Ethical and Social Dilemmas in Community-based Controlled Trials in Situations of Poverty: A View from a South African Project

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ABSTRACT

All psychological and social research presents ethical dilemmas, many of which centre around the difficulties which flow from the power imbalances between those conducting the research and the research respondents or participants. Issues of power are magnified in research undertaken in contexts of poverty, and there is a burgeoning literature on ethical issues in research in developing countries. In this article, we augment the existing literature by focusing on the experiences of an assessor working in a controlled trial of a mother–infant intervention in a poor South African community. We consider issues of community expectations, the presentation to our project of physical health problems, the issue of HIV/AIDS, cultural beliefs which impact on the research, child protection issues, and the tensions between research assessment and ubuntu—a cultural norm which requires helpful engagement with others. We suggest that our experiences may assist with the development of further research. Copyright © 2002 John Wiley & Sons, Ltd.

Key words: ethics; poverty; South Africa; developing countries; randomized controlled trials; research design; cultural factors; early intervention; infancy

INTRODUCTION

There are many debates internationally about what constitute the best ways in which to conduct research, and there is a growing literature which argues that many research endeavours may have negative outcomes for respondents and for communities (Benatar, 2001). Psychologists, as researchers and practitioners, face ethical dilemmas wherever they work, and considerable effort continues to go into providing useful guidelines by which research and practice can be planned and evaluated (American Psychological Association, 1992; Azar, 2002; British Psychological Society, 2000).

At the heart of much of the concern about ethics is the reality that there is usually a power imbalance between professionals and their clients, and between those conducting...
research and research respondents (Schüklenk, 2000). Particular concern has been raised in the literature about the importance for ethics of being sensitive to issues of power imbalances on the bases of gender (Westmarland, 2001), race and ethnicity (Baldwin-Ragaven, de Gruchy, & London, 1999; Hall, 2001), sexual minority status (de Gruchy & Lewin, 2001), as well as mental disability and illness (Macklin, 2001; Schüklenk, 2000). Informed consent, to name one key, though at times controversial (Kahn, Mastroianni, & Sugarman, 1998), issue, is hard to assess when respondents are vulnerable, needy, or from a different cultural context to the researchers.

Poverty and deprivation are risk factors for many poor outcomes, including many diseases and many adverse social conditions, including violence, demoralization, and difficulties in human development (Desjarlais, Eisenberg, Good, & Kleinman, 1995; Gibson, Swartz, & Sandenbergh, 2002). These risk factors are not however evenly distributed across the globe. Poor countries carry a much greater burden of human misery and ill-health than do richer countries (World Bank, 2001a, 2001b). It is therefore essential that researchers interested in global wellbeing conduct research in low-income countries, and especially research which carefully explores the possibilities for interventions which can improve life in these countries (Isaakidis, Swingler, Pienaar, Volminck, & Ioannidis, 2002). The paradox of the situation is, though, that all the difficult issues of power imbalances and cultural differences discussed above can all too easily be magnified when research is conducted in developing country contexts. There is a rapidly increasing literature on the enormous difficulties, both logistically and ethically, even the most resourceful and best-intentioned researchers face in working in poor countries (Arnot, Jepsen, & Kilama, 2000; Benatar, 2002; Jesus & Higgs, 2002; Rugemalila & Kilama, 2001). There have been innovative contributions both about how we should be reconceptualizing ethical issues in such countries (Lindegger & Richter, 2000), and on how we can begin to assess whether ethical targets have been met in such contexts (Leach et al., 1999). Much of the literature on these issues addresses important broad questions about ethics and research design and practice, as well as the key question of how best to develop and strengthen research capacity in poor countries (Nchinda, 2002). Far more rare, however, is a consideration of how these issues are realized at the microlevel of actual research projects (Haney & Lykes, 2000), and we have been unable to find detailed descriptions of challenges facing fieldworkers in psychological intervention research in Africa. Such descriptions may be useful in contextualizing the broader issues, giving them a human face, and providing qualitative data which may be helpful to spur new thinking both within individual projects but also in broader research design.

In this article we focus on the experiences of an assessor within a controlled trial of an intervention in South Africa. First, we introduce our project, before moving on to a consideration of the assessor’s role. We then consider issues related to collecting data in a developing country, before discussing the implications of our work for our own research, and that of others.

THE THULA SANA PROJECT

The Thula Sana Project is a community-based intervention with mothers and infants in Khayelitsha, Cape Town, South Africa. Khayelitsha is a peri-urban settlement with a population of between 500,000 and 1 million, many of whom are migrants to the city from impoverished rural areas (Cooper et al., 1999; Mash, 1998). Fewer than one in five of

the dwellings are formal houses; most residents live in shacks. Migration patterns to and from rural areas make for an unstable and shifting population. Unemployment runs at approximately 66%. There is no social security in South Africa, so unemployed people receive no money at all. Of those who are employed, most earn less than the household subsistence level. Education levels are commensurately low, with a functional illiteracy rate approaching 25%. In some areas (including part of the area in which the project is situated) there is no electricity, no running water, and communal taps are shared by up to 50 households. Services such as rubbish removal are irregular and inefficient at best in some areas (Cooper et al., 1999; Mash, 1998).

A community-based survey was conducted in part of Khayelitsha, and the rate of post-partum depression was found to be 34.7%, around three times that found in Britain and similar countries (Cooper et al., 1999). International research has shown that both maternal depression and social adversity lead to compromised social, cognitive, and emotional outcomes for infants (Murray & Cooper, 1997; Murray, Fiori-Cowley, Hooper, & Cooper, 1996; Olds et al., 1998). An important follow-up question is whether it is possible to intervene with mothers to improve maternal mood and to facilitate improved mother–child interaction, and to impact on cognitive, emotional, and social outcomes (Murray & Cooper, 1997).

Given the situation in Khayelitsha both with respect to social adversity and with respect to maternal mood, an intervention was designed to attempt to improve outcomes. The project is called the Thula Sana Project—this name literally means ‘Hush little baby’ in Xhosa. It is a controlled trial, with one group receiving a home visiting programme by trained community workers, and the other receiving the usual care offered in that community. The randomized controlled trial design is one which has been argued to be well suited to the assessment of treatment effects, and is well regarded as a method for research into interventions in Africa (Birckmayer & Weiss, 2000; Fetterman, Kaftarian, & Wandersman, 1996; IJsselmuiden, 1997; Isaakidis et al., 2002; Joubert & Katzenellenbogen, 1997; Rothman, 1986).

In designing our project in a context of extreme poverty and very little infrastructure, we were faced with both logistical and ethical questions. From a logistic point of view, we were concerned that it would be difficult to keep track of a highly mobile population. Adding to this difficulty is the fact that in some parts of Khayelitsha, addresses are not fixed to specific geographical locations—for example, though many shacks are numbered, if the residents of a shack decide to move and to build a new shack elsewhere, they may take the number of their shack with them to the new location. As far as ethics are concerned, we were worried about providing any intervention to some members of a community desperately short of services, while withholding services from other community members. We were fortunate to begin to address some of the ethical and the logistic concerns by attaching the project to an existing community health project. This is a non-governmental health programme with university links which, amongst other services, offers assistance to new mothers in the physical care of their infants, focusing on such issues as breastfeeding, nutrition and hygiene. The project has an existing cadre of staff experienced in keeping in touch with a mobile population. The project does not however explicitly offer emotional support and an intervention designed to impact on mother–infant interaction, which is the extra component our intervention addresses. In attaching ourselves to this project, we were aware that Khayelitsha residents served by the project—including those in the control group—were receiving more services than average in the township. This decision could have affected the external validity of the project, but was ethically necessary.
The home visiting programme itself is undertaken by trained women from the community. Assessments of mothers and later of infants as well are undertaken antenatally, and at 2 months, 6 months and 18 months post-partum. The nature of the assessments themselves is not important to the present discussion, but some information about our approach to assessment can be found in Cooper et al. (2002). The assessments are conducted by the assessment team, a member of whom is the first author (NN). The assessment team, in keeping with the controlled trial design, is blind to who is receiving the intervention home visiting programme. NN is a Xhosa-speaking African resident of Cape Town who has a background in mother–infant work and training as an occupational therapy assistant. She does not live in Khayelitsha, but goes to work there 5 days per week.

THE DEVELOPMENT OF THE ASSESSOR’S ROLE

NN was one of the first employees of the project and had the important role of introducing the project to the community and establishing credibility, which is essential if any endeavour is to begin successfully in South Africa. Local communities are very much aware of the fact that in the past researchers (who were mainly White) would collect data on impoverished people without making any contribution to improvement of their lives (Dawes, 1985). Since the late 1980s in particular, communities have been vigilant about this form of exploitation, and it is only through consultation with local community and political structures that access can be gained. In this regard, NN’s experience of and sensitivity to community issues was central to the project’s beginning. She had to attend meetings and to promise various organizations that the project would benefit the community. As NN became better known in the community, the more she became seen as a person able to offer assistance in the community.

As further funding was secured and the project itself began, NN’s role changed. She became an assessor, blind to the intervention status of the mothers and infants with whom she was working. This is a very different role from the original one of advocate for the project and its benefits. It can be argued that there are inherent problems with an advocate for a project then becoming an assessor in that same project. In an ideal world, these roles should be separate—the assessor should not be seen by the community to have any investment in the outcome of the project. Given the resource constraints under which we were working, however, coupled with local politics, this dual role was necessary. This may well have had implications for how the assessor’s role developed, as we discuss later.

COLLECTING DATA IN A DEVELOPING COUNTRY

Community expectations

As the assessor on the project, NN must not provide any service to the community. There are of course the obvious exceptions of crises where ethical considerations call for immediate action regardless of the research implications.

As mentioned earlier, we attached our project to an existing community-based health programme which provides services in the area within which we work. In practice, we have erected prefabricated buildings on the grounds of that project. This means that we are, in the eyes of community members, associated with a project which is a service project and which assists all people who come to it. The basis on which we gained access to the community, furthermore, was that we would be assessing a way of helping mothers...
and infants. It is therefore understandable that members of the community may regard all our staff—including the assessment team—as there to provide immediate services. It is difficult to dispel this perception for at least three reasons. First, the change in role of one of the assessors (NN) from project advocate to data collector may have caused confusion. Second, the levels of functional literacy in the community are low, so printed material reminding residents of our particular role would be of limited value. Third, and most crucially, there are so few resources that people find it hard to accept that a project which clearly has resources and expertise would not want always to provide immediate assistance.

Physical health problems

An example of how the assessor role is understood by the public can be seen in the common occurrence of mothers bringing their physically ill children to NN for help. There are clearly two understandable misperceptions at work here. The first is that assessors will see it as part of their work to provide assistance—a reasonable assumption given previous experience of services and interpretations of our entry to the community. Secondly, because our assessments focus on mental health issues and also include collection of various indices of physical growth and health, such as anthropometric data, community members may assume that our assessors have training in intervening with physical illness in children.

When our assessment team is confronted with a child who is ill, the decision about what to do is relatively easy—the child is referred to the community health workers who have access to skills and medication in the physical health area. From a research point of view, this referral is probably not a serious breach of the assessor role as the chances are that the mothers would have approached the community health project anyway for help. It is possible that control group mothers are more likely to use the assessors on our project as a means of accessing the physical health project. By contrast, the intervention group mothers may be approaching the intervention team to access the physical health project. For reasons of maintaining blindness to the intervention, we cannot currently know whether this is the case, but this is something which can be assessed at the end of the project. Other issues, though, are more complex and difficult to gauge.

On occasion, mothers have come for their assessments with infants who are clearly ill. Some of these mothers have not identified their children as ill, however. For example on one occasion a mother brought a child in for the assessment and the child was running a fever and lying limply in the mother’s arms. Under these circumstances, it was not possible to assess mother–infant interaction (an important variable in our study), and the mother was referred to health services for treatment, and asked to return when the child was well. This intervention in the infant’s life—referral to health services—may clearly have had an impact on the outcomes we are assessing, but it was ethically necessary.

HIV/AIDS

The rate of HIV in South Africa is very high. In 1999, National Department of Health figures estimated that 22.4% of South African women using antenatal health care services were HIV positive (Tshabalala-Msimang, 2000). The Western Cape province, where Khayelitsha is situated, has the lowest rate in the country, with an estimated prevalence of 7.1% amongst women using antenatal services (Tshabalala-Msimang, 2000), but this is still a very high figure, and is rising. Disclosure of HIV status is a complicated matter.
in South Africa—some years ago, for example, a health worker in the KwaZulu/Natal province, where rates are very high, disclosed publicly that she was HIV positive, and was stoned to death as a consequence.

There are also currently fierce debates in South Africa about the advisability of giving antiretroviral therapy to pregnant women. Antiretrovirals have been shown to reduce the risk of transmission of HIV infection to infants of HIV positive women. For the duration of much of our study, the Ministry of Health was arguing that the efficacy of antiretrovirals in this context has not yet been proved, and that the provision of these drugs was too expensive (Le Page, 2000). In Khayelitsha, though, there has been a pilot study of antiretrovirals for pregnant women, and this study is being closely watched by the rest of the country.

Against this complex background, HIV-positive women are giving birth in the situation of poverty of Khayelitsha, and some of them are seen by our project. On one occasion, NN undertook an assessment of a mother and a 2-month-old infant who appeared very ill. The child’s HIV status was not revealed to NN, but she learned about a month later that the child had died of AIDS not long after the assessment. Apart from the emotional toll that this takes on an assessor (an issue to which we shall be returning later), an opportunity was lost to offer appropriate support to a mother and her dying child.

Because of the stigma surrounding AIDS, some mothers will report to us that they have been instructed not to breastfeed their infants, and we have learned that this is a way of telling us about their positive HIV status. Sometimes mothers do disclose that they are HIV positive—this has been happening in our more recent assessments. Increased rates of disclosure may be related to increasing confidence about our project in the community. Most of these women, understandably, are very distressed and they score high on measures of depression. One pregnant woman, however, who reported that she was HIV-positive seemed unperturbed and did not rate as depressed. This led us to wonder about whether she was fully aware of what the implications of positive HIV status was for her in her context. Many questions were raised for us. Was the mother fully aware about HIV? Had she been adequately counselled? Was she in denial? The woman, furthermore, was married, and was probably having unprotected sex with her husband. We were unsure whether she had been infected by him or whether he was at risk of infection from her. The assessor role on this project, which is not to intervene, leaves us in a quandary. Apart from our responsibility towards the woman herself, there are broader public health issues at stake.

All of this takes place against the background of a very personal relationship between the assessor and the mother and child. The assessor has ongoing contact with these children at least (within our current research grant) to the age of 18 months. This contact is not purely instrumental—an emotional relationship develops which is fostered partly by the physical contact an assessor has with a child—helping pick the child up and seat him or her comfortably in an infant seat, for example. A relationship of trust develops between the mother and the assessor, and there may be an implicit (and reasonable) expectation from the mother that the assessor will assist with promoting the health and safety of the child. Where HIV status is understood fully by the mother, this is complex; it is more so when the mother does not fully understand.

Cultural beliefs in witchcraft

Beliefs in supernatural forces are found throughout the world and across all social classes (Swartz, 1998). These beliefs may however interact with local conditions of poverty and deprivation, as the following two examples show.
On one occasion, a pregnant woman came for her assessment claiming that she was not pregnant. (She had been identified as clearly pregnant by one of our project’s recruiters.) She explained her pregnant shape by saying that her aunt had put evil spirits in her stomach. NN decided on this occasion not to proceed with an assessment but suggested instead to the mother that she consults with a doctor to enquire about pregnancy. The mother was encouraged to return after this visit, but she did not return until later the following week, when she arrived with her newborn baby, and asked for food for the baby.

In a different context, there might have been serious concerns about this mother’s mental state—there could even be questions about whether she was psychotic when she first came to see us. In Khayelitsha, however, belief in witchcraft is not always culturally strange, and certainly does not always imply psychosis (Swartz, 1998). Nevertheless, it is important methodologically for us to consider the possible impact on our data of a case such as this. For the safety of herself and the child, the mother was referred to another mental health project for full assessment and possible intervention. Her needs however related not just to mental health issues. Cultural factors may have played a part in suggesting to this woman that she was not pregnant. This belief in turn led to lack of preparation for the birth, a factor which can have devastating implications where money is scarce and it takes time to amass what is necessary for the care of an infant.

Child protection issues

Another case involves an infant, the youngest of four children. All the children in the family were living with the father and the paternal grandmother. This occurred after the paternal grandmother had moved to Khayelitsha from a rural area to live with the parents and the children. Following conflict between the mother and her mother-in-law, the father of the children took his own mother’s side and ordered the mother of the children to leave the home. He said further that if she took the children with her, he would not provide for them financially. Being unemployed herself, and with little chance of finding employment and no social security, the mother chose to leave the children with their father and paternal grandmother. The mother continued to see the children when she could, but was not living in the home. On an assessment visit when the infant was 18 months old, the mother was very depressed and agitated because she alleged that her 14-year-old daughter was being used by the paternal grandmother for witchcraft purposes. She reported that the 4-year-old had told her that the maternal grandmother required her to fly naked with the grandmother through the air at night. On one occasion, the child had been lost for 3 days. When she was eventually found, the child said that she had been under the maternal grandmother’s bed, where a snake had been licking her body.

On further exploration by NN, the mother said that she had witnesses to these events. The mother had reported the alleged witchcraft to the local street committee (the informal local political organization). They had called the family to a meeting at which the 4-year-old had repeated her claims about the maternal grandmother. The maternal grandmother herself had agreed that she was indeed a witch who kept a snake under her bed. The mother lived under such impoverished conditions that she could not without assistance take custody of her children. NN was concerned for the wellbeing of the children and felt compelled to refer the matter for further action to the local social worker. Because of case loads, it was unlikely that the case will be seen soon by the social worker. Similarly, the mother was advised to apply to the Maintenance Office for assistance. The most desirable outcome would have been that the husband would be ordered to support the children
financially while they are in the mother’s care. Again, waiting time for an intervention could take months or even years.

More recently the mother claimed that she had had a period in which she had been dead. She said that she had come to life again only after her family had consulted an indigenous healer. This alleged death was, she said, as a result of witchcraft on the part of her mother-in-law.

This case, apart from being of intrinsic interest, highlights some of the dilemmas of our work. It was not possible to assess the child when the mother was in an agitated state so the appointment for the assessment was postponed. There are also questions however about the assessment as a whole: the children are not in the care of the mother, and the grandmother is effectively the primary caregiver. Our protocol allows for assessment of whoever the primary caregiver is at the time, but the grandmother because of her alleged status as a witch was not amenable to co-operate in the study.

From a Western perspective, the entire context of assessment in this case may appear foreign or bizarre, but there is no question in the community that the grandmother is a witch. The mother herself believes the grandmother to be a witch. Community members believe strongly that the children should be with the mother. There are however no resources to return the children to the mother’s care.

If there were adequate social service facilities in the community, it would have been possible to refer the entire family for an urgent and comprehensive assessment. This assessment would examine, amongst other things, questions of appropriate custody and placement. In our role as assessors, we have clearly done more than simply assess according to the variables we are studying. We have also done less than these children almost certainly need. This once again places us in the unclear area of being assessors who also are forced by circumstances to intervene. We do not know, however, whether what we have done has made an appreciable difference to the children involved.

Ubuntu and the cultural imperative to help

In all research projects taking up people’s time and imposing on them to a degree, there is a question of compensation for the respondents. In our own study design, we give mothers a set of infant requirements such as soap and shampoo, before the babies are born. At 2 months we provide each mother with a romper for her child, at 6 months a baby food hamper, and at 12 and 18 months an item of clothing for the children. Mothers are also compensated financially if they lose wages as a result of an assessment visit. While mothers wait with their babies they are given tea and biscuits and juice and biscuits for the older children. When the project was planned, the project team decided against giving financial incentives to mothers for their attendance and rather to give items for the children as we were concerned about the effects in the community of these mothers’ being paid. In a deprived and often violent community, a person who receives financial compensation, however small, for participation in research, may become targeted by others who wish to have the money. Women in particular (and, by extension, their infants), in a country with exceptionally high rates of gender violence (Gibson et al., 2002), may be vulnerable to having money they have been given taken away by men.

Some mothers arrive for the assessment in desperate circumstances. In some cases, it is possible to refer the mothers to local nutrition and child health services, but on occasion, the need is immediate and extreme. Sometimes, NN gives money to the mothers from her own pocket. This is done out of a sense of humanity which, within Xhosa culture is
expressed in the term ‘ubuntu’. This term literally means ‘humanness’, and relates to the Xhosa proverb ‘Umntu ngumntu ngabantu’, which means that a person is a complete person only through humane dealings with other people (Burger, 1996). This ethical principle, which has deep cultural roots and resonance, overrides concerns about study design and the analytic division between assessment and intervention in a controlled trial. We discuss this issue further in the discussion later.

DISCUSSION: SCIENCE, ETHICS, AND THE LOCAL POLITICS OF RESPONSIBILITY

When our controlled trial was designed, it was approved ethically by the appropriate university committee. It is clearly essential from a research point of view to have a way of assessing the impact of an intervention free from contamination.

We have shown through various examples that local considerations, all related in some way to poverty and deprivation, have led to two important unintended outcomes. Firstly, in our case, the needs are so great that the question of breaking the research protocol such that assessors may intervene is raised exceptionally often. Secondly, the experience of working as an assessor under conditions of extreme poverty leads to what may be an exceptionally high level of distress and discomfort for the assessor.

In the community of Khayelitsha, where levels of education are not high, and many people are not accustomed to research, the concept of a controlled trial is completely unfamiliar. Notions of scientific ethics, or the ethics of policy appraisal and implementation, mean little to our respondents and their neighbours. These ethical notions depend not only on people being educated into the rules of research but also on people’s tolerance for participation in projects where benefit to the participants may be minimal. In well-resourced situations, being part of a control group in an intervention study may be an irritation or possibly interesting, and there may be a sense of achievement in contributing in a small way to the advancement of knowledge. Where there is endemic poverty, however, any contact with the relative wealth of a research enterprise may hold to some participants the promise of resources. Contact with a research project may represent a lifeline to the outside world and the possibility of a link with a more hopeful reality. It would be strange to expect people living in great poverty not to notice our resources and at some level to wish for what we have or may offer. The material goods that we have, furthermore, are less important ultimately than the human resources any good project will have. If any project is to succeed optimally, the personnel will be reliable, innovative, committed to the work, and trusted and respected by the community. It is only reasonable that such personnel in themselves should represent to community members a source of help and linking with the outside world.

This raises the more fundamental question of whether we should be doing psychological research in this type of community at all. Indeed, it is commonly said that basic needs are more important than psychological needs (in this regard Maslow’s hierarchy—Maslow, 1954—is usually cited), and that money spent on psychological research could better go into food or social programmes. For community psychologists, furthermore, endeavours which focus on the prevention of deprivation and oppression should be prioritized. The fact is though that if we were simply to disburse the amount of money we spend on our project, it would make little impact on people’s lives in anything but the very short term. In addition, if we are able to show that our intervention works, we will have developed an
affordable model which has the potential to impact positively on the development (and hence the material lives) of millions of people. Furthermore, the psychological consequences of deprivation and oppression require intervention in themselves, and impact on the ability people may have to change their circumstances of poverty. Interventions such as ours, if they succeed in assisting mothers in their interaction with their infants, may form the basis for broader prevention initiatives. Prevention activities depend strongly on empowered interpersonal interaction (Galano et al., 2001; Wandersman, 2000).

The constant movement in our thinking back and forth from the local ethics of immediate need to the broader ethics of the design of community-based interventions is not unique to our work, and is a feature of any similar project conducted in a context of poverty. If community psychology is truly to serve one of its central missions—that of engaging with broad social issues and taking on the challenge of addressing these—then it will more and more be operating in very poor environments across the globe. It is important to consider, when designing any such project, the impact of this work on the workers themselves. It is well established that community health workers working in poor communities have high rates of work stress and drop out from these programmes (Wood, 1990). Researchers, for slightly different reasons, are at similar risks. If we believe that community psychology has something to offer, we need to anticipate and deal with these difficulties. There is no way to make the dilemmas go away—they are part of the work. What we can do, however, is to open discussion about them and to provide support for those who bear what may often be a large burden in important projects. This burden may often be invisible to the outside world. Further research focusing more widely than the discussion of our own case is necessary to establish in what ways our situation is either unique or similar to others; we hope, however, that we have contributed to broadening the debate.

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