

Learning from young people about their lives: using participatory methods to research the impacts of AIDS in southern Africa

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Abstract

Methods of participatory research have become popular among children's geographers as they are believed to enable young people to speak openly about their lives in unthreatening contexts. In this paper we reflect on our experience of using participatory methods to explore the sensitive topic of (indirect) impacts of AIDS on young people's livelihoods in Malawi and Lesotho. We examine how different methodological approaches generate varying knowledges of children's lived realities; challenges of using 'insider' and 'outsider' research assistants, place of group-based approaches in participatory research and ethical issues. We suggest that researchers of young people's lives should take full account of the relationship between epistemology and methodology in selecting and employing methods appropriate to particular research questions.

Introduction

Participatory research methods have been widely used in recent geographical research with young people, drawing on traditions from development studies (Chambers 1994), childhood studies (Boyden and Ennew 1997) and social geography (Pain 2004). Participatory approaches are diverse, with varied ideological underpinnings (Hickey and Mohan 2004; Kindon et al 2007), and some differences between discourses prevalent in development and child research (Lund 2007). In general, however, participatory research is concerned with producing knowledge *with*, rather than *about*, those who are the subjects of the research.¹ Various methods are associated with the approach: commonly participants produce diagrams, drawings, drama or photographs that become the focus for group discussion and collective analysis. It is not the methods themselves that make the research participatory, but rather the social relations involved in the data production and analysis, particularly with respect to where the locus of control and power lies (e.g. Gallagher 2008). These social relations involve the co-production of knowledge by a group of participants alongside 'professional' researchers. Yet, as we will demonstrate when researching sensitive subjects, producing generalised accounts may not be the most desirable. This paper reflects on our research on the impact of AIDS on young people's livelihoods and offers a conceptual contribution to the methodology of participatory research with children: that researchers of

¹ We focus on methods that actively involve participants in the production and analysis of data, rather than broader ethnographic engagement with research subjects.

young people's lives should take full account of the relationship between epistemology and methodology in selecting and employing methods appropriate to particular research questions.

Different methods – different knowledges

This paper emerges from our experience of using participatory methods to undertake research into the impacts of AIDS on young people's livelihoods in rural Malawi and Lesotho. While participatory methods proved useful in enabling young people to discuss some general aspects of their lives, they were less effective in facilitating the direct sharing of personal experiences in group contexts. Moreover, the accounts that emerged from collective participatory activities often contradicted those produced using more individualised research methods such as life history interviews (or even more individually-focused 'participatory' techniques), as well as with direct observation. Diagramming methods, for instance, elicited dire stories about what happens to children when their parents die: yet in many cases the children engaged in producing these accounts had very positive stories to tell about their own lives as orphans. Participatory research usually involves the collective production of generalised knowledges (although not exclusively so: these are also the focus of some other methodological approaches).

A number of challenges were encountered which we explore in this paper including the different kinds of knowledges that are generated by different methodological approaches; the challenges of using insider and outsider research assistants and ethical issues. The paper begins by outlining ethical and practical arguments for undertaking participatory research in general, and specifically with young people. We examine recent critiques of participatory approaches, and suggest these emerge from a narrow epistemological perspective and that other aspects of the participatory epistemology also merit questioning. We then present some background to our research with young people in Malawi and Lesotho, our research questions and methods. We discuss the types of data produced through the research, and focus on contradictions between the knowledges produced using different methods. We examine how some participatory methods aim to build generalised accounts from individual specific knowledges, but in practice confront challenges that relate partly to the social context of the research. We conclude by suggesting that those researching young people's lives should take full account of the relationship between epistemology and methodology in selecting and employing methods appropriate to particular research questions.

Participatory research: justifications

Participatory research is favoured by many researchers, particularly those researching children and youth, for both ethical and practical reasons, or what Warshak (2003) terms 'empowerment' and 'enlightenment' rationales. Ethically, a participatory approach is considered more respectful of those whose lives are scrutinised. It entails researching *with* people, rather than extracting data *from* them and treats them not as objects but subjects in their own lives (Beazley and Ennew 2006, Cahill 2004).

From a methodological standpoint, participatory research approaches are advocated for their ability to produce 'situated, rich and layered accounts' (Pain 2004:653). By involving participants in analysing the

conditions of their lives, the methods are also said to be better at capturing complex non-linear interrelationships than methods that collect descriptive data for subsequent analysis.

Participatory researchers involve participants directly in some or (ideally) all stages of research, from problem definition through data collection, analysis and dissemination to action (see Kesby et al 2005, Kindon 2005, Pain and Francis 2003). Innovative research techniques are often used to facilitate this, enabling participants to define and analyse problems (Kesby 2000). Non-verbal techniques frequently provide a stimulus for discussion, and may also provide data directly (O'Kane 2004).

Participatory research is said, however, to require not merely *techniques* but a participatory *process*, (O'Kane 2004) whereby researchers need to 'hand over the stick' to participants, and attention shifts from individuals to the collective, with groups engaged in investigating, analysis, presentation and learning (Chambers 1994). In practice, participation levels vary greatly and the ideal ('deep participation' (Kesby 2007a)) is seldom achieved (Clever 2001). Although many researchers use participatory techniques without a full participatory approach (Kesby et al 2005; Pain and Francis 2003), the use of, for instance, visual methods without significant discussion with children of all aspects of the research process (aims, methods, level of involvement, dissemination etc) has been criticised by Boyden and Ennew (1997) among others.

For research with children and young people participatory techniques are understood to shift power relations, giving young people greater control over their involvement in the research. Moreover, young people's insights into their own lives are said to be most readily expressed when they are facilitated through self-directed methods (Boyden and Ennew 1997; Hart 1992; Johnson *et al* 1995; Young and Barrett 2001). Different young people prefer different methods (Chawla and Kjørholt 1996; Punch 2002) so a multi-method approach enables most to contribute (Morrow 2008). Participatory research is also likely to retain children's interests, enhancing the richness of the information they provide (Punch 2002). As when working with adults, not all such research with children involves deep participation. Hart's (1997) 'ladder of participation' describes a spectrum of ways of involving young people, and although the most basic may be tokenistic and even exploitative, participation of children at the highest level is not considered universally desirable. Indeed, participants might not desire full participation; hence it is most appropriate to work with young people on their own terms (Kindon et al 2007).

However, as we explore in this paper, by adopting participatory approaches to research with young people researchers may face a number of challenges. However, firstly, we briefly outline some epistemological critiques of participatory research to situate our contribution in wider debates.

Participatory research: epistemological critiques

In the 1990s participation in research was predominantly viewed as intrinsically good and rarely questioned (Clever 2001). By the turn of the millennium, however, it became subject to various critiques, falling into three broad categories (Pain and Francis 2003): tokenistic uses of participatory

techniques, without a wider participatory approach; technical limitations such as lack of rigour, reflexivity and validity; and a broader critique of fundamental concepts (see Cooke and Kothari 2001). Although participatory research has been described as a theory of knowledge (Reason and Bradbury 2001), the key to this fundamental critique was the failure of participatory researchers to problematise knowledge production processes.

The dominant critique of participatory research emerges from a poststructuralist, constructivist perspective. Participatory methods clearly cannot directly tap objective experience or unmediated perspectives, but produce particular types of knowledge (Kesby 2000). While celebrating how participants, as meaning-making agents, engage actively in knowledge production, practitioners have attended less to the implications of the social contexts of that production (Cooke and Kothari 2001).

Two connected areas have been neglected. The first is the impact of local social inequalities and power relations (Clever 1999, Mohan and Stokke 2001). Participatory research emphasises local knowledge, but some individuals may have the skills and authority to present their personal interests as community interests (Mosse 2001). Apparent consensus views generally conceal powerful agendas (Guijt and Kaul Shah 1998) and the multiple/conflicting knowledges held within any group or individual (Cameron and Gibson 2005). Moreover, knowledges produced not only reflect the interests of the powerful, they can also reinforce their power (Hailey 2001, Schäfer and Yarwood 2008).

The second element of the social context is the participatory process itself, which is not a neutral means of generating knowledge. Participatory techniques may systematically facilitate certain dominant voices and subdue others. In a society where young people are not expected to speak publicly, they may effectively be silenced by a method that requires public speaking (Kapoor 2002). The effects of participatory methods on knowledge production are not coincidental. The methods are not only embedded in local contexts imbued with power, but are also products of wider power relations. The knowledge produced reflects the relationships entailed (Mosse 2001).

A number of scholars have argued that these constructivist critiques are surmountable. Participatory research is a locus of knowledge construction and potentially offers insight into knowledge processes, if engaged in with reflexive awareness of the role of the context. Kesby (2007a), for instance, attempts to reconcile participatory research and poststructuralism through attention to power relations. He argues that while arenas of participatory research are 'contrivances', 'they hold the potential to enable participants to explore the contrived nature of all social relations' (Kesby 2007b:203). Participation may, in such ways, serve as a tool for social change (Cahill et al 2007). Cahill (2007) considers participation as an arena for the construction of new (fluid and multiple) subjectivities. Cameron and Gibson (2005) view participatory research as a means of producing counter-stories that challenge the status quo. It is also worth noting Gallagher's (2008) observation that given the pervasiveness of power, the challenge for children's geographers is not to avoid using power in research but using it to resist domination.

Critiques of participatory methods do not always spring from a constructivist position. Other limitations of the types of knowledge produced through participatory research have been highlighted. The

techniques are criticised for producing mainly linguistic representations of knowledge (diagrams, drawings and drama are used to elicit discussion rather than providing direct insight), thus revealing little about matters that cannot be expressed verbally (Mohan 1999). Other critics have argued persuasively that through focusing on the 'local' and local knowledge, attention is shifted away from underlying socioeconomic and political forces shaping people's livelihoods (Hickey and Mohan 2004, Mosse 2001).

A perspective from which there has been little critique, but which is addressed in this paper, is the relationship between participatory methods and the production of knowledge grounded in concrete experience. Participatory methods have been described as generally empiricist (Kapoor 2002), yet the data they produce might not always relate closely to grounded realities.

Such grounded realities have seldom been at the forefront of children's geographies, which have long embraced a rather rigid epistemological stance, centred on three tenets: children are competent social actors (and therefore capable of participation in research); childhood and childhood experiences are socially constructed; and research should prioritise children's voices. The focus of much research in children's geographies has been on how young people make sense of, and are constituted by, experience/knowledge. Embedded in humanistic or poststructuralist epistemologies, both meaning-making and subject-making are arguably well suited to investigation through a participatory approach with children. However, there is a need to generate knowledge that reveals not just the meanings young people attach to experiences, but experiences themselves and how these are produced. Questions, such as the one addressed through the research discussed below ('how does AIDS impact on young people's livelihoods?') seem to us both legitimate and broadly answerable. Experiences may be explored through questions such as 'what happened?' which generate answers that are shaped by individual attributes and social contexts but can also be expected to have a relation (albeit not direct and unmediated) to concrete experience. In our research we sought to learn about children's experiences from their own perspectives, but our interest was not just in how they constructed their experiences, but how their experiences were constructed. This is a different form of knowledge from that sought by most children's geographers using participatory methods.

The research project

In 2007 and 2008 we undertook an 18 month project entitled 'Averting 'New Variant Famine' in Southern Africa: building food-secure rural livelihoods with AIDS-affected young people'. The research team comprised four academic researchers, including one full-time research assistant (Flora Hajdu) who undertook most of the fieldwork while resident for 2-3 months in two case study villages in Malawi and Lesotho. National steering groups, comprising potential research users, were established to advise on the research, including the appropriateness of the participatory methods selected. We also worked informally with local collaborators, and employed field assistants to help with translation.

The focus of the research was the 'new variant famine' hypothesis. This hypothesis suggests that the coincidence of extremely high HIV prevalence and recurrent food insecurity in southern Africa reflects a causal relationship: that AIDS is contributing to hunger. Of the causal mechanisms proposed, several relate to the impacts of AIDS on young people. For instance, young people's livelihoods may be rendered vulnerable if household property is lost when parents die (to cover medical and funeral costs or through misappropriation by relatives); if usufruct rights to land are lost because children are considered too young to farm, or have to migrate elsewhere; or if the intergenerational transfer of knowledge and skills from adults to children is interrupted. We did not seek to 'test' the hypothesis in any formal way, but to explore the relationship between AIDS and young people's livelihoods and prospective food security.

The methods employed

A range of broadly ethnographic methods were employed in the two case study villages. The research began with community profiling workshops (Hawtin *et al* 1994; Messer and Townsley 2003). These were intended to seek community consent for the research, build rapport, learn how people talked about the research topics and develop an understanding of the villages and their recent history. To further contextualise the information to be provided by young people in the participatory research, we undertook household profiling. The research was again introduced to every household, consent sought and basic data obtained from all households willing to participate (a very small number declined). The main data collection stage involved using participatory methods with young people. This was not 'deep' participation, inasmuch as the research questions and broad shape of the methodology had been established in advance, as is generally expected by funders, but it was conducted in a way that was broadly in line with Boyden and Ennew's (1997) prescriptions for participatory research with children. The aim was to work with young people to generate new knowledge in relation to the research questions.

The participatory research involved around thirty 10-24-year-olds in each village. They were selected on the basis of the data collected through household profiling with around half deemed to be 'AIDS-affected', usually meaning they were orphans or had experienced the chronic illness or death of an adult household member in the recent past. As in many studies of AIDS' impacts in southern Africa, chronic illness was taken as a proxy for AIDS owing to the high levels of ignorance (of diagnosis), denial and stigma associated with the disease. For most activities the young people were divided into four groups by age and gender (girls and boys aged 10-17 and young men and women 18-24), although some opted to join a group based on their marital status rather than chronological age. In Lesotho, a (fifth) group of herd boys met at the mountainside cattle post rather than in the village. We did not distinguish between those affected and unaffected by AIDS in selecting groups or dwell on these distinctions (which were in practice somewhat blurred) during the activities, although we did focus our interest on the impacts on the participants of chronic sickness and death among household members.

The suite of participatory tools employed included drawing mental maps; daily and weekly activity charts and seasonal calendars; photography; guided transect walks; life maps; socio-spatial network and knowledge transfer diagrams; asset matrices and problem trees; emotional storyboards; and videoed drama performances. These methods were selected and developed by the research team, to ensure that they would cover all aspects of the types of knowledge required to address the research questions and would allow comparability between the two settings. However, they were often modified in light of the preferences and characteristics of a particular group and previous experience with other groups. With most techniques, participants were involved in self- or group-directed production of a diagram, visual or dramatic output. Some, such as the dramas, were very much collective activities; others, notably the transect walks, were more individual or involved pairs of young people. In all cases, the fact that attention is not on the researcher should enable less dominant individuals to participate more comfortably, and sensitive subjects to be addressed relatively easily (Kesby 2000). Individually produced outputs were elaborated upon by their authors, and, whether individually or collectively produced, the outputs were generally then used to promote group discussion. Local interpreters translated, full notes were taken and discussions taped, transcribed and translated. In addition to these participatory activities, semi-structured interviews were conducted with key informants from the villages and local areas, as well as interviews with policy makers and practitioners in the cities.

Several months after the original research, the team returned to the field for what had been planned as a dissemination visit. However, preliminary analysis had uncovered some of the gaps in the data that are highlighted in this paper, hence we decided also to conduct individual in-depth life history interviews to collect more specific accounts of the impacts of AIDS on young people's lives. In both villages most resident 18-24-year-olds were interviewed. We targeted this age group due to the limited time available, and the fact that older youth could reflect over a longer life span as well as generally being more forthcoming about their lives. The interviews were conducted by Flora, Elsbeth and Nicola using outsider graduate interpreters, partly because the local interpreters tended to relate to youth in excessively hierarchical ways and were unable to translate with sufficient subtlety to capture the nuances of personal stories.

During the return visits initial findings were also fed back to the participants through a reverse-cascade series of participatory dissemination and feedback workshops. There were three sets of workshops: with the young participants, the two communities and with policy makers and practitioners, each group being offered the opportunity to comment on and offer their own interpretations of the findings and to feed these onward to the next workshop, principally through drama and posters. Again, graduate interpreters were employed.

The positionality of researchers is interwoven into the power relations of how we learn about young people's lives and the creation of situated knowledges. The methodological and ethical issues, challenges, advantages/disadvantages of 'insider' and 'outsider' positioning is a rich theme of reflection in the social sciences including Geography with various threads including the politics of outside researchers (Sidaway 1992), researching at home (Panini 1991, Ite 1997, Gilbert 1994), racial and gender positioning of researchers and research participants (Kobayashi 1994, Oakley 1981, Graham 1983, Nast

et al 1994, Golde 1970), impacts of researchers' personal biographies on fieldwork and research (England 1994, Worth 2008). More recently attention has also been focussed on personality (Moser 2008) as an aspect of positionality, positionality of outside researchers in crisis situations (Bachmann 2011) and translators (Twyman et al 1999) whose positionality is often neglected but is also significant. We pick up this particular less-prominent theme by exploring the challenges of using both 'insider' and 'outsider' research assistants in the last section of the paper.

The data produced

At the outset of the project we envisaged that our participatory methods to research the sensitive topic of impacts of AIDS would generate five main forms of data: observed behaviour and reports of facts, perceived causal relationships, and attitudes/ values/ aspirations, all embedded in discourse. Observed behaviour was to be noted through ethnographic observation undertaken while resident in the villages, but supplemented by information gleaned through transect walks and examination of the photographs young people took of livelihood activities. Reports of facts, causal relationships and attitudes/ values/ aspirations were expected to be generated through the participatory activities (although the community and household profiling would also furnish the project team with facts). Discourse would be tapped through the full range of methods, but in particular the participatory methods. In practice, however, while participatory methods proved to be a valuable means of generating knowledge in relation to perceived causal relationships and, to a large extent, people's attitudes, values and aspirations, they proved less well suited to the reporting of 'factual' information: the events and concrete circumstances that contribute to individual and collective experience.

In exploring the production of factual information, we make two further distinctions between the types of knowledges produced through different methods: between individual and collective knowledges and (closely related but not synonymous) between specific and generalised knowledges. Participatory methods are generally group methods and ultimately produce collective knowledges (as do a range of other methods such as focus groups). This is not to suggest that any knowledge is wholly individual: all knowledge is mediated and discursively produced in a social context. Yet participatory research is frequently explicitly concerned with the production of collective knowledges. Specific knowledges are those that relate to actual conditions that pertain or have pertained, and events that have taken place,² whereas generalised knowledges are those that are presented as a general truth that extends beyond a particular moment.

² Our research did not focus exclusively on the present and past. As Langevang (2007) points out, combining methods enables researchers to explore young people's lives in transition, and to investigate trajectories from past events to future prospects and aspirations. In this paper, however, we focus on the production of empirically grounded conditions and events of the past and present.

In undertaking our research, we were ultimately concerned with the general question: '*what happens when ...?*' (in our case when a child is affected by AIDS). In conventional empirical research, we would answer this question by exploring with a number of individuals the specific question '*what happened when ...?*' (a close relative was sick or died). However, in participatory research, where analysis by the participants is part of the process, participants themselves address the question '*what happens when ...?*' and the relationship of that generalised answer to specific happenings or experiences may not be explicit. Moreover, it is noteworthy that collectively produced generalised knowledges are often highly normative in their construction: it is likely that the generalised answer concerns '*what should happen?*' or '*what would one expect to happen?*'.

The research methods fell broadly into three categories. Some were aimed purely at producing generalised (and collective) knowledges. For instance, participants developed dramas focused on problems faced by young people in the community, or on routes by which households end up hungry, followed by discussion. Similarly, during the dissemination workshops groups produced spidergrams indicating chains of consequences following the sickness or death of a parent, and possible means of preventing these consequences. Semi-structured life history interviews, by contrast aimed at producing specific (and individual) knowledges. The third, and most common, type of research method aimed to elicit specific knowledges and build generalised knowledges from them. In a group setting, individuals began by producing, for instance, an activity calendar representing their personal time use, or a life map illustrating key events in their lives. The group then discussed general patterns emerging from these and explored patterns of difference.

Some group activities did produce specific collective knowledges, such as village profiling workshops producing historical timelines, wherein individual villagers contributed and collectively built a consensual narrative (notwithstanding the criticisms of consensus knowledges alluded to above). Similarly, groups of young people generated apparently accurate information about school fees (which include multiple elements) and livestock prices. This type of collective production of specific grounded knowledges was, however, uncommon.

Contradictions in specific accounts

Different kinds of methods resulted in different kinds of knowledges or understandings. Thus, 'factual' information generated through diverse specific data production methods was often contradictory. In a number of cases, alternative reports of facts were produced in different settings. Different people – perhaps siblings – offered conflicting accounts of the same event. Sometimes one person would provide contradictory information on different occasions. Emily's life story included quite different details when she told it during the life maps activity from her account a year later in an individual interview. Other accounts were internally inconsistent, with, for instance ages and years failing to tie up in many of the life history interviews, despite efforts to gain clarification (see discussion of Rex's account of his life in Ansell et al 2011). Sometimes observed behaviour conflicted with reported behaviour. On their activity

calendars, for instance, some children indicated they attended school every day but were often observed in the village during school hours. Jamiya, in Malawi, said she made a livelihood by selling rice that her husband brought her from town. However, she was never seen selling rice, nor did her husband visit during the fieldwork period, and it was rumoured that he had left her. More frequently, young people said they had no source of income, or named one or two activities, but later revealed further, more lucrative livelihood activities they were engaged in. One young man in Malawi, for instance, missed a session because he was busy slaughtering a pig; butchering turned out to be an occasional source of income.

The reasons behind these alternative accounts are not always evident but may give insights into different aspects of children's lived realities. For example, it might be shameful to admit in front of friends and neighbours that one is not attending school or has no independent income. Perhaps a source of income is omitted on the assumption (however strongly denied by the researchers) that the researcher team will bring benefits to those lacking independent livelihoods. Moreover, memories are not infallible, and events will be recalled differently on different occasions. Alternatively, what is presented, even in an individual interview, might be tailored (consciously or unconsciously) to conform to an idealised, or normalised, version of life. That inconsistencies arise in young people's accounts is not particularly surprising or a novel finding: indeed, it is a reason for the widespread advocacy of 'triangulation' (not only in participatory research) through which multiple methods construct diverse knowledges in these areas, relating to attitudes and interpretations. Moreover, contradictions can be revealing and enhance understanding, not least by throwing up material for further investigation.

Contradictions between generalised and specific knowledges

Whatever the contradictions within specific accounts, conflicts between individual reports of personal circumstances and histories and collectively produced accounts of causal relationships were even more apparent. The following extracts are from a village-level dissemination exercise in Malawi in which groups of young people, facilitated by a field assistant, developed spidergrams (Figure 1) indicating what happened as a consequence of the sickness and subsequent death of a parent. The discussion leading to the production of the diagram was recorded.

Assistant: How does it affect the future of youths whose parents are sick?

Participant 1: Your future is doomed.

Participant 2: Your future is doomed. If you were in school, it means your school ends there.

Participant 3: If you were doing business, your capital is used up.

Assistant: Why is it used up?

Participant 4: It is used up because you are at home and use the money in helping your parents.

Yet this picture, which was repeated by other groups of young people and also told by adults in the community dissemination workshops, conflicted with the personal narratives obtained through other methods (both the life history interviews and more individualised elements of the participatory activities). In both villages, orphaned youth were more likely (by their own accounts) to be attending school, and those who had left had remained in school to higher levels, than those who were not orphaned. In-depth life history interviews with young people revealed no systematic differences between the livelihood activities pursued by those who were directly affected by AIDS and those who were not. That is not to deny that there were many individual stories of children who left school or were hampered in their livelihood pursuits as a consequence of parental death. However, poverty in the villages was such that most young people (irrespective of whether they were affected by AIDS) had to drop out due to lack of school fees, clothes or soap to wash their clothes, and bursaries were available to orphans, which enhanced their prospects of remaining in school.

Specific accounts from individual young people highlight many stories of exception. A considerable number of children told positive stories about their lives as orphans. Among the Malawian youth, for instance, Mary was helped by her uncle and through a bursary to complete secondary education following her father's death. David had a great deal of help from relatives to continue in school following orphanhood. Edison thought he would have to leave secondary school for lack of money, but the church choir he was active in surprised him by offering him a bursary enabling him to finish school, as his father had died. In terms of livelihoods, Emily was helped to find a job after she was orphaned. Victor and Blessings, two young orphans, were able to continue to farm their mother's field which they inherited when she died, even though they are only 12 and 10 years old, with help from their grandmother and several relatives. In the emotional storyboard activity in Lesotho, Lisebo revealed that she had been helped by the government to get shoes and clothing since she was orphaned. The one sibling-headed household in the village said their neighbours always look out for their interests at village meetings. It is perhaps unsurprising that, when asked to produce generalised knowledge, young people do not think of specific situations of this type that might help certain individuals. It is also unsurprising that they do not think about the fact that many other poor people who still have parents have problems too. It does, however, mean that the generalised accounts generated deviate substantially from individually recalled experience.

Another group gave a very similar generalised account:

Assistant: What is the problem when parents are sick?

Participant: People are panicking; people are panicking a lot when thinking of their relatives/parents [who] perhaps always go to the fields. Then things at the fields won't be completed, then years...[in] the coming year there will be hunger at home.

Assistant: Now if things don't go well up to the extent of dying, what can happen?

...

Participant: The problem is you think that since your parents have died you can start stealing, you don't worry as even if you die you can follow your mother.

The theme of orphans becoming thieves was repeated in the drama activities, along with a host of other dire consequences, yet no mention of actual thefts in the Malawi village (of which there were several during the fieldwork period) could be related to orphans, and no young person revealed such problems when interviewed individually. The extract again reveals that collective accounts tend to produce generalised knowledges that appear to conflict with specific experiences. Peters et al (2008:34) similarly observe in Zomba District, Malawi, '[s]tereotypical opinions tend to be elicited in response to a general question about orphans, namely, that orphans tend to be neglected. When one asks about specific examples of orphans (in neighbouring families, for example), then the answers tend to be far more diverse.' In some instances, it is likely that individual accounts are censored by the interviewees. Equally, the collective accounts almost certainly drew on locally circulating narratives, as much as personal experience. Narratives about orphanhood and its consequences circulate within schools³ and the media, as well as through the storytelling of rural communities. Chimombo's (2007) examination of the portrayal of AIDS in Malawian short stories, poetry and the arts, for instance, finds that orphans are portrayed as innocent victims, helpless, under sentence of death, vulnerable and abused. Similarly, Malawian local newspaper cuttings (2006-8)⁴ concerning orphans describe them as hopeless, needy, poor, disadvantaged, underprivileged, deprived and vulnerable to mistreatment by relatives. This negative discourse of orphanhood is reminiscent of the myth of a degraded Savannah that was co-produced between media, educational material and policy in West Africa to become taken-for-granted truth with little basis in empirical evidence (Fairhead and Leach 2003). Both 'disaster' discourses may contain elements of exaggeration in order to justify action and assistance in form of donor and other responses. It is also possible that time plays a role. The 'myths' in circulation might not be entirely without basis, but rather describe the situation as it was in the past, before policies and programmes were introduced to assist orphans and to keep them in school. While they may be revealing of some significant 'truths', it is important to recognise that such myths do not always directly correspond to contemporary individual experiences.

Building generalised knowledges from specific knowledges

Most participatory activities began with the individual production of a drawing, diagram or other output, intended to produce personal accounts. Combining individual with collective methods to build generalised from specific knowledges proved challenging. Part of the challenge was associated with the use of drawings and diagrams, with which some participants were uncomfortable. In some cases this

³ The headteacher interviewed at the primary school in Malawi described AIDS as a key reason for children dropping out.

⁴ Collected and analysed by the research team.

was because they lacked pen-handling skills, having never attended school; in others, particularly among the older youth, it may have been because they did not view such activities as in keeping with their status (see Mohan 2001).⁵ Even where young people took to the activity with enthusiasm, it was not always productive. In Lesotho, drawing is strongly associated with school, and activities requiring use of a pen or pencil made the atmosphere more school-like, which did not encourage discussion (although less school-like activities such as drama and photography also failed to generate much discussion). Drawing of any kind was also highly time-consuming (the life maps took the Lesotho girls nearly two hours to draw) and delayed the progression to discussion, which was problematic when the weather was cold and children inadequately dressed (as was often the case in Lesotho), or where the time was restricted and the young people were expected home.

Where participants were asked to draw something individually, they often did so slowly and in near silence, and when the time came for discussion they would present their own drawing, in turn, but with relatively little engagement with each other's drawings. For the activity calendar exercise in Malawi, therefore, Flora chose to begin with a group drawing, encouraging all to contribute their ideas, generating generic knowledge of daily and weekly activities, and followed this by inviting young people to produce their individual variants. With the girls, it took prompting from Flora to include school in their daily routine, although most do attend school. Reasons for non-attendance were probed, but information provided was mostly generic (a child might be sick or might need to go to the field). Alice, a 13-year old orphan, however, used the opportunity to explain the difficulties she had encountered obtaining a transfer letter to enable her to attend the local school when she moved to live with her aunt following her grandmother's death. Nonetheless, ordering the activity in this way tended to produce generalised (albeit useful) information.

Another difficulty was that where young people were asked to represent details of their lives in the individual part of the activity, these were not always very individual or grounded in their own realities. First, because activities took place in a group setting, with young people sitting side-by-side, some were tempted to copy. On their life maps, most of the boys in Lesotho drew a hospital where they were born, a church where they went on Sundays, a grandmother whom they sometimes visited, a cattle post where they went often and a future in which they married. Among the group of young women in Malawi, all claimed to have left school early because they lacked nice clothes, although when subsequently interviewed individually, their reasons were more diverse and complex. On the 'emotional storyboard', the young people were asked to depict the happiest and saddest times in their lives, their biggest success and biggest disappointment and hopes and fears for the future. Group members often highlighted similar events. The young women in Malawi, for instance, generally claimed that their wedding day had been the happiest time; young women in Lesotho claimed marriage as the most disappointing. Such 'groupthink' has been noted by others to be a characteristic aspect of collective

⁵ It is argued that participatory methods are based in Western rationality and modes of cognition; that supposedly neutral participatory techniques such as diagramming actually rely on Western modes of seeing, understanding and representing the world and may be unfamiliar to those not educated in a Western tradition (Mohan 2001).

knowledge production which, while revealing useful understanding of the construction of discourse (Sathiparsad 2010), can be problematic when it disguises individual voices and experiences (Yuen 2004). Attempts to discourage copying sometimes backfired, with individuals presenting contrasting stories to avoid repetition, even where their experiences were actually very similar. This sometimes resulted in inconsistencies within individual accounts. In these instances, it was the group setting rather than the actual method that inhibited the production of personally grounded outputs.

Rather than copy from one another, some accounts appeared to reflect a social norm more than actual experience. Some of the Lesotho girls' activity calendars appeared aspirational or normative rather than descriptive of their daily lives. They depicted, for instance, how they sleep in at weekends and go to church every Sunday, which conflicted with their observed practices. The young married women, by contrast, depicted their daily routines as never-ending work, which might reflect the expectations of a *makoti* (new wife), as much as their actual lives.

Lastly, it often proved difficult to generate group analysis of the individual drawings, diagrams and narratives. Where questions were left open, with little prompting, discussion tended to be very brief. The Lesotho boys' answer to the open question of why some boys' daily workloads appeared much greater on their activity calendars compared to others, for example, produced a single simple explanation. With prompting and probing they suggested a variety of other possible explanations, but there is a danger that discussion produced through prompting overemphasises matters closely connected with the researchers' expectations.

Moreover, there are some issues on which discussion is very difficult to generate. Describing events following the boys' life map drawing in Lesotho, Flora wrote:

This 'discussion' consisted mainly of me asking questions, and one or another boy answering the question with a sentence or two, while turning their faces away from me and each other, shy to talk. It was very difficult to ask questions about what happens to young people when their parents pass away and they have to move. It felt like everyone thought that this was obvious – these children's lives become worse – and a strange thing to ask about. (Fieldwork notes, 12/03/08)

In this instance, some specific details of the boys' lives were gleaned through the activity, but it could hardly be described as participatory.

Social context of the research and 'insider'/'outsider' research assistants

All research methods, but in particular participatory methods involve the co-construction of knowledge. Inevitably, then, the social context of that co-production affects the nature (and groundedness) of the knowledges produced. This context includes the relationships between the researcher, research assistants and the participants themselves.

The young people knew one another, and were, perhaps as a consequence, reluctant to be entirely open about all their experiences. This was most apparent in the emotional storyboards activity. In Malawi, some boys declared falling off a bicycle or out of a tree to be the saddest moments in their lives, rather than referring to their parents' deaths. A girl in Lesotho drew being bitten by a snake as her saddest time. Two others in the same group also drew snakes; they hadn't been bitten but insisted that seeing a snake had been their saddest time. It seemed that these children simply did not want to share emotionally charged experiences and/or were following cultural taboos about discussing death. Such silences are not unusual among youth, particularly those who have experienced trauma. Kohli (2006), for instance, discusses young asylum seekers' use of silence in ways that are protective: as a psychological space to reflect on and make sense of their experiences; for concealing and managing hurt; and as part of the process of growing up and becoming autonomous.⁶ However, while silences and absences are revealing, they do not provide accounts of concrete experience. The young people least keen to share were often those most gossiped about or ostracised. It would have been unethical to probe unwilling children further to reveal upsetting experiences and risk causing distress, embarrassment, loss of self-esteem and being re-traumatised by interview-engendered distress (Amaya-Jackson et al 2000 cited in Alderson and Morrow 2011: 29). Collective methods most encourage the accounts of the more popular, thus reinforcing existing social relations as well as generating knowledge that fails to reflect the experiences of the most marginalised.

The use of, and characteristics of, research assistants also shape knowledge production. For the participatory activities, local interpreters were selected from the villages or nearby, from among the very few individuals who had completed secondary education. In Malawi these 'insider' assistants (one male, one female) were themselves quite young; in Lesotho, where there were fewer people with the requisite level of English, we selected one middle-aged woman.

For each planned activity, the local research assistants were given training. If the activity involved young people producing maps or diagrams, the assistants would learn what was expected by producing their own version, then use this with the young people as an illustration. Modelling form without influencing content proved difficult, however. The fact that most of the Malawian girls marked graveyards on their personal village maps might not signify that these were places of particular significance to themselves, but rather that the 'model' map showed a graveyard. Equally, many girls produced social network maps that included people with the same kin relations as appeared on the assistant's example (a grandmother, mother and paternal uncle). The significance attached to paternal uncles was out of line with what would be expected in matrilineal southern Malawi and conflicted with the maps produced by other groups where maternal uncles were much more important. Here, the collective activity seemingly gave undue prominence to one exception rather than simply replicating a social norm. The tendency for assistants to model was exacerbated by their lack of confidence in the younger children's capacity to understand what was expected of an activity, which led them to give examples or hints.

⁶ Similarly, from researching the sensitive topic of citizenship among Singaporean transmigrants Ho (2008) interrogates the many instances of silence or self-censorship.

These local research assistants at times involved themselves more directly in knowledge production. Sometimes they appeared to 'censor' answers they did not like (for whatever reason), requiring the child to supply an alternative and denying to the researcher that a previous answer had been given. Because they were insiders, they had a complex relationship to the production of specific local knowledges. Being older and better educated than the participants, they were deferred to, and this doubtless inhibited participants from expressing certain information. At the same time, the assistants could judge the accuracy of children's testimony – which might either deter the young people from certain revelations, or equally inhibit them from telling falsehoods. At times this local knowledge and power-imbued relationship was problematic. Sometimes assistants would contradict what children said. A boy in Lesotho drew his grandparents on his social network map and said his grandmother had died in 1991. The assistant ridiculed him for forgetting that his grandmother had actually died in 2008. It was impossible to gain any real clarification of his story (perhaps it was another grandmother or other significant relative) as the boy, visibly upset, deferred to the assistant and agreed that he had been mistaken.

Given the unhelpful tendency for 'insider' researchers to act like teachers,⁷ for the life history interviews and dissemination workshops we altered our strategy and appointed 'outsider' assistants, selected from a pool of graduate applicants for their experience of research and of working with young people, and on the basis of our reading of their personalities. De facto they spoke better English and had more education/training. In the individual interviews, young people seemed very open with us, although the outsider status of the assistants meant that they could not assess with any certainty the veracity of the accounts given. However most young people interviewed had also participated in participatory activities, meaning that we had some means of gauging the veracity - mostly the interviews confirmed and deepened earlier knowledge about the young people, so it is unlikely that they were telling us "stories". It is difficult to gauge how far the difference between the outcomes of the interviews and the participatory research related to the characteristics and abilities of the research assistants. Moreover, the power relations underlying individual interviews, particularly with marginalised young people, are not unproblematic, as has been widely discussed elsewhere (e.g. McDowell 2001), and have a significant bearing on the knowledge production process.

The social context of the research included not only the participants, researchers and research assistants but also very often spectators. Not unusually for researchers in both Majority and Minority world contexts (Abebe 2009, Alderson and Morrow 2011:38), trying to respect children's privacy was all often impossible. It proved difficult to undertake research with children in either setting without an audience, but would not have been ethically or culturally appropriate to have done the research behind closed doors even if a large enough enclosed space had been available. Undoubtedly, this (uninvited) audience had some impact on what children felt able to mention.

⁷ Ennew et al (2009: 2.15) emphasise very strongly that in respecting children's rights to be properly researched, researchers should not act like teachers in order to minimise power inequalities between adult researchers and child participants as far as possible. This laudable ethical ideal is difficult to achieve.

Conclusions

Trying to do participatory research to learn from young people in Southern Africa about the sensitive issue of the impacts of AIDS on their lives raised a number of epistemological, methodological and ethical challenges which have been explored in the preceding sections of this paper. Participatory research methods are principally geared to the collective construction of generalised knowledges. These knowledges at times contradict the specific personal accounts produced in other research settings. Such contradictions raise some significant epistemological questions about the status of the knowledges produced using participatory methods (or, indeed, other collective data production methods such as focus groups). A constructivist perspective on research is founded on an understanding that all research encounters produce knowledges, but none offers direct insight into empirical realities. Participatory research methods produce collective knowledges (with the researcher(s)) that have a correspondence with the empirical realities of participants' lives, but cannot be read as direct mappings of those realities. The consensus-seeking element of participatory research inevitably simplifies diversity and may lead to 'a process of controlling to produce the norm, the usual and the expected' (Kothari 2001:147). This is particularly true in sensitive areas, such as research relating to AIDS, where individuals are reluctant to draw directly on their own (or others') experiences in constructing group knowledges. There is, moreover, a danger that, without direct empirical grounding in personal experience, the knowledges produced may (re)produce myths and stereotypes rather than reliable information.

This is not to dismiss the value and validity of collectively produced, generalised knowledges. While limited in their capacity to reveal lived realities, they offer insight into normative knowledges and discourses which enhances understanding of diverse phenomena and is invaluable in informing policy and practice. It does raise important questions about the 'truths' of alternative accounts, and about whether drawing on individual accounts provides 'better' data. It is worth noting that individual accounts are very diverse, and where the number of participants is small, these might not be representative of wider trends.

We believe that participatory research *can* be used to generate empirically grounded accounts. In conventional research, empirical data is gathered from individuals about their experiences, which researchers analyse to make generalisations. When undertaking group-based participatory research we encourage participants to arrive at generalisations that we usually assume are based on their personal experiences. The evidence presented in this paper suggests researchers should question such assumptions. However, rather than revert to exclusively individual methods of data collection for the construction of empirical knowledges, we propose some alternative ways to ensure that participatory methods of collective data production are more empirically grounded. One possibility is to enable participants to share their accounts with researchers initially in less public arenas. This does not preclude the use of 'participatory' techniques such as drawing and diagramming that moderate the unequal power relations of individual interviews. These methods were often productive in our own research, even where the social context of the research was not amenable to the production of

grounded collective accounts. The outputs, or a summary thereof, may then be presented, anonymised, to other participants for collective analysis involving, for instance, discussion, ranking and debating (see van Blerk and Ansell 2007), thus enabling collective production of generalisable accounts in a second research stage. Another option, perhaps best suited to less sensitive subjects, is to encourage research participants to think about their evidence base or the effects of their positionality on the testimony they present. Clearly considerable facilitation skills are required to guide participants to be critically reflexive and to present evidence. Equally, participatory ethnography might have advantages as researchers can engage with participants individually as well as collectively producing knowledge and action with them over time and through direct involvement in their lives and communities. The ethnographic nature of such involvement can help to produce grounded accounts, although it is subject to the reflection of researchers and participants (see Blazek, 2011 for an example of participatory ethnography).

In summary, while we are conscious of weaknesses in the implementation of participatory methods in our own research, and in particular the limitations imposed by working with inexperienced assistants, as well as working cross-culturally, as outsider adults, we believe there are systematic difficulties associated with using (collective) participatory methods to undertake empirical research with young people on sensitive subjects. As a consequence, our conceptual contribution to the methodological debates is to argue that when seeking to learn from young people about their lives, researchers should be more aware of the types of knowledge required, and whether participatory methods are appropriate and sufficient for generating that knowledge. It might be possible to use participatory research to produce empirically grounded accounts, even relating to sensitive subjects, but in doing so, we should consider appropriate strategies. This might involve offering opportunities for participants to share their stories initially in a more private arena, or asking them to provide evidence for their assertions, rather than reifying their voices (Ansell 2009) and accepting what they say as grounded truth. Participatory methods are doubtless valuable for understanding *how* stories are produced and circulate, but there is a danger that unless accounts are interpreted critically, our research may serve to reproduce harmful myths. Finally, when seeking empirically grounded knowledge on sensitive subjects, participatory methods which require specific personal accounts to be brought into discussion in a group setting might not be the most ethical way to undertake research.

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