

Ethics issues and research in vulnerable communities: a case study from the North West province of South Africa

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Abstract: Through the lens of a case-study, this paper outlines some of the problems that arise when implementing ethics requirements in vulnerable communities. There is a mismatch between positivistic ethics norms and those required in the field. In the case study described here, researchers used a community-based participatory research design to study the impact of an ICT intervention on a group of largely illiterate, low status elderly woman in a rural village in the North West province of South Africa. The case study highlights some of the ethical and practical issues that were faced by the researchers who were from a professional research institute. The study consequently provides novice and experienced ICT4D researchers alike with a deeper understanding of the unique actions and choices – and inevitable uncertainties, complexities and compromises – that can arise when addressing ethical issues such as informed consent, which is necessary to obtain legitimised entry into a traditional community.

Keywords: informed consent, ICT4D, vulnerable populations, ethics, rural communities

Introduction

This paper first gives a brief introduction to individual rights in the South African context; recounts a field experience in the piloting and implementation of an ethics process; and then discusses the traditional positivist approach to ethics and what bearing it has on the field experience described in the case study. Lastly, further observations and conclusions are made.

The following excerpt from the South African Constitution (South Africa 1996:1248) highlights individual rights which, in the authors' opinion, are sacrosanct and should form the foundation of all research involving people:

“Everyone has inherent dignity and the right to have their dignity respected and protected”.

“Everyone has the right to bodily and psychological integrity, which includes the right:

- *to security in and control over their body; and*
- *not to be subjected to medical or scientific experiments without their informed consent”.*

“Everyone has the right to privacy”.

It is important to remember that during the apartheid era black South Africans grew up without the right to equality, and that this violation of human rights particularly affected rural women, whose husbands were often away from home for many years at a time as migrant labourers on the mines. Family breakdown was not uncommon. In the new South Africa, the right to equality is a significant achievement. However, rural women are still disadvantaged due to poverty, isolation and other factors. Thus conducting research in remote rural communities with research participants who often meet the criteria of what is known as a ‘vulnerable population or community’ presents ethical challenges not only to the researcher, but also to the ethics boards who must approve the research. Indeed, how is a vulnerable population or community distinct from the individual embedded in it? What does it mean to be ethical or unethical, how are these terms defined in qualitative community-based research

and by whom, and how is it judged whether a qualitative researcher is behaving ethically or not? It is important that researchers operating in this context are aware of these challenges. They must ensure that the challenges are addressed and acknowledged by other researchers who do similar work in the same contexts (Denison & Stillman 2012).

A further complicating factor which necessitates the responsive adaptation of ethics processes to meet specific needs is that culture, values and ways of discussing, doing and coming to agreement vary between different kinds of communities, for example whether they are formal Western organisations or rural community associations. This is particularly relevant for those communities that are somehow distressed or vulnerable (Byrne & Alexander 2006; Denison & Stillman 2012). This is in contrast to communities in which conventional ethics can be applied, which are embedded in a particular world frame and discourse, and which, adapting Nicholls, serve as a “regulatory technology of governance: in favour of the research body, rather than the community” (Nicholls 2007: 4).

This paper describes the endeavours of a research team to ensure that the ethics process that is followed meets the requirements of the ethics boards of a research institution and a University, as well as the needs of the rural community in which the research project is being conducted. The research team’s intention was to a) protect the rights of all participants, and b) ensure that good research was conducted in a just and fair manner. The welfare and collective interests of all the participants and their respective communities was at all times of utmost importance. The researchers endeavoured to adhere to the principles of:

- Privacy, anonymity and confidentiality
- Informed consent
- Voluntary participation and the right to withdraw
- Accountability
- Good research.

Although this paper focuses on the principle of informed consent, the problem is introduced by pointing out that adhering to the first principle listed above turned out to be a greater challenge than expected for a completely unforeseen reason. The following anecdote serves as an example of the unforeseen challenges that researchers may run into and need to respond to:

The research team bought light refreshments (fruit juice, water and biscuits) for the research participants during the discussions with them. When the expenses claim form was submitted to the finance department of the research institution, the department required the names of the people who participated in ‘the meeting’. The research team felt that the principle of privacy, anonymity and confidentiality as stipulated by the ethics clearance received, as well as the informed consent form that the participants signed, precluded them from sharing this information with outside parties. This decision was ultimately accepted, although it caused serious internal institutional concern because it violated standard financial, rather than ethical procedures.

Research ethics defined

Research ethics, as defined by McAreevey (2014:74), is “the moral principles guiding research, from its inception through to completion and publication of results and beyond”. Research ethics are monitored by review boards or research ethics committees (RECs), and are regulated by the ethical codes of professional bodies. Ethics are the “norms and standards of behaviour that guide moral choices about our behaviour and our relationships with others” (Cooper and Schindler in Saunders, Lewis et al. 2009). Webster’s New World Dictionary defines the term ethical as “conforming to the standards of conduct of a given profession or group”. However, context is everything. What is regarded as acceptable, moral or ethical depends on the particular community involved (Zimbardo 1973; Babbie 2005; Brydon-Miller & Greenwood 2006; Pimple 2008). This is an important principle which is often forgotten in the attempts of ethics boards and researchers to apply narrow and prescriptive ethical frameworks in community-based socio-technical research. It is important for IS researchers

not only to be aware “of the general agreements shared by researchers about what is proper and improper in the conduct of scientific inquiry” in the IS and social science domains (Babbie 2005:62; University of Pretoria n.d.), but also to be able to critique these in terms of their actual form of research practice.

Ethical treatment of human research subjects came sharply under review after the Second World War as a result of the genocidal medical ‘experiments’ of the Third Reich (Anderson in Larson 2005; Brydon-Miller & Greenwood 2006; Pimple 2008). These violations led to the formulation of various international codes governing research involving human beings. The first of these, the Nuremberg Code, was formulated in 1947. Its opening sentence reads: “The voluntary consent of the human subject is absolutely essential” (Larson 2005; Brydon-Miller & Greenwood 2006; Pimple 2008:xvi). The continued relevance of this statement for today is emphasised by the South African Constitution, as quoted in the introduction.

In addition to the above, there has been a general increase in oversight of research on national and international levels through the development of ethics committees and the formulation of professional codes of ethics and conduct (Anderson & Linders in Brydon-Miller & Greenwood 2006; Pimple 2009). The aim of ethical standards in research is to provide guidance for the decision-making process and actions relating to research to ensure that researchers “protect the welfare, rights, and dignity of those individuals participating in institutionally sanctioned research” (Larson 2005; Brydon-Miller & Greenwood 2006:120).

The list in Table 1 reflects the most important ethical dimensions and standards that currently prevail in research involving human participants (Babbie 2005; Brydon-Miller & Greenwood 2006; Williams 2006; Pimple 2008; Denison & Stillman 2012; University of Pretoria n.d.).

Table 1: Ethical dimensions and standards in human research

- Voluntary participation vs. coercion
- Informed consent vs. deception
- Right to withdraw
- Respect vs. disrespect
- No harm to the participants vs. possible benefits to the larger population
- Beneficence: research has a benefit for those involved and research participants are involved in all stages of the research process
- Benefits must be at least as great as the risks
- Distributive justice: benefit and burdens must be fairly distributed
- People must not be marginalised as a result of the research
- Anonymity and confidentiality vs. exposure
- Analysis and reporting
- Predictability, replicability and generalisation
- Independent ethics committees and oversight

The diagram in Figure 1 shows the relationship between the requirements for ethical conduct and good research – which can be defined as research that displays scientific merit and has rigour with objectively grounded results – when applying the principles listed above.

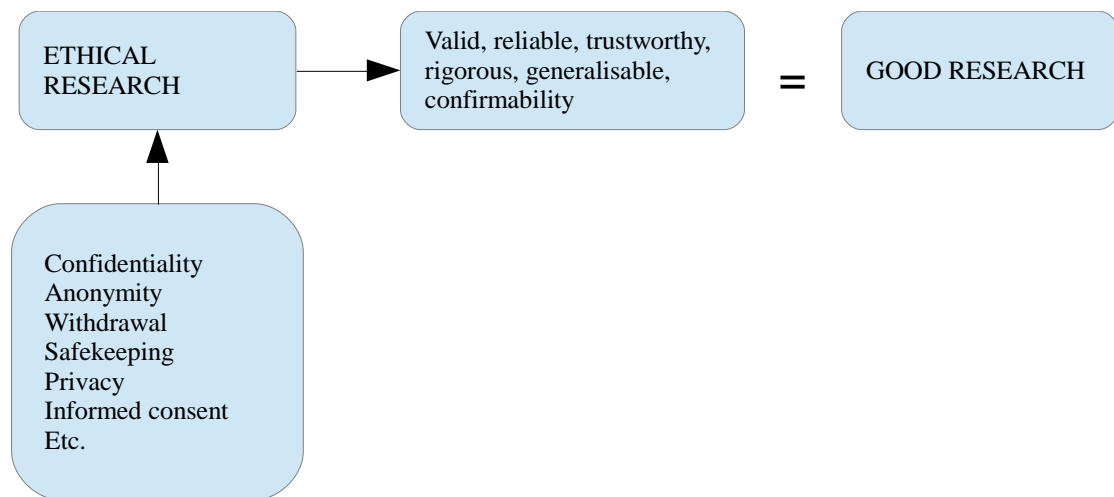


Figure 1: Relationship between ethics and good research

Although the approach to ethics discussed above has the wellbeing of research participants at its core, it cannot simply be applied ‘as is’ in the socio-technical domain to which IS research belongs because it assumes a culturally equal playing field when it comes to core assumptions about particular ethics norms. Many researchers complain that ethical standards and guidelines complicate the research process if the local context is not taken into account, and that the process of obtaining well-informed consent is impeded or hampered by arduous and prescriptive requirements (Wiles, Heath et al. 2005; Brydon-Miller & Greenwood 2006). Some go so far as to argue that “adhering to specific ethical rules in relation to research can affect the very issue that is being studied, such that it becomes impossible to conduct the research” (Wiles, Heath et al. 2005:6).

The case study: the installation of an ICT platform for rural middle-aged women involved in agriculture in Ramatlabama, North West province

The Itlhabolole project, which is located in Ikopeleng village in Ramatlabama, a rural area outside Mafikeng in South Africa’s North West province, was selected as the first site for a research project on the Digital Doorway Project¹. Another community has also been the subject of a research paper about the consultation process (Rampa, Mulamo et al. 2103). The inhabitants of the community in North West province are Batswana people. It is a hot arid area that receives little rainfall. Most people living in the area are engaged in subsistence farming. Water supply is a problem because the municipality’s water pumping system frequently fails, forcing villagers to use borehole water. This ‘solution’ is also problematic as the borehole pumps use electricity, the supply of which is also unreliable.

The project, which has an agricultural as well as a needlecraft component, was initiated by a group of women in 2000 as a way of creating employment, learning new skills and using their agricultural and needlework skills to generate income. The women were later joined by

¹ The Digital Doorway project is an initiative of the South African government to install robust multi-terminal computers and multi-user solar powered container units in high needs communities. Conducted by the Meraka institute of the South African Council for Scientific and Industrial Research, over 260 units have been installed since 2004. See Stillman, L., M. Herselman, *et al.* (2012). "Digital doorway: social-technical innovation for high-needs communities." Electronic Journal of Information Systems in Developing Countries 50(2): 1-19.

several men. During the period 2008 to 2011 the project received funding from the South African Department of Arts and Culture and from the National Development Agency. The project sometimes receives orders from external buyers. The agriculture part of the project supplies vegetables, mainly to the local market and to households. Vegetables that are most often planted include spinach, onions, cabbage, tomatoes, beetroot, carrots, green peppers and lettuce. No government funding has been available from 2012 onwards, and the project relies on the crop farming component as the main source of income. Community members who are involved include approximately 10 women and two men, all of whom are 40 to 50 years of age.

The documents that were used to obtain consent from the community were prepared in both English and Setswana, the local language. They consisted of a one-page explanation of the Digital Doorway project and the proposed research, a letter to be signed by the chief giving permission for the research project to be conducted in the community, and a detailed and comprehensive informed consent form to be signed by the women participating in the research.

Piloting the ethics process

In order to ensure the integrity of the ethics process, the process of obtaining consent was piloted over two days at an NGO in Mabopane, a settlement north of Pretoria which is relatively accessible. The process was piloted with a group of women of similar profile to that of the intended research participants. The women were guided through the whole process, from being provided with the background information, to working through the informed consent document, to answering any questions that arose, and to signing of the informed consent form. The intention was to check the comprehensibility of the information and the consent form, to assess whether the Sepedi and Setswana translations were correct, to establish whether the process worked and to see whether any other issues arose which the researcher had not considered.

The original plan was to conduct one-on-one sessions with the research participants. This approach was tested on day one. It was a time-consuming and tiring process, as it took about an hour for each participant. Similar questions and comments arose from the ten interviews. Interviewing the women individually in a separate room created an impression of 'secrecy'. With a planned sample size of around twenty women, the researchers realised that this was not a feasible approach. It was decided to test a focus group approach as an alternative. One of the senior women, who had completed the ethics process the previous day, was approached to gauge her willingness to lead the focus group. She was taken through the document again. She then led the remaining women, as well as some of those who had already completed the consent process, through the documents. The researchers acted as observers. The questions that were raised were addressed in the group. Opportunity was provided for the group to discuss issues raised among themselves. Once the women had been guided through the consent document, the researchers went through the signature process on a one-on-one basis.

Feedback received:

- The research team was concerned that the lengthy and comprehensive document based on the template provided by the CSIR ethics board would be too detailed. The women were asked whether the document should be condensed. However, they all indicated that they preferred as much information as possible because then they would "know that we are receiving all the information".
- The consent form states that the data collected will be stored in a safe place for three years and then destroyed. One respondent expressed concern about what would happen after the three years. The researcher explained that the paper documentation would be shredded and that all electronic records would be deleted.
- The respondents suggested that the statement "no names will be mentioned in any publications" be expanded to include specific examples of publications, such as newspapers, and academic papers.

- In the part of the research institutions' consent form where signatures are required, provision is made for the name and signature of the participant and/or the name and signature of the 'legal representative'. All the participants associated 'legal representative' with somebody who is called in if there is trouble with the police. A number of participants also felt that if that clause were included on the form, the chief would insist on signing it and thereby remove the decision making from the participants themselves. All the participants strongly insisted that the clause be removed from the form. The research team had to get permission from the CSIR's Legal Department as well as the Research Ethics Committee to remove the clause. A separate letter to obtain consent to conduct research in the community was drafted for the chief's signature.
- In some places in the consent form reference is made to other sections or pages in the document. A number of respondents asked to be shown those sections.
- One sentence reads "Allow us to take photographs and make a couple of videos of you using the Digital Doorway". One respondent asked what type of photographs would be taken and where they would be stored.
- One respondent said that she did not understand what was meant by potential risk and discomforts or potential benefits to subjects and/or to society. The problem lay with the word 'potential'.
- A number of respondents mentioned that although the English version of the consent form was quite lengthy, it was acceptable in Sepedi as the latter is quite a verbose language.

The ethics process followed in the selected community

This section describes the ethics process followed by the researchers when they approached the Ramatlabama community to obtain consent to conduct research in the community.

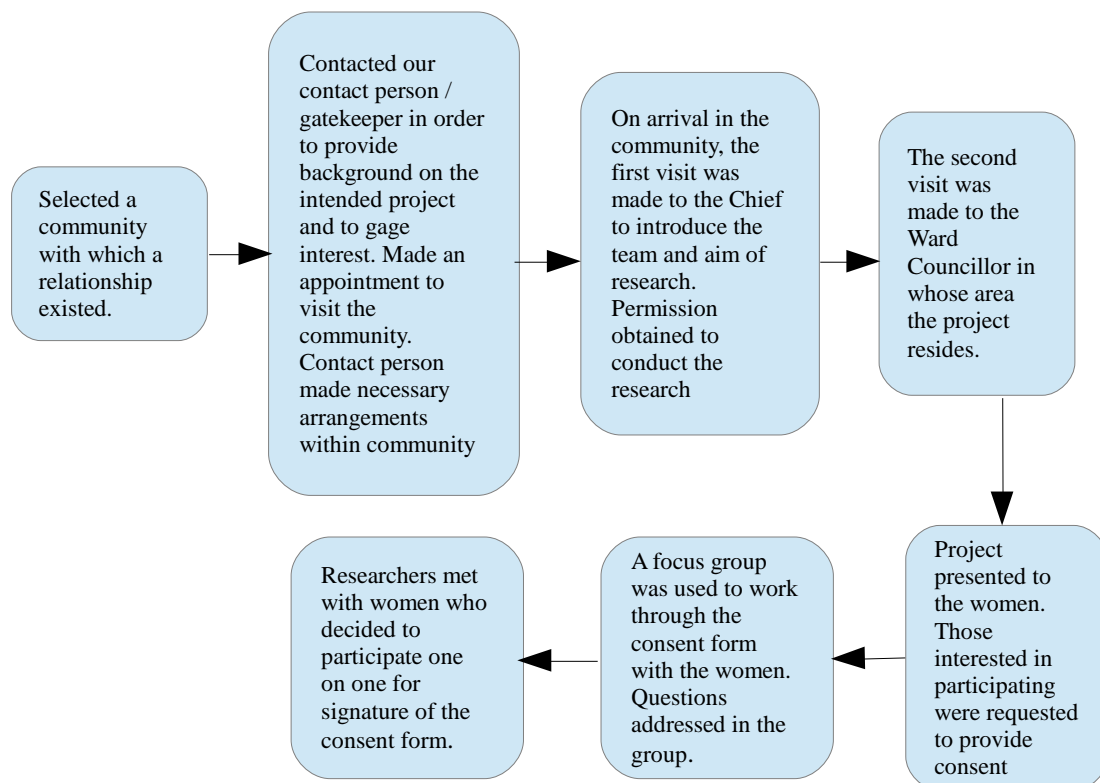


Figure 2: Community ethics process

According to the established protocol in South African rural communities, authorisation must be obtained from the chief before any research can be conducted and before the team can meet with the target group. Therefore, upon arrival at Ramatlabama, the research team's first stop was the Tribal Office to introduce themselves to the Chief, Mr G.G. Shole and to explain the purpose of the visit. Mr Shole was abroad at the time and his deputy instructed the team to leave the authorisation form with her for signature by the Chief. The authorisation form provided details of the project in writing, including the names and contact details of the researchers. Acting on behalf of the Chief, the deputy gave permission for the team to proceed. She also referred them to the Ward Councillor in charge of the community in Ikopeleng. Once permission had been obtained from the Ward Councillor, the team proceeded to the Itlhabolole project where they were expected.

The aim of this first site visit was to introduce the Digital Doorway project in general and the research project in particular to the potential participants, to obtain their consent to participate, to get to know the potential participants and to determine the current situation regarding ICT usage and food production. The feedback from the participants would be used to update the content of the Digital Doorway computers to meet the information needs that were expressed during the interviews with the community prior to deployment.

All proceedings were conducted in Setswana, the local language, and interpreted for the non-Setswana speakers. The focus group's approach to the ethics process was adopted as piloted at the NGO in Mabopane. Each participant was given a consent form. One of the researchers worked through the form with the participants, addressing questions as they arose. Most questions related to the assumption that the team was there to provide funding for the project. This was clarified during the focus group and also later during the one-on-one interviews. Once this process had been completed, the participants signed the forms.

Because the interview guide should serve as a means of guiding the discussions with the participants rather than as a formal questionnaire, it was the only document that was not translated into Setswana and Sepedi. Before the site visit the Setswana speakers on the team were confident that they could manage, given this arrangement. However, the 'on-the-fly' translation proved to be a challenge, and this document was subsequently translated into both Setswana and Sepedi.

One older woman arrived late, and as a result missed the ethics focus group session. She immediately assumed that the team was there to provide some form of funding for the existing project. She was briefed individually to ensure that she fully understood the purpose of the project.

Positivist ethics in socio-technical research

Critical approaches to research ethics which emphasise the concepts of informed consent, privacy, confidentiality and anonymity, as well as a closely structured research methodology, are largely based on a positivist research paradigm (Byrne and Alexander 2006; Denison and Stillman 2012). By positivism we mean "that the social sciences and sociology in particular, are natural sciences in which abstract laws of human organisation can be formulated to explain the operative dynamics of the social universe. The plausibility of these laws are then to be assessed against systematically collected empirical data" (Turner 2001: 11827). Information Systems practice can be regarded as an applied social science that uses technological artefacts, and as such it needs ethics because it works with human subjects. From this perspective, ethics requirements can be substantially 'checked off' against a particular pre-set list. However, the question still arises whether positivistic norms, developed from a generally Western, individual and industrialised context, are appropriate in all situations. In certain situations, such as in culturally complex non-Western field research, the notion of easy-to-gain systematic, empirical and verifiable data is fraught with difficulty. Factuality is in the eye of the beholder, and multiple perceptions, narratives and roles interplay in the interaction between the researcher and the research partner in the community (Geertz 2000). In this regard Capurro (2008:124) highlights the important issue of "universality of values versus the locality of cultures".

The researcher must be open to self-questioning about ethical issues when describing a project, and to involving the community in the identification and resolution of ethical questions (Stahl 2011). Although extensive debate on how to conduct and validate such research has taken place in the IS domain, consensus has not been reached as to whether a single ethics code can be applied in different research contexts and in different research approaches (Byrne and Alexander 2006).

This necessitates adaptation of ethics processes to meet the needs of specific communities, as well as an acceptance that research methodologies need to be more flexible than allowed for by a positivist ethics framework (Wiles, Heath et al. 2005:6; Byrne & Alexander 2006; Denison & Stillman 2012). Also important is the involvement of, and collaboration with, individuals with local knowledge and understanding. This is particularly true when the researcher(s) has a significantly different educational and cultural background to the members of the community in which the research is being conducted (Byrne & Alexander 2006).

Discussion based on the case study

Rather than presenting the community with a pre-set ethics form, it was decided to be far more flexible and engage in 1) piloting, and 2) a process of ethics enquiry and discourse with the subject community, making them active participants in the process, rather than just signatories who sign a form. This more open form of ethics enquiry stands in contrast to a prescribed form based on particular assumptions about the nature of relationships between people. As Nicholls puts it in Foucauldian terms, “discourse shifts away from regulating risk through *connaissance* (legal and institutional ethical regulations) and provides an alternative, ingrained within the ethical *savoir faire*” (Nicholls 2007: 5).

For example, the notion of a legal representative having the right to sign on behalf of a person (a strong legal principle) was viewed by a number of people as highly negative, and this had to be removed from the ethics form. This negative view of a legal representative is contrary to what is assumed to be a positive affirmation of the protection of rights. The question then arises (and has not been resolved here): would a community’s view and *savoir faire* on such matters over-ride the legal requirements from which an ethics committee derives its authority?

Relativist approach to ethics

Ess (in Capurro 2008:119) argues that it is important to “avoid imperialistic homogenisation while simultaneously preserving the irreducible differences between cultures and people” when considering the appropriate ethics approach. Proponents of a relativist ethical approach hold that “there are many different ethical perspectives on an issue, each of which contains part of the truth, and that some are better than others, but that none of them contains the whole answer” (Allan 2011:19). What is important is how to decide on which objective standard applies. This can be achieved by seeking points of agreement between different parties, and moving to consensus from there on. Ethical relativists are of the opinion that, while common research processes and strategies should be considered, the ethics approach should be context-based and culturally appropriate for the specific setting (Byrne & Alexander 2006). This calls for a careful and detailed situational analysis of the local conditions as opposed to ‘mono-cultural chauvinism’ (Capurro 2008:120). This is also familiar from work which warns against re-colonisation of indigenous or native people in the research process (Nicholls 2007).

Discussion based on the case study

The relativist approach takes into account the reality of the very different social and cultural relations that exist in traditional communities. While outsiders may object to traditional patronage or patriarchy, it is not their right to interfere in it, at least when first initiating research activity. The chief’s authority and all that goes with it is in operation and

has to be respected. It must be noted that traditional authority and rulers are legally recognised in South Africa.

Vulnerable populations

The way in which the positivistic ethical frameworks which dominate Western research institutions has developed lacks the ability to address the complexity of working with vulnerable populations (Pittaway, Bartolomei et al. 2010:232; McAreavey 2014).

Johnstone (2007:73) summarises the root cause of the challenge to applying what are regarded as acceptable 'Western' ethics norms in rural communities when she states that ethics theory "has typically been concerned with the normative analysis of *individual intentional action* or, somewhat less commonly, the character of individual actors" (authors' italics). This approach has led to the emphasis on issues such as informed consent, invasions of privacy, ownership of intellectual property and misuse of personal data. Of particular interest is whether members of so-called vulnerable populations can in fact give informed consent as understood in the Western positivist ethical framework as groups or collectives rather than as individuals. If not, how does it affect the research process?

The power imbalance between the researcher and the participants of remote rural communities raises complex ethical challenges for research in general, and for securing informed consent in particular (Pittaway, Bartolomei et al. 2010). Issues that must be considered are, for example, a) the limitation of autonomous decision-making, such as for women in patriarchal communities; b) the fact that researchers are often perceived as having the ability to affect change in the lives of individual participants or their community; and c) that researchers are often regarded as authority figures.

The traditional view of informed consent and vulnerable populations

For informed consent to be given, the prospective research participants must be made "fully aware of the issues surrounding the choices that they are making, including the expectations, consequences, potential pitfalls and benefits as well as the alternative choices and courses of action available to them before deciding to become actively involved in research" (Steel 2004:9). This information must be given in a way that they are fully able to understand.

Byrne and Alexander (2006) point out that the traditional positivist understanding of informed consent relates to "the right of individuals to be informed about the nature and consequences of experiments in which they are involved. Participants must voluntarily agree to participate based on full and open information". The individuals concerned should not suffer from impairments to reasoning and judgement, and must be in possession of all the relevant facts. Factors that make it impossible for people to give informed consent include severe mental impairment, intellectual and emotional immaturity, high levels of stress, intoxication, severe sleep deprivation, extreme poverty, illiteracy or limited literacy, lack of sufficient information, and information not being available in a language that they understand. People ordinarily described as vulnerable include children, older people, people with physical and mental health problems, and people who do not have the ability to fully understand what participating in a specific research project entails or what the consequences of their participation might be (Wiles, Heath et al. 2005).

In this view of ethics and informed consent, obtaining true informed consent from individuals, groups and collectives in vulnerable populations) is a challenge (Yan & Munir 2010:33). The International Ethical Guidelines for Biomedical Research Involving Human Subjects highlights the fact that strict adherence to informed consent might be impossible for vulnerable populations, and proposes conditions for "the appropriate inclusion of these populations while protecting their liberties" (Yan & Munir 2010:35).

Homan (in Wiles, Heath et al. 2005:10) argues that "the notion of true informed consent, where study participants are given a full explanation and are able to reach a clear

understanding of what participation involves, exists more in rhetoric than reality.” He ascribes this amongst others to the “difficulties of explaining fully in a way a participant can understand and the impossibility of knowing all the consequences of participating before a study has commenced”, and states that “because of the tension between the participant’s right to refuse and the motivation of the researcher to achieve a high response rate, researchers use various strategies at their disposal (including providing less than full information and incentives to participate) to encourage participation” (Wiles, Heath et al. 2005:11).

Despite the difficulties highlighted above, Yan and Munir (2010) are of the opinion that the inclusion of vulnerable populations in research is important as it ensures that these populations benefit equally from research. Excluding them is unacceptable if the research is “ethically defensible and when individuals stand to benefit from it” (Yan and Munir 2010:33). Steel (2004) agrees, arguing that the inclusion of a wide range of vulnerable and marginalised people in research is important as members of these groups do have something important to offer through their involvement in research.

Informed consent in rural communities

Denison and Stillman (2012:1047) offer a definition of informed consent which accepts the requirements of the traditional view of informed consent, but leaves room for adaptation to specific conditions: informed consent requires that participants be provided with sufficient information, in a language that they understand “which describes the purpose, methods, demands, risks, inconveniences, discomforts, and possible outcomes of the research to be undertaken ... Depending on the community involved, this may mean not only obtaining the individual’s consent, but also that of the ... community or collectivity, to which they belong”, and allowing for consultation between community members (Allan 2011).

Informed consent is closely related to, and interacts with, other values such as trust, privacy and security (Friedman, Lin et al. 2005). How these values are defined has implications for the identification of the actions that require informed consent. Informed consent should be underpinned by the researcher’s respect for the research participants, and not merely by the fact that the researcher has to comply with REC requirements. Research conducted in rural communities must be ethically and culturally appropriate. Indigenous ethical protocols must shape research methods according to local cultural imperatives (Botha 2011).

In addition to the issues discussed above, there are others that must be considered when discussing informed consent in rural communities. The discussion is underpinned by the case study.

Discussion based on the case study

The case study discussed here is being conducted in a remote rural community which has a patriarchal tribal authority structure, where the traditional chief’s endorsement and support is necessary for many forms of collective activity, including engagement with outside researchers. The target group of the research, middle-aged women, are the most disenfranchised members of the community, who are subject to the chief’s power and authority, and would not participate either as individuals or collectively without his permission.

Signing a pro-forma document does not constitute true consent. True consent can only be given as a result of an iterative process during which the researcher provides information to potential research participants in a way and language that they can understand and interpret correctly and who are competent to make informed decisions within their own socio-cultural context. Informed consent must therefore be a ‘shared decision-making process’ during which the parties reach consensus about all the essential elements of a valid contract, as well as an agreement to work collaboratively (Allan 2011:151). Sin (in Byrne & Alexander 2006:118) supports this approach to informed consent: “The constant renegotiation of consent is underlain by the understanding that the complexity of research demands forms of consent,

some more explicit than others, depending on the stage and nature of research at different points of time”.

The definition of ‘vulnerable’ differs depending on the context. Individuals and communities that would be described as vulnerable and therefore disabled in a Western bio-medical context (e.g. those who are HIV positive) might very well be fully capable of making informed decisions in their own culture and community (where HIV-positive status or other conditions may be the norm). In one study which takes up the definition of vulnerability of African children, it is noted that “A consultative meeting in Kenya defined children as vulnerable if they lived in households with a chronically ill parent or caregiver, and in terms of access to key resources such as food, shelter, education, psychosocial and emotional support. These categories focus on factors related to HIV. There is an entire set of variables that needs to be considered that relate to more general aspects of the child’s context, such as poverty, access to shelter, education and other basic services, disability, impact of drought, stigma and political repression – all factors that could influence vulnerability” (Skinner, Tsheko et al. 2006:620). However, there is at the same time a danger that the use of the term ‘vulnerable’ leads to stigmatisation and incapacitation. These factors equally apply to women in deprived communities, the subject of the case study here. Indeed, as Amartya Sen has argued, what is considered to be a ‘disability’ in the West, namely poverty, ethnicity or caste status, homelessness, gendering, age, landlessness and so on, should be considered as normative rather than non-normative in the development context (Sen 2001). It is across these ‘axes of inequality’ that their lives are constituted (Kleine 2013:45).

Second, as is well known, the term ‘community’ is almost impossible to define and has been subject to endless discussion in research practice literature. Is it a geographic or social entity, or a social construct, subject to all sorts of social play? The problem cannot be solved here, but for this case study the communities are seen as small and distinct isolated clusters of people, bounded by language, livelihood and location. They are aware that they belong in a place or locality.

Thus the degree to which the capacity for independent and individual decision-making presented in normative ethical requirements is possible in these communities must be re-considered. Traditional beliefs, ideologies and power relations influence the capacity of people to act outside of community or communal boundaries. There is often a strong patriarchal-hierarchical structure in which the authority of the chiefs, traditional leaders or gatekeepers supersedes individual autonomy. Independent action can be limited because of the chief’s or others’ instructions or more subtle hints, and the fear of being victimised should the individual community member decide not to participate or to withdraw. Alternatively, the individual may of course consider that deference to the chief’s wishes is the correct way to do things (Pittaway, Bartolomei et al. 2010). Is agreement with the chief’s way of doing things in opposition to the normative principle of ‘true and informed (and individual) consent’, or rather should ‘true and informed (collectivised) consent’ be qualified by the understanding that this is part of a particular cultural system?

Further Discussion

Research of this type in impoverished rural communities places an additional burden on the researcher to conduct the research with integrity and accountability. These communities often have one overriding goal: to ensure their survival on a day-to-day basis. This aspect is very clear from the circumstances of the case study. It is therefore very possible that people will regard the researcher as somebody who is in a position to contribute to their wellbeing and survival, and therefore agree to participate in order to benefit in some way. This may not be obviously stated, but it is clear from the authors’ experiences in the past in many other communities that researchers are seen as a resource. It can also lead to understandable confusion because expectations are often not voiced directly when communicating with researchers. In a similar project in another community with which the authors were involved, a clear obstacle to acceptance of the ICT project (which was eventually overcome after considerable discussion) was the community’s desire for a new project about a different

matter, namely water. It is possible that past experiences with researchers had given them the impression that behind-the-back scheming could ensure the execution of the desired project. What they said in effect was “you can do the ICT project in the community if you also do something about the water issue”. There was little understanding that funding was tied up for particular purposes. On the other hand, the community was making a good point – their priority was for water, not new computers, and researchers who enter the community with a bright idea may find it very difficult to justify their activity in the face of community needs and preferences.

Indeed, there will inevitably also be unseen politics that go on behind the backs of the researchers, as well as naturally occurring role plays, both on the part of the researchers and the participants, and these will compromise any form of ethical consent process as understood within the rigid prescription of RECs.

Ideally, when conducting research in rural communities it is therefore important to recognise and honour potential research participants’ agency and capacity to respond within their own socio-cultural context, even though they might be described as ‘vulnerable’ within a Western research context. Members of such communities deserve to be treated with respect. As far as possible, researchers must ensure that community members genuinely understand what the research project is about, what the foreseeable outcomes are and what benefits (tangible, immediate and longer term) the participants can expect (Byrne & Alexander 2006). Researchers must present the intention of the research project in such a way that mismatches of expectations are prevented. They must make a genuine effort to ensure that individuals are not unduly pressurised to participate, difficult as this may be to achieve in culturally choreographed performances to which researchers will probably always be outsiders. In such situations, ways must be found to communicate that assist potential participants to understand the implications of what they are signing up for or giving informed consent to. In the words of Denison and Stillman (2012:1047) “... ethical behaviour requires ongoing attention to detail, and regular self-reflection about the effect of action”. Self-reflection here means that it is the researcher’s responsibility to make sure, as far as possible, despite the politics of the situation, that research participants are not harmed or exploited in the particular context in which the research work is taking place.

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