over time, a trust-based relationship has developed, participants talk fairly openly about their experience and, without meaning to, may often reveal things they would really rather have kept private. As researchers, we must ensure we do not make malicious use of this information, and that we do not exploit the honesty or vulnerability of the person we have invited to participate in our study.

Simons (2009) argues that giving participants control over what information about themselves is made public is a good procedure in

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this sense, although it may not be the only one required in order to guarantee that no harm is done. When reports are published, participants should not feel abandoned, 'at risk' or unempowered when reading of the experiences they shared with us in the intimacy of the study. At the same time, and as Plummer (2001) argues, we also need to be as honest as possible.

Sometimes, participants say things that researchers may wish they had not said. What should we do, for example, with hurtful comments made by participants about other people? Upon reflection, and when reading the transcriptions and reports, informants may sometimes correct these comments to avoid hurting either themselves or other people; but if they do not, the decision as to whether or not to include the hurtful remarks will depend on the researcher's professional judgment. Sabar and Sabar (2017) identify two ethical dilemmas in this respect: Should we publish declarations that we think may harm participants, even when we have their consent to do so? And should we include pejorative comments about third parties named by participants?

8 | CONCLUSIONS

Different steps must be taken to guarantee the ethical nature of studies conducted in the health and social sciences (Vermeylen & Clark, 2017). Some of these steps have been analysed in this paper and, while they are not the only ones, they nevertheless constitute a basic set of principles which should be taken into consideration by any researcher undertaking sensitive research involving people.

The manuscript highlights the need for more participatory and democratic research which takes into account the opinions and perspectives of those participating in it, since many ethical questions are linked to the right to participate in and withdraw from the study at any moment, as well as to anonymity, confidentiality and the relationships established. These issues are difficult to resolve without ongoing negotiations and sustained relationships between researcher and participant, who should always be on an equal footing. Both parties change during the research process. The relationships established, therefore, are dynamic rather than static, and growing and learning form part of the process. Thus, as we indeed stated in a previous work (Moriña, 2020), what is needed are studies which research *with* rather than *on* people.

This is particularly necessary in studies involving more vulnerable groups, such as people with disabilities or children, who may need a greater degree of protection and ethical surveillance (Isham et al., 2019). Power relationships, which are sometimes generated by certain methodological choices, give rise to imbalances which may in turn result in situations of disadvantage that are unjustifiable from an ethical perspective. This is why a different type of research is required, centred, as Nind (2017) and Porter (2016) recommend, around more participatory or collaborative approaches. Unless we guarantee that studies respect certain ethical principles, we run the risk of having the opposite effect to the

one we intended, and rendering participants more vulnerable than they already were.

In this sense, some habitual practices in research, such as only using an initial informed consent form or not negotiating and reviewing anonymity and confidentiality, should be abandoned. Efforts should be made to involve participants more in the decisions made both during and at the end of the research process (Flewiit, 2005; Josselson, 2005). To do this, certain assumptions made by traditional research methods need to be transformed in order to pave the way to a more accessible, natural and democratic process. Research should no longer be distant, but rather committed, as a transformational social practice.

Anonymity is a dilemma has no easy solution. In our opinion, the anonymity will depend on the type of study and the sensitivity of the data. It should be taken into account that in many qualitative studies the participants decide that their real names should appear and this should also be respected. In any case, anonymity should be revised through ongoing negotiations between participants and researchers, and everyone participating in the study should feel that their anonymity is being protected or if they wish to disclose their personal data ask the participants in the informed consent their position regarding the inclusion of such data or not.

One particularly delicate issue is how to present the situation narrated by participants as honestly as possible, while at the same time ensuring no harm is done to either them or any third parties they may name. This is a basic ethical principle which has already been defended by other authors (McDonand et al., 2017; Sabar & Sabar, 2017; Taylor & Bogdan, 1998) and which demands that research be committed to and carried out for people, at the service of society.

The dilemma here is that if we exclude data, we contravene the principle stating that people should be able to control the use made of information about themselves. If we include it, however, we run the risk of doing harm. If the publication of certain data paints an inaccurate picture of someone and generates undue conflict in the research scenario, perhaps the most sensible option, both to protect that person and to ensure the continuity of the study, would (in our opinion) be to omit the information.

Although there are a number of ethical questions that should be addressed before the start of any study (informed consent and data protection, for example), it is during the course of the collaborative effort that the most complex issues tend to emerge. Thus, ethics in research cannot be limited to the start of a process and the initial approval of the methodology by an ethics review board. Ethics in practice must be present in any qualitative study within the health and social sciences, since, to our mind, research not conducted in accordance with ethical principles in all its different phases, from start to finish, is not research at all.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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