
Mapping HIV/Aids as a barrier to education: a reflection on the methodological and ethical challenges to child participation

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Abstract

The authors reflect on a qualitative research project on mapping the impact of HIV/AIDS as a potential barrier to education for young, vulnerable children. The methodological and ethical challenges in this project are explored in terms of the multiple layers of context, topic and skills that impinged on the nature and process of the research design. The means of obtaining informed consent, negotiating the bounds of confidentiality and addressing beneficence and nonmaleficence are discussed. A four-stage focus group design is related to the underlying principles of valuing the child and a process approach to research. Strategies, including participatory research techniques with vulnerable children are described. The researchers argue that especially in developing contexts, the ethical and methodological issues are interrelated and result in inherent tensions in the research process.

Introduction

This paper arose out of a broader South African study exploring the barriers to education that may have been precipitated by the HIV/AIDS pandemic.¹ The paper reflects on the complex ethical and methodological challenges that arose when conducting focus groups with children from a marginalized and developing context on the highly sensitive topic of HIV/AIDS. Five central issues related to the site of study, the target population and the topic of research are discussed. Firstly, conducting research in a developing context characterised by unemployment and extreme poverty generates particular dynamics of power. Secondly, the research context has a history of political

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violence and the research participants were likely to have experienced high degrees of stress and trauma, as well as be suspicious of external investigators. Thirdly, the stigma associated with the HIV/AIDS pandemic creates a culture of silence affecting the degree to which the pandemic can be openly discussed particularly in terms of the children's understanding of the illness. Fourthly, language and race differences typical of the South African context create particular dynamics amongst members of the research team, and between the research assistants and the participants. Lastly, it was challenging to find ways of accessing credible data and facilitating the expression of the children's voices.

The project

In 2004, a team of researchers from the disciplines of education and psychology at the University of KwaZulu-Natal engaged in a project to map the barriers to learning precipitated by HIV/AIDS in a small KwaZulu-Natal town. The project targeted numerous stakeholders ranging from learners (Grade 3, 6 and 9) to local health services and local government. This paper focuses on the pilot phase of this project with particular reference to the Grade 3 learners.

Researchers have acknowledged that access to quality formal education may be a combatant strategy against HIV transmission (Kelly, 2000, cited in Baxen, 2004) and may enhance resilience (Foster and Williamson, 2000). However, children exposed to the HIV/AIDS pandemic are likely to experience disrupted education. This is a strong motivation for an exploration of the nature of barriers to learning. Studies have acknowledged a gap in research within the educational sector in relation to HIV suggesting that it neglects the "social and cultural embeddedness of the disease" (Baxen, 2004, p.1). This highlights the need for localised research and alternative methodologies.

The research context

A small rural town in the KwaZulu-Natal Province of South Africa was selected as the research site. The town is surrounded by agricultural productivity with a population of approximately 70 000 people living in semi-formal and informal settlements. The population tends to be dominated by

young people and grandparents. In addition to a predominantly migrant labour force, the unemployment rate is approximately 40%, and 75% of the households earn less than R1 500 (£15) per month (Sinani, 2003). This town was a site of intense prolonged political conflict, with an estimated 20 000 people being killed and many more becoming refugees over the last twenty years, leaving the communities impoverished, fragmented and struggling for basic daily survival (Higson-Smith and Killian, 2000). Although the town has been actively engaged in a process of peace and reconstruction over the last four years, the high population mobility, high unemployment rates, and the continued social fragmentation have contributed to the extremely high rate of HIV/AIDS infections (Whiteside and Sunter, 2000). In fact, the KwaZulu-Natal region has one of the highest HIV/AIDS infection rates in the country. The pandemic has a major impact on all the biopsychosocial systems in which children develop with many children directly experiencing HIV/AIDS related deaths and illness in their families (Shisana and Simbayi, 2002). The problems most frequently associated with psychosocial risk variables are low self esteem, hopelessness, anxiety, aggression, depression, behavioural, cognitive and emotional difficulties, inadequate communication and life skills, and poorly developed problem solving, decision-making, and conflict resolution skills. In addition, the stigma associated with HIV/AIDS brings shame, fear and rejection that exacerbate the anguish of the children (Germann and Madörin, 2002; Hunter and Williamson, 2002).

The larger research project was responsible for identifying a range of community sites in which the research could be located. Sampling was partially random and purposive (Henry, 1998) addressing different rural and urban localities, political alignment, historical access to resources and racial integration. This aspect of the pilot phase of the research project considered two very different schools: a rural primary school with extremely limited resources where all the children and educators were *isiZulu* speakers; and a large urban primary and secondary combined school, in the centre of the town, with a racially mixed learner group, predominantly English speaking educators, and slightly better access to resources. Unlike the more rural schools, this school's position in the centre of town gives the learners access to many other attractions that compete with the basic activities of school.

Approaches to research

As discussed above, there has been a perceived gap in research that has sought a situated understanding of the effects of HIV. A qualitative and social constructivist (Fraser and Robinson, 2004) research approach recognises that language and action only derive meaning within a context – an inherited, cultural, historical and social background (Durrheim, 1997). This study sought in-depth knowledge of how children construct an understanding of barriers to learning. In discussing some of the ethical considerations and methodological processes that were adopted, it is important to recognise the following principles that guided our approach to this research: seeking depth and richness of description in the data; recognising the researcher and the research participants as co-constructors of the data; recognising the importance of active involvement of participants in the research; valuing the child; recognising the importance of developing particular processes and methods for working with children; acknowledging the issues of power, control and authority; and understanding the context as inextricable from the data.

Valuing the child as co-constructor of the research data

Research has moved away from seeing children as passive recipients of socialisation to recognising them as active participants in constructing meaning of their experiences (Christensen and James, 2000). Inherent in our approach was the assumption that the child's experience and perspective is critical and contributes significantly to our understanding of the phenomenon in this site of study, since children bear the brunt of the impact of HIV/Aids, emotionally, practically and economically.

Research with child participants presents unique challenges in conceptualising and implementing the research process (Jones, 2004; O'Kane, 2000). Working in a cultural and historical context in which children's voices have been marginalised, has highlighted the need to address the power imbalances that exist between adults and children, to develop techniques to maximise the participation of children, and to provide ways in which they could express their understanding and experiences without relying solely on verbal communication. The participatory techniques were developed in a collaborative process in the research team and arose from our accumulated experience of working with vulnerable children in developing contexts.

Participatory research techniques have their origins in development and agricultural interventions and are designed to proactively deal with the power dimensions within research interactions, and to reliably access the resource of local knowledge that develops in relation to the everyday activities of the participants (Chambers, 1992; Van Vlaenderen and Neves, 2004; Kelly and Van der Riet, 2001). The first principle is realised by giving participants a sense of control over the research process, the data and the dissemination of findings (Johnson and Mayoux, 1998). The second principle emphasises ways of accessing local and situated understandings of a phenomenon. The participative process results in the emergence of local categories and frameworks for understanding an experience. In conventional research the researcher's questions, in the form of an interview schedule or questionnaire, define the way in which data is extracted from the participants (Theis and Grady, 1991; Van Vlaenderen and Neves, 2004).

This study has used a participatory approach in an attempt to address the power differentials in the dynamic inherent in the relationship between researchers and the researched. Participatory techniques have also been used to access the participants' frameworks of understanding, and to facilitate the meaningful involvement of participants in the process (Kellett and Ding, 2004). Participatory techniques were considered fitting vehicles to facilitate participatory research with children without focussing on verbal fluency, but rather on applying methods to access particularly young children's perspectives.

The importance of process

Data collection processes in research studies are frequently once-off engagements with participants, for example, conducting a single interview or the administering of a questionnaire in a defined time period in a particular setting. Developments in qualitative research have highlighted the need to collect data on several different occasions over a time period (Seidman, 1991). This process-approach is assumed to be closer to activities in real life, where people's opinions change and develop over time and in relationship with the researcher. Employing this principle facilitated the accessing of participants' perspectives on their experience and was also used by the research assistants, as focus group facilitators, to develop relationships with the child subjects.

Ethical challenges

The intrinsic dynamics of exploring the barriers to education within the South African context posed ethical challenges. The young children are learners within hierarchical educational settings, who live in poverty-stricken communities in which racial discrimination, stigmatisation and HIV/AIDS predominate. All of these factors accentuated their position as disempowered and marginalized members of these communities, making it difficult to access their ideas about potential barriers to education. This situation posed potential threats to the overall validity and credibility of the research data.

The United Nations Convention on the Rights of the Child (UNICEF, 1989), the African Charter on the Rights and Responsibilities of the African Child (OAU, 1994) and the UNGASS Agreement (2002) advocate strongly for children's right to participate in research and intervention endeavours, recognising them as fully-fledged individuals with the potential to share their perspectives and to fully contribute as actors of social interchange, with the right to express their views in matters affecting them, in accordance with their age and maturity. The researchers attempted to design the study so that these principles would be evident for both the children and other role players.

Standard ethical research practice includes consideration of the three major ethical principles: i.e. autonomy, nonmaleficence and beneficence (Durrheim and Wassenaar, 1999; Emmanuel, Wendler, and Grady, 2000; Mason, 2004). These are considered necessary for research to be both scientifically and socially acceptable. They are especially important considerations when one works with disempowered and vulnerable population groups, such as young children, on sensitive topics such as HIV/AIDS. Situated ethics are an eclectic set of practices that can broadly be categorised as post-modern, feminist, post-colonial and democratic, particularly well suited to working with disenfranchised research participants. In this view, ethical principles are mediated within different research practices, questioning the notions of scientific objectivity and value neutrality by recognising the socio-political context of all research (Simons and Usher, 2000). This situated ethics approach led the researchers to take careful account of the local and specific factors that prevailed at multiple levels within the research site. In particular, special attention had to be given to the perceived power differentials between the university-based researchers, the research assistants who are masters students and facilitated the focus groups, and the child subjects – learners within mainly historically-disadvantaged and resource-limited schools.

The children, and the young children in particular, had had little previous exposure to the concept of research and were unlikely to be spontaneous in their participation (Nieuwenhuys, 2004). The challenge for the researchers was thus to find ways to afford the children the opportunity to decide if they wished to participate and to give their informed assent to engage in the focus groups and other data gathering exercises. This process had to acknowledge that even though young children might be limited in their ability to articulate experiences, their perceptions were critical to the research question. The researchers considered the basic guidelines for working ethically with children (Boyden and Ennew, 1997; Mason, 2004) and then developed strategies to apply these within the research context.

Informed consent procedures

Special attention had to be given to ways in which informed consent could be obtained from the community, the children's legal guardians (parents or caregivers) and the young child participants. It was essential that all the role players be fully aware of the nature of the research content and process so that they could truly make an informed decision about participation. Obtaining informed consent involved a threefold process.

Since the schools were considered to be the nucleus of the research site, the first step involved meeting with the school principals and staff to explain the nature and purpose of the research, and to discuss ways of informing the community about the research process. Political and traditional leadership, religious leaders, parents, community members, health carers and NGO representatives were then invited to community meetings so that the process of gaining entry into the community could be fully negotiated.

The next step involved random sampling of learners from three grades within each school using the class registers. The principle of the random sampling of learners (where each learner in the grade had an equal opportunity of being selected) was not well understood by the educators who at times tried to suggest children who were doing well, or children whom they perceived as being affected by HIV/Aids.

The parents of the subject sample were then sent letters, written in their home language, and asked to attend a meeting. At the meeting the research project was explained and parents were given the opportunity to express concerns and

ask questions, before being asked to sign consent forms. The major concerns raised by the parents revolved around the emotional state of the children, and a questioning of the need for confidentiality. The researcher's emphasis on the need for confidentiality and that children's identities would not be revealed to allow for freedom of expression was in tension with parents' concern that we might be asking about issues that could harm their children. From the researcher's perspective, the need for confidentiality is prescribed by the principle of nonmaleficence, but it is also perceived to affect the validity of the participant's accounts. An environment in which a participant can be free to express him/herself without fear of reprisal or discrimination, is one that allows for accounts that more closely reflect the real life experience and perceptions of that individual. Parents also asked if they would be held responsible should anything negative emerge about what was happening to the child, fearing that they could be called to account. Whilst these concerns can be regarded as typical of parents, if the participants had known that we were obliged to 'report' issues back to their caregivers, it might have inhibited them from revealing issues that may reflect negatively on their caregivers and home circumstances. Many of the parents seemed to perceive expert knowledge as resting with the researchers, undervaluing their own understanding of the child. This perception is not uncommon in resource-constrained contexts, where any research process is perceived as a potential source of resources and opportunities. It is debatable whether caregivers in this position would ever truly challenge the research intervention or feel empowered enough to deny permission for their child to participate. In the three schools mentioned, no caregivers/parents refused permission for their children to be involved in the research process.

The third step involved obtaining informed consent from the young children. The research was explained to the children individually in initial individual interviews where they were given the opportunity to commit to, or withdraw from the research process. Although in practice, it was unlikely that children would refuse to participate in a programme that had been accepted on their behalf by community leaders, educators and caregivers, it was vital that the children understood the research aims and were given the opportunity to give informed assent.

As the pilot study continued it became apparent that people in a resource-deprived community acquiesce to requests whereas in better resourced situations, where people have greater self confidence, they are more likely to be a position in which to make autonomous decisions, to refuse requests and

to be aware of their roles as child advocates. In as much as many children obey without question, so do adults who perceive themselves to be in a less powerful position than the people who are making the requests.

Confidentiality issues

Since the data gathering was to occur through focus groups when the children would be exposed to the individual stories of other child participants, the researchers had to ensure that the concept of confidentiality was fully understood. This required firstly, ensuring a secure and emotionally containing context in which sensitive topics could be openly discussed; secondly, establishing group norms, and lastly, the use of confidentiality pledges.

Creating a therapeutic frame (McMahon, 1992) involved several considerations. Firstly, a suitable venue had to be found in which interruptions were minimised, privacy ensured and the children could feel safe enough to express emotionally sensitive material. This was a difficult task in resource-constrained environments with limited physical spaces. It was difficult to maintain privacy in the face of the curiosity of the other learners who tried to peep into the room during the focus groups. In one school, the focus groups were conducted in the staff room and some educators remained seated in the same room. In other venues, educators came in to 'check' on the group discussion. Nevertheless, the researchers tried to establish a confidential space for the focus group through asking the participants to sit on a blanket in a circle to give credence to the idea of equal rights of participation and containment; by clearly explaining the research process, and by maintaining defined time and venues.

In discussing the group norms, the child participants were encouraged to contribute and establish their own criteria for the safety of the group. This provided procedures to manage the group in terms of respect for each participant, discipline and logistical concerns as well as communicating to the children that their opinions were valued.

In addition, Confidentiality Pledges were supplied, written in the children's own language and in easily understood terms. These pledges were explained to the group and each child was asked to sign assent in front of the facilitator as a witness and then retain their pledges. This made explicit the importance of

maintaining and respecting confidentiality as an individual and group responsibility.

As an additional precaution in terms of endorsing the need for confidentiality, children were asked to select pseudonyms, or code names, that they would use throughout the research process. The pseudonym was written on a name-tag and as the children entered the room they were given their name-tags, and these were then collected at the conclusion of each group session. The children responded positively to this idea and demonstrated awareness that the name belonged within the group context by spontaneously removing their name-tags at the end of each session.

Beneficence and nonmaleficence

The ethical principle of beneficence requires that the research be of social benefit, even though the subjects themselves may not directly benefit from participating. The principle of non-maleficence demands that the researchers be particularly sensitive to potential harm that may befall subjects and take the necessary steps to avert detrimental consequences of participation. These principles were difficult concepts to implement. Exploration of sensitive, possibly stigmatizing topics inevitably raises tension between the need to collect data and the child's need to be offered a contained context in which to express their feelings and experiences. The focus group facilitators had limited research experience and struggled to manage the emotional dimension of the focus group processes, commenting that “you see the feelings in them (the participants) and the mood (of the group) changes”. One of the facilitator's comments that the focus group sessions “takes a bit out of us” highlighted the need for debriefing sessions after each focus group.

Methodological challenges

In addition to these ethical issues, the sensitive nature of the topic of research and the characteristics of these particular child participants necessitated the adoption of a particular data collection methodology. There were particular reasons for using qualitative research techniques in this part of the research process (Kellett and Ding, 2004). Qualitative research prioritises subjective accounts and meanings and enables researchers to pay attention to process issues.

Two qualitative data collection techniques were used. Firstly, each learner was interviewed using a structured questionnaire that focussed on biographical and contextual information. This interview was the initial step in building rapport with the participants and it provided the forum for accessing relatively sensitive information such as financial status and difficulties. The second data collection technique was a four-stage focus group process. The focus group methodology prioritises the perspectives and experiences of the research participants, enables participants to jointly reflect on topics, and provides a critical context for exploration guided by the facilitator (Stewart and Shamdasani, 1998). Kitzinger (1994, cited in O’Kane, 2000) describes focus groups as encouraging communication especially around difficult issues, allowing for the exploration of differences as well as similarities in experiences and thought. The group format of focus groups also potentially decreases the power dynamics between the researcher and the participants, enabling the children to converse with other participants rather than having to always respond individually to an interviewer. Focus groups facilitate the expression of multiple views through individual stories and enable sharing of information thereby potentially decreasing the isolation that individual learners might experience about their own painful realities.

A critical aspect of the methodology was that the focus groups were conducted in a series of four clearly defined, but inter-related, sessions. Each focus group session was designed to address specific potential indicators of barriers to learning. For example, a barrier to learning would potentially be revealed in patterns of school attendance, or the child’s state of mental and physical health. The list of indicators in relation to each focus group is presented in Table 1 on the next page. This four-stage approach facilitated the development of rapport and trust within the group and between the facilitator and the participants. In addition, the theme for each focus group built on the previous theme, with the more sensitive issues being dealt within the later focus groups. The focus groups began with a focus on external contexts and factors (the school), and progressed to more personal and individual factors (issues related to self, illness, and finally to HIV/AIDS (see Table 1). This four-stage focus group procedure exemplifies the process approach adopted as basic methodological and ethical principles for the research.

Table 1

	FOCUS GROUP 1	FOCUS GROUP 2	FOCUS GROUP 3	FOCUS GROUP 4
<i>Theme:</i>	<i>School</i>	<i>Self</i>	<i>Sickness</i>	<i>Experience of HIV/Aids</i>
Introductory tasks/icebreakers	Code names Name game Name & action game Establish group norms Confidentiality pledge	Greeting game Remember group norms Put on code-name tags	Finding animal pairs (cards) through noises Put on code-name tags	Circles cut into pieces find people in group Put on code-name tags
Activities in Focus group (FG)	Topic 1: Motivation for going to school Method: FG discussion	Topic 1: Telling life story Method: Timeline/Road of life drawing	Topic 1: What is sickness? Method: Drawing someone who is sick & FG discussion	Topic 1: Knowledge of HIV Method: FG discussion of statements
	Topic 2: What you like/dislike about school Method: FG discussion.	Topic 2: Self concept: what you like & dislike re self Method: FG discussion	Topic 2: Assessing knowledge and stigma re HIV/AIDS Method: FG discussion & 3 rd person projection onto photo	Topic 2: Accessing support Method: 3 rd person projection onto picture/photo
	Topic 3: Level of participation in class Method: Line ordering exercise & FG discussion.	Topic 3: Worries and strengths Method: Bean exercise & FG discussion	Topic 3: HIV/AIDS in your area Method: FG discussion	Topic 3: Feelings & experiences of HIV Method: Body Map Drawing
	Topic 4: Popularity and marginalisation Method: 3 rd person projection onto pictures/photos	Topic 4: Resilience factors Method: Written sentence completion		Topic 4: Perceptions around relationship. (For grade 9's only) Method: FG discussion
	Topic 5: What is helpful & difficult at school? Method: FG discussion Ranking exercise and bean exercise			Topic 5: Reflection on group process Method: Group drawing and reflection/FG discussion
	Topic 4: Homework and support system Method: FG discussion			
	Topic 7: Absenteeism Method: 3 rd person projection onto photos			
Closing tasks	Reflect on something nice about today	Reflect on hope for future	Where will you be in 2010?	Affirmations & power circle
Indicators	Motivation; Attitudes Participation Homework; Support system; Absenteeism Popularity/stigma	Support systems Health: emotional state Mortality Resilience factors	Support systems Knowledge and awareness of HIV/AIDS Stigma	Support systems Knowledge and awareness of HIV/AIDS Health: emotional state

Methods used in the focus groups

Different techniques and strategies were used in the data collection process. These included process-related activities such as icebreakers, diagrammatic mapping and drawing activities, projective techniques, ranking exercises, and activities to draw the sessions to a close with a positively affirming activity.

Icebreakers, used at the commencement of each focus group, created an environment conducive to the formation of group cohesion, promoting participation and helping participants to relax (Rooth, 1995). For example, a game relating actions to each child's code name helped familiarise facilitators and participants with each other's names, provided an opportunity to laugh and develop group identity. McMahon (1992) argues that play is often used when working with children as it is believed to be children's natural means of expression. Table 1 contains an outline of the activities used in each focus group.

The sensitive and emotional nature of the research topic created the need to provide a containing environment in which to share personal information. In addition to the processes discussed above, at the beginning of each session children were asked to recall the previously established group norms. The extract below from Focus Group 2, Grade 3 illustrates that the young children had to some extent internalised and understood the group norms:

- Researcher: Hauw, I have forgotten, can you remind me of the group rules. . . Ja Nonhlanhla?
- Participant: Do not say it outside.
- Researcher: Yes. . .
- Participant: Something we discuss in the group.
- Researcher: Yes.
- Participant: When someone talks not to laugh at him or her.
- Researcher: Yes. . . Nokwanda?. . . Siboniso?. . .
- Participant: When someone is talking not to interrupt.
- Researcher: Yes Thokozani?
- Participant: Do not tell people of your code name.
- Researcher I: Yes. . . Mbali.
- Participant: This is confidential.
- Researcher: Okay. . . right.

Lastly, in line with maintaining a ‘holding’ space, it was important to have processes of closure for each group session and at the end of the four sessions. At the end of each session, there was a small reflective activity with children to express something affirming about themselves. The risk and resilience literature argues that part of being able to build resilience is the ability to articulate positive things that one is, one has, or one can do (Grotberg, 1995). These closing activities served as a reminder to keep information confidential and to distinguish the focus group activity from other school-based activities. At the end of the last focus group, learners discussed what they had done in the four focus groups through a collective drawing. The young children participated enthusiastically in this activity and surprised the facilitators by accurately recording all of the activities in the focus group process.

Techniques used in the focus groups

In terms of facilitating expression within the focus groups, diagrammatic, mapping and drawing activities, projective techniques and ranking exercises, were used. Many of these techniques draw on the participatory research literature (Theis and Grady, 1991; Johnson and Mayoux, 1989; Chambers, 1992) and do not rely heavily on reading or writing skills, emphasising “the power of visual impressions and the active representation of ideas” (O’Kane, 2000, p.138). Children, particularly younger children, respond better with techniques that encourage more than verbal discussion. The mediums of drawings, stories and activities enabled expression and facilitated children’s active participation.

Projective techniques

A projective technique used in Focus Groups 1, 3 and 4 asked the children to reflect on a picture of a child in relation to particular issues. For example, how they would react and feel if someone in this child’s family was HIV positive, and how it might affect his/her learning. In Focus Group 1, the purpose of the activity was to gain an understanding of factors that might prevent some children from attending school. Pictures of a boy and girl were included to ascertain if there were gendered differences in reasons given for absenteeism/lack of progress. It was also important to use pictures of children of the same race group, with neutral facial expressions, and with clothing indicating similar socioeconomic status as the child participants. Examples of the questions used by the facilitators to progress through different levels of subjectivity are as follows:

1. This is Siphon. He didn't go to school. Tell me a story about why he didn't come to school. (*Probe for more reasons*). Could there be other reasons why he didn't come to school? (*Elicit a list of possible reasons*).
2. What happened to him when he didn't come to school? What did he do during the time that he was not at school? What did his family do?
3. What did the teachers or school do?
4. Are there learners in (*name of school*) who do not come to school?
5. Why do they not come? (*Elicit a list of possible reasons*).
6. Have you ever not been to school? Why did you not go to school?

Using concrete situations helps to facilitate younger children's participation and ability to enter the discussion (O'Kane, 2000). The strategy of moving from the general and less threatening issues to the more personal and potentially sensitive areas enables the establishment of trust and for children to hear others' experiences. Enabling children to project onto a picture (an 'other') circumvents them having to talk directly about potentially anxiety and stigma provoking personal issues. The respondent's real feelings are then inferred from what she/he says about others. This also reduces researcher bias by asking the participants to assign ideas about a phenomenon, in this case reasons for absence from school (Levin-Rozalis, 2004). The same technique was used in Focus Group 4 to implicitly encourage the development of resilience through exploring the types of support children could access and their knowledge of support systems.

Drawing exercises

Children's drawings have been used as psychological assessment tools to explore developmental maturity, group values, perceptions of self in relation to others, and personality (Klepsch and Logie, 1982). Oaklander (1988, p.53) argues that, "pictures can be used in endless ways, for a variety of purposes and at different levels. The very act of drawing, with no therapist intervention whatsoever, is a powerful expression of self. . . and provides a way of expressing feelings." Drawings were used several times in the focus group process, with the main aim of facilitating and enabling expression.

In Focus Group 2 children drew 'A road of life' to share their life stories through the metaphor of their life as a journey or road, and to expose significant life events, including whether the children had experienced loss and/or illness of others during their lives. In Focus Group 3, children reflected on their drawings of a 'sick' person, and in Focus Group 4, they drew body

maps, a technique used by NGOs along with memory boxes as a process to facilitate talking about loss and grief (Thoms, 2003).

Ranking exercises

Drawing on participatory techniques, we used two types of ranking exercises (Theis and Grady, 1991). In one of these, children were asked to discuss and rank what made school difficult or what they did not like about school. The children then ranked these issues in order of difficulty using a diamond shape (Kellett and Ding, 2004; O’Kane, 2000), which allowed for several issues to be ranked as equivalent.

In another exercise participants discussed the things that worried them. These ‘worries’ were written on pieces of paper and spread out on the floor. Each learner was given two beans and told, “Perhaps someone also mentioned something that also worries you. Put your beans on two of the things that have worried you, that you agree with.” Although not a direct numerical evaluation, this technique provided insight into which issues concerned these children the most. A similar exercise was repeated to establish what may help children feel supported and strong.

Reflection on methodology

Using focus groups and participatory techniques provided a forum for the expression of young children’s concerns whilst at the same time providing the researchers with a window onto their perspectives on barriers to learning, illness and HIV/Aids. The characteristics of these two forms of data collection facilitated the meaningful involvement of the participants in the focus group process. However, several critical tensions permeated this research process.

There is an inherent, and possibly unresolvable tension between the use of playful mechanisms such as ice-breakers and energisers to build rapport and trust between participants within the group, and the seriousness of the topic under discussion, illness, death and HIV/Aids. In addition to this, embedded in this research process is a tension between the useful, child-friendly and inclusive participatory techniques and the difficulties that arise in managing the form of data, which emerges from these techniques. For example, diagrams, time-lines, line-exercises and body-maps are fascinating, but pose additional challenges in recording, analysing and interpretation.

The two different records of the data collection process (an audio and video version) pose further challenges as to how one accurately and incisively transfers and relates the audio and video recording of the event and activities of the focus group sessions into analysable form. The tension here is that a text version alone would not do justice to the activity of the focus group that involves conversation and non-verbal interaction. How then do we transcribe the recordings in such a way as to provide the fullest account of the event? If one of the main aims of the research is to identify a local and contextualised perspective on barriers to learning, the challenge for the transcriber is to adequately contextualise respondents' perspectives and their behaviour, when their own perspective is necessarily selective.

In this site there was the added dimension of the original focus group discussions being in *isiZulu*, whereas the medium of interaction within the research team was English. There is a double burden placed on the facilitators/student researchers to conduct the focus groups in one language, and translate the discussion in these groups into English, for use in their own projects, but also for use by the broader research team. Translation is not an easy task and the skill does not automatically exist because an individual can speak two languages. There was extensive debate amongst the group facilitators when developing the focus group questions and finding the appropriate *isiZulu* equivalent.

The site of the research generated a particular tension. Working across different contexts and different school 'cultures,' in the sense of norms and conditions meant that the facilitators had to adapt their expectations and their facilitation skills. For example, one school context was permeated by a norm of a disciplined, respectful learner body who listened to educators and other adults. In another school context, there seemed to be very little respect of learners for educators and vice versa. A few educators were seen with *sjamboks* and threatened to use them on the learners. The learners took this dynamic into the focus group sessions where they resisted attempts by the facilitator to establish and adhere to group norms without the presence of this disciplinary measure. It is possible that the racial diversity in the school played a role in the tensions between educators and learners. It is also possible that because the facilitators were of a different racial group from most of the educators and adults in the school, that the learners had less respect for them.

The development of research and facilitation skills

The data collection process was facilitated by *isiZulu*-speaking masters students as research assistants who were simultaneously collecting data for their own theses as well as for the research project as a whole. Whilst having the support of the project team, they had the responsibility of conducting the data collection process according to the decisions made by this team. As masters' students, they were developing an understanding of how research and reflective practice works and the research project therefore had to incorporate the development of research and facilitation skills. This included basic research skills such as operationalising the research question into research instruments; the negotiation of access to the sites, obtaining consent from parents/caregivers and learners; and training workshops to facilitate the development of the skills needed to conduct interviews and focus groups with young child participants.

The nature of the research topic further complicated the research process. The sensitivity of the issue of HIV/AIDS and the likelihood of there being a strong emotional component to the discussion meant that ethically, the facilitators also had to perform a therapeutic function. The research team utilised reflection and debriefing sessions in an action-reflection process to develop these skills.

The facilitative function in conducting a focus group is critical to the adequate and directed collection of quality data. O'Kane (2000) argues that while the participatory techniques are useful, the dialogue around activities is what provides the richest sources of interpretation and meaning. In this particular study, the facilitation included the skills of engaging with children in ways that encouraged further participation and enabled the children to feel heard and supported. Facilitators also need skills of mediating and being able to probe responses to elicit deeper meanings. This is particularly difficult with young children who do not reflect easily on the responses of others within a group, demanding that their own views be taken into account. There is also a tension in this practice between adhering to a structured set of questions for the focus group, and recognising the appropriate times to adapt this structure to incorporate and explore the responses of the participants. This is not an easy skill to 'teach' as the skill develops with increased awareness of the way in which the research process works. It is probable that the facilitators' lack of confidence in adapting and changing the focus group questions or deviating from the defined steps reflected the dynamics within the research team.

Inexperienced students are unlikely to challenge more experienced staff. They are also more likely to want there to be a single, correct way of implementing a data collection process. However, the facilitators in this research process have been through an incredible process of self-reflection, development and growth, and cognisance must also be taken of the intensity, and at times overwhelmingly, emotional nature of the research process. Working with vulnerable groups, and young children, requires researchers to be sensitive to the inherent tension between data collection and playing a facilitative and, at times, a therapeutic role. In this sense, the competence of the facilitators becomes an ethical issue. The adequate and appropriate management of the emotional dimension of the focus group process was essential, however, this demand goes beyond the role and skill expected of a research assistant.

Conclusion

Research with young, vulnerable children about the sensitive issues of HIV/AIDS raised particular ethical and methodological challenges. We have argued that a process approach that values the child as an active participant in the research addresses some of these challenges. A four-stage focus group method that utilised participatory techniques increased the child participants' active involvement in the process. We have illustrated that the ethical dimensions of working with young child participants about HIV/AIDS can be addressed through innovative approaches to informed consent, confidentiality, beneficence and nonmaleficence. Research in this developing context, however, led to numerous tensions that permeate the research process.

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