

Researching to make a difference: Possibilities for social science research in the age of AIDS

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Abstract

HIV and AIDS is recognized as one of the most devastating pandemics of sub-Saharan Africa, and South Africa in particular, with adverse effect on individuals, families, schools, communities and society at large. Research is therefore required to provide a deeper understanding of the complexities of HIV and AIDS in order to mitigate the effect of the pandemic. Much of the excellent research that has been done has been undertaken within a positivist paradigm and has focused on the biomedical aspects of HIV and AIDS, as well as the social aspects of the pandemic. This theoretical position paper draws on various projects in the field of HIV and AIDS education in rural KwaZulu-Natal to argue that more social science research should be framed within a participatory research paradigm, foregrounding participant engagement and process, and which simultaneously has a 'research-as-intervention' focus. Such research adheres to the requirement of knowledge production, but also engages the participants as knowledge producers who, through the research process, are enabled to shift towards taking up their own agency. Reflecting on the findings from the various projects suggests that visual participatory methodologies are particularly useful when working with marginalized persons whose voices are seldom heard especially when exploring topics which are difficult to discuss. Furthermore, it brings issues to the fore and opens up debate, while at the same time democratizing research and allowing universities to take up their social responsibility and to contribute towards making a difference in the communities they serve.

Keywords: HIV and AIDS, participatory research, visual methodologies, democratizing research, social change, research as intervention

Résumé

Le VIH/SIDA est reconnu comme une des pandémies les plus dévastatrices de l'Afrique subsaharienne et de l'Afrique du Sud en particulier. Il a un effet négatif sur les individus, les familles, les écoles, les communautés et la société en général. Il est par conséquent nécessaire de mieux comprendre la complexité du VIH et du SIDA afin d'atténuer l'effet de la pandémie. Une grande partie de l'excellente recherche jusqu'à ce jour a été entreprise sur base d'un paradigme positiviste et s'est concentrée sur les aspects biomédicaux du VIH et du SIDA, ainsi que les aspects sociaux de la pandémie. La thèse de cet article s'appuie sur divers projets dans le domaine de l'éducation en matière de VIH et SIDA dans les zones rurales du KwaZulu-Natal pour soutenir que davantage de recherche en sciences sociales doit être inscrite dans un paradigme de recherche participative, mettant en avant l'engagement et les méthodes des participants tout en ayant une orientation « recherche d'intervention ». Ce type de recherche est à la fois conforme à l'exigence de production de connaissances et traite les participants en producteurs de connaissances qui, durant la recherche, sont à même de prendre contrôle du processus. L'analyse des résultats des différents projets suggère que les méthodes participatives visuelles sont particulièrement utiles lorsqu'on travaille avec des personnes marginalisées dont les voix se font rarement entendre, surtout lors de l'exploration de sujets qui sont difficiles à discuter. En outre, cela met des problèmes en évidence et ouvre la porte aux débats tout en démocratisant la recherche et permettant aux universités d'assumer leur responsabilité sociale et de contribuer au changement des communautés qu'elles servent.

Mots clés: VIH et SIDA, recherche participative, méthodes visuelles, démocratisation de la recherche, transformation sociale, recherche d'intervention.

Introduction

A headline, 'The times they are a-changin' in the *Mail & Guardian* (Parker 2010), published at the time of the XVIIIth International AIDS Conference in Vienna, has the subtitle: 'Standing ovations for microbicide gel team as South Africa's Aids about-turn is feted' (Parker 2010:32). Indeed, a moment to be proud of, showing that times might be 'a-changin' in terms of

responding to HIV and AIDS in South Africa. 'The times they are a-changin'', sang Bob Dylan in the 1960s. His lyrics addressed the major issues affecting America of the 1960s, such as racism, poverty, and social change. He captured the feelings of the people at a time of great social and political upheaval. A line from one of his songs runs: 'come senators, congressmen, please

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heed the call'. He was calling the politicians of his day to action. Indeed, politicians have not changed, if one considers how long it took the 'senators to heed the call' in allowing HIV-positive persons to travel into the USA – the 22-year-old ban was only lifted in January 2010. In the context of this article, it is useful to adapt Dylan's lyrics: 'come academic researchers, please heed the call!' and contribute to times that 'are a-changin'" and address – through pushing the boundaries of research – the challenges of HIV and AIDS in the next decade.

The purpose of this article is to explore how social science research can contribute towards making a difference in the lives of people in the communities that universities serve, but also to interrogate what 'our doing does' (Foucault, as cited in and rephrased by Dreyfus & Rabinow (1992)). The paper focuses on social science research in the context of HIV and AIDS in South Africa. More than 16 years into South Africa's new democracy, universities need to think harder about what democracy means in relation to HIV and AIDS research. The article will put forward the argument that social science research should be 'democratized', in order to bring researchers and communities closer to each other. This can be achieved by drawing on research methodologies of a participatory nature, which are often used in development work. In this instance, visual participatory methodologies allow academic researchers to engage with the communities they serve and to take up their social responsibility.

This article will be presented in four parts. First, it will provide an overview of where South Africa stands in terms of HIV and AIDS, and reflect on what many may regard as an about-turn in the government's approach to addressing the pandemic. Second, it will be put forward that the about-turn should be augmented and accelerated through the core business of universities, i.e. research as engagement. Indeed, it will require all role players to sustain the about-turn. Third, it will be posited that there needs to be more research located within a critical paradigm, which is participatory in nature and which has a social change agenda, for example, visual participatory research. In this way, researchers can contribute towards making a difference in this age of AIDS, especially in the lives of the people in the communities where university researchers conduct their research. The article concludes by highlighting the implications of 'democratizing' research and the importance of undertaking research in order to make a difference in South Africa in the age of AIDS.

What their 'doing' has done: a brief (his-) story about HIV and AIDS in South Africa

Consider the following: If a large piece of paper is folded over once, and then the same folded paper is folded over again, and then again and again, until you have refolded it 50 times, how high will the stack of paper be? It will stretch from the earth to the sun. If you folded it over once more, the stack would be as high as the distance from the earth to the sun and back again. Mathematicians refer to this as geometric progression. Gladwell (2000) posits that epidemics are another example of geometric progression, in that 'when a virus spreads through a population, it doubles and doubles again, until it has grown (figuratively

speaking) from a single sheet of paper all the way to the sun in 50 steps' (11). This is difficult to understand 'because the end result – the effect – seems far out of proportion to the cause' (Gladwell 2000:11). Back in 1981 – a 'small' event – the first case of AIDS, was reported in the United States of America. In 1982, two cases were reported in South Africa (Palitza, Ridgard, Struthers & Harber 2010) and since then the disease has grown exponentially, evolving into an epidemic.

The virus has moved rapidly from its original host populations and has spread globally, compelling world governments to join forces to combat and contain the disease (Rohleder, Swartz, Kalichman & Simbayi 2009). However, despite the recent progress made at government level, the preceding years of confusion and disagreement regarding South Africa's HIV and AIDS policy has left the country reeling under the effects of HIV and AIDS. With a population of approximately 46 million people, it is estimated that 5.7 million people are living with HIV, making South Africa the country with the highest number of people living with HIV in the world (UNAIDS 2008). The South African epidemic is described by the Human Sciences Research Council (HSRC) as 'a hyper-endemic epidemic', because more than 15% of the population aged 15–49 is living with HIV (Shisana, Rehle, Simbayi, Zuma, Jooste, Pillay-van Wyk, *et al.* 2009:1). Almost a 1000 AIDS-related deaths are recorded every day, with 71% of these deaths being in the 15–49 age bracket (AVERT 2009). Not all provinces are equally affected. For example, in 2008, the prevalence rate in KwaZulu-Natal was highest at 15.8%; Mpumalanga 15.4%; Free State 12.6%; North West 11.3%; Gauteng 10.3%; Eastern Cape 9.0%; Limpopo 8.8%; Northern Cape 5.9% and Western Cape 3.8% (Shisana *et al.* 2009:xvi). However, even within a province, districts have uneven prevalence rates. For example, in KwaZulu-Natal, in some districts more than 25% of young people are HIV-positive (CAPRISA 2006). Turning to South Africa's higher education sector and in particular the student population, a recent study conducted by HEAIDS indicated that the mean HIV prevalence rate for students across the country was 3.4%, with the Eastern Cape the highest at 6.4%. The Eastern Cape displays uneven HIV prevalence rates for students, as one of its higher education institutions (HEIs) has the lowest prevalence nationally, and another HEI has the second highest HIV prevalence in the country (HEAIDS 2010).

The statistics clearly show the magnitude of the epidemic and thus the urgent need to continue addressing it. Furthermore, South Africa's newspapers continue to show us the 'face of AIDS', as the newspaper reports bear testimony, not only to the politicizing of the epidemic and the complicity of the government, but they also demonstrate the complexity of the epidemic and the challenge of how to address it. More recently newspaper reports reveal that the 'times they are a-changin' regarding how South Africa is addressing the epidemic, with some positive advances, as the following newspaper headlines illustrate: 'The AIDS struggle: Ten tragic years', 'Confusion leads to AIDS deaths', 'Deadly secret that a mother dares not tell', 'The young and the reckless', 'Older men are fuelling SA's AIDS epidemic', 'Sexual abuse rampant at rural schools', 'Donors put a cap on AIDS funding', 'New hope for HIV + moms', 'Sex talk a setback for

AIDS, 'Grannies of the Valley of Care' 'Can cell phones promote safe sex?', 'Edging closer to an AIDS vaccine' 'Fast-track anti-HIV gel, says minister', 'Plan to halt HIV transfer', 'Wanted: caring universities' and 'Where AIDS is everyone's problem'. The media, according to Palitza *et al.* (2010), have paid too much attention to the politicization of HIV and AIDS. However, it is ordinary people like Thembinkosi, a young teacher in rural KwaZulu-Natal and a participant in the *Every Voice Counts* project, who tell the real stories through their visual narratives. Such stories evoke 'visceral and emotional responses in ways that are memorable, coupled with their capacity to help us empathize or see another's point of view and to provoke new ways of looking at things critically . . .' (Weber 2008:41).

Thembinkosi speaks of the impact of the pandemic on his people, his rural community, and about the vulnerability of children and young people, about orphans, stigma and the general despair of the people (de Lange, Mitchell, Moletsane, Balfour, Wedekind, Pillay, *et al.* 2010). Thembinkosi's narrative points to the social embeddedness of the epidemic (Baxen & Breidlid 2004) that is so often ignored in research. He says: 'It's a challenge. It's a call to everybody. Everybody has to respond positively to it' (de Lange *et al.* 2010:45). So how can universities take up Thembinkosi's challenge?

'Doing' things differently: researching for social change

The second part of this article begins with a quote from *Expecting Adam*, a story about a married couple studying for their doctorates at Harvard University. They find themselves expecting a baby who has Down's syndrome. The father has an appointment with his supervising professor, as the following excerpt demonstrates:

He looked at the stacks of journal articles on the professor's desk. He knew that his mentor's life consisted largely of reading such articles, in order to write other articles almost exactly like them. These would be read only by other academics, who in turn would use them to churn out more. (Beck 1999:208)

This is an exaggerated view of social science research, but perhaps a view that many people believe describes academic research at a university. This 'picture' is challenged by, for example, Louw, Johnson and Smit (2009), who quite appropriately argue for 'new generation universities'. Such universities should 'serve society', and 'more particularly their immediate communities', in order to address the 'challenges faced by their constituent communities' (Louw *et al.* 2009:2). For example, the recent HSRC survey (Shisana *et al.* 2009) highlighted a number of key problem areas in the field of HIV and AIDS that still require urgent research. These include issues around the vulnerability of females (e.g. in 2008, in the 25–29 age group, 1 in 3 females were HIV-positive); the problem of early sexual debut among youth before the age of 15; the prevalence of age-disparate relationships; high turnover of sexual partners; low levels of HIV and AIDS knowledge among most-at-risk persons; and the

need to reach older population groups in the fight against HIV. Shisana (2010:34), implores researchers to do research which 'respond[s] to the needs of vulnerable and marginalized groups in society'. Indeed, the need for the times to be 'a-changin'' in academic research endeavours is more urgent than ever before.

There has been a proliferation of HIV and AIDS research over the last decade. Indeed, when Andrews and Pouris (2010) investigated the nature and extent of global HIV- and AIDS-related research publications they came to the conclusion that South Africa is indeed a 'scientific powerhouse' of research publications. They based their findings on the number of journal articles published by South Africans in the period 2005–2009. South Africa was ranked fifth in the world, with most of the research being in the social sciences. How has this research impacted upon the AIDS-affected communities of South Africa? The continued high HIV prevalence rates suggest that the impact is very small. How can researchers at academic institutions do things differently so that Mark Twain's wise words: 'If you do what you've always done, you'll get what you always got' can be heeded? Can researchers not work towards 'democratizing' research? Or are researchers guilty of only conducting research in the manner of the professor in *Expecting Adam*?

Democratizing research

The notion of 'democratizing research' has been addressed by Burt and Code (1995), Ansley and Gaventa (1997), Cole and Knowles (2008), and others, and has also been considered in South Africa. According to Ansley and Gaventa (1997), 'democratizing research' is not a new concept, and has been referred to broadly as research that enables academic engagement and participation in community life, which allows academic researchers to take up their social responsibility in society. Cole and Knowles (2008) use the analogy of building a bridge across the moat which separates 'ivory tower' research from the community, and which allows the academic researcher access to the community, and which in turn allows the community access to the research endeavour. Democratizing research then implies engaging in modes of research that promote a more democratic inquiry, by allowing the participants a greater say with regard to the research agenda. The participants will then play an important role in defining the problem, and reducing power imbalances between researchers and participants. They will help generate, analyse, represent and disseminate the data derived from their communities (Burt & Code 1995). This data will enable them to take action and thereby make a difference in the communities where the research takes place. Such modes of inquiry allow for reciprocal relationships and the establishment of collaborative projects between research institutions and communities (Ansley & Gaventa 1997), which contribute to social change.

The importance of the community in the democratization of research and in bringing about social change is also foregrounded in community psychology (Ebersöhn, Ferreira-Prévost & Maree 2007), whereby community members are positioned as collaborators in the research endeavour, but also as rich in assets (Ebersöhn & Eloff 2003) to be drawn upon in bringing about social change. The work of Ebersöhn and Ferreira (2012), with teachers in rural communities in South Africa, takes up a similar agenda,

positioning themselves as researchers in collaboration with the community. Skovdal's (2010) work with vulnerable children and youth in a social action fund programme in Kenya is another example of community engagement in research, underscoring youth participation and ownership, highlighting the benefits to both the youth participants (empowerment, skills and development) as well as the community, and explaining the influence of the research on intra-community relations. Skovdal and Campbell (2010) argue for the need to acknowledge what the community already has in terms of strengths or mechanisms in order to address existing problems, but also to take cognizance of the complex dynamics within a community, when researching with the community.

In South Africa, Mitchell used the term 'democratizing research' at the *Education and Democracy Conference* in Johannesburg in 2004, while Marcus and Hofmaenner (2006), in their work, *Shifting the Boundaries of Knowledge*, set the agenda for such research in South Africa.

On the international front, there is burgeoning evidence of social science research that takes up this position and which is being recognized as intellectually legitimate (Ansley & Gaventa 1997). There are works with titles such as *Appreciative Inquiry: Research for Change* (Reed 2007), which positions research as an inquiry with '... different ways of thinking and doing ...' (Reed 2007:26). Such research is underpinned by the principle of 'simultaneity', which supports the argument for research that is both (simultaneously) theoretical and empirical, and intervention-oriented. This notion of simultaneity is also put forward in Schratz and Walker's (1995) work, entitled *Research as Social Change*, which informed this researcher's initial attempts into research that aims to 'make a difference'. Furthermore, Jipson and Paley, in their work, *Daredevil Research* (1997), push the boundaries of what counts as research and what is accepted and acceptable by the academe. Such an approach requires new ways of thinking about, and doing research. Jansen (2009:198) concurs, and also refers to a 'multiplicity of ways of knowing', suggesting a shift in our way of thinking about research.

Such 'multiplicity' is seen in the growing number of research genres, for example, action research (McNiff & Whitehead 2006); participatory action research (Hughes & Seymour-Rolls 2000); self-study (Pithouse, Mitchell & Moletsane 2009); auto-ethnography (Ellis 2004; Grossi 2007); community-based participatory research (O'Fallon, Tyson & Dearry 2000); visual participatory research (Mitchell 2008; Olivier, Wood & de Lange 2009), and so on, in the field of Education. Such genres place an emphasis on the possibility of social change, at both the individual level, as well as at the community level. The importance of these new emerging genres is of particular relevance to the field of AIDS research.

At the Nelson Mandela Metropolitan University's Education Faculty, for example, much research has been undertaken which bridges the divide between research and engagement. Athiemoolam's (2009) drama-in-education work; Wood and Olivier's (2011) *Walmer Schools Initiative*, which addresses teacher self-efficacy, youth resilience, conflict resolution and peer mentoring,

and which aimed to help teachers to make a difference in their community; Webb and Austin's (2009) *Family Maths and Science* programme; Webb's (2010) *Integrated School Development and Improvement Project*, and Zinn's (2010) *Centre for Community School*, and so on. Such work is relevant, exciting and rewarding, and it takes researchers out of their 'ivory towers' and places them in the community. Hence, by 'democratizing' their research (Mitchell 2008), they are able to 'make a difference'. It is against this background that visual participatory methodologies are positioned as a means towards 'democratizing' research, especially in the age of AIDS, with a view towards making a difference.

Visual participatory research

'We know more than we can tell', says Polanyi in Eisner (2008:5). So how can researchers and communities access that which is difficult to tell? The visual can capture that which cannot be 'articulated linguistically' says Eisner (2008:5), opening up the possibility for using the visual in relation to the research questions, or the phenomena being explored. Imagine asking educators to *draw* how they view HIV and AIDS, or asking them to *take photographs* showing HIV-related discrimination (stigma), or asking them to *make a video* of the most important issues affecting their lives, or asking teachers to *work with a digital archive* in addressing school health. Such visual participatory approaches, which are also called 'visual arts-based', 'image-based' or 'critical visual', refer to participatory research methodologies, and are used to engage people at grassroots level. By using visual arts, such as drawing, collage, photographs and video work, opportunities are created for further discussion (Mayoux 2008; Weber 2008). Chambers (1994) refers to these approaches and methods as enabling people to express, enhance, share and analyse their knowledge of life and their circumstances and to plan and act upon them as well. It is for such reasons that visual participatory methods could be used in the context of HIV and AIDS research, as they operate as interventions in and of themselves. Visual participatory approaches heighten the engagement of the participants, add a sense of playfulness, and create contexts in which the participants become aware of their own agency, and in the process contribute to bringing about change. Weber (2008) notes the methods that put data production in the hands of ordinary people can 'project a credibility and authenticity that more polished and accomplished works of art cannot achieve' (47). While the visual can serve as a mode of inquiry, mode of representation and mode of dissemination (Mitchell 2004), it does not come without challenges of its own, for example, challenges around visual ethics. However, it is a methodology which enables all the participants to draw on individual and collective strengths in addressing HIV and AIDS within their communities. The following examples demonstrate what is meant by this.

Showing what we have been 'Doing'

The third part of this article presents examples from the researcher's experiences in the field. The 'field' over the past seven years has been a rural district in KwaZulu-Natal, which has been deeply affected by poverty, unemployment, gender-based violence, teenage pregnancy and of course HIV. Pregnant women, for example, have HIV prevalence rates of 10.6% for girls younger than 16; 21.3% for those aged 17–18; 33% for those

aged 19–20; 44.3% for those aged 21–22; and 51.1% for those aged 23–24 (Abdool Karim 2010). In such a sensitive socio-economic environment, the researcher together with her fellow researchers deliberately chose to work ‘deeper’ and not ‘wider’, and to not do ‘blitzkrieg’ research. For this reason, we have worked intensively with the same schools over a long period.

Drawing towards understanding each other

In a community so deeply affected by the epidemic, the researcher and her team had a great desire to address HIV and AIDS problems through the research, but together with the community. The team needed to work with educators and community healthcare workers who work with the youth (a target population in the project) in the community (de Lange, Mitchell, Moletsane, Stuart, Buthelezi, Taylor, *et al.* 2003). The researcher and her colleagues chose to use drawing as an ‘entry point’, to facilitate the establishment of a relationship with and between the participants, and to deepen their understanding of each others’ roles. They were asked to draw how they saw each other and then to explain their drawings to the group. The findings showed that each group had positive and negative perceptions of each other, bringing contentious issues into the discussions around the drawings. For example, the community healthcare workers depicted the educators as well-educated, caring and supportive, but also that some of the educators physically and sexually abuse learners. The educators perceived the community healthcare workers mostly in a positive light and were appreciative of their work, with only one picture showing a healthcare worker as angry and ill-treating her patients (de Lange, Mitchell & Stuart 2011). This undemanding and low technological research method (used with adults), opened up a space that allowed the two groups to engage with each other, to share perceptions, to interrogate these perceptions and to begin understanding each other. This created an opportunity, for example, for intersectoral collaboration between community healthcare workers and educators. The informal interaction between the two groups enabled the healthcare workers to feel more comfortable with the prospect of entering the school terrain (and the domain of the educators), in order to work with the learners (de Lange *et al.* 2011).

This opportunity to analyse the participants’ perceptions of each other placed the researchers in a better position to develop a ‘research as intervention’ strategy in this particular rural community (Mitchell, de Lange, Moletsane, Stuart & Buthelezi 2005). Furthermore, it also enabled the participants to explore their understanding of each other’s work, thus allowing them to address HIV and AIDS issues more effectively, with the learners with whom they work. This example also demonstrates the importance of the process of participation. A recent publication, *Picturing Research: Drawing(s) as Visual Methodology* (Theron, Mitchell, Smith & Stuart 2011) provides a deeper understanding of drawing as an arts-based methodology, strengthening the theoretical underpinnings of the approach, and adding to the rigor of such methodologies.

Taking/making photographs to show discrimination (stigma)

The term ‘photovoice’, coined by Wang and Burris (1997:369), is a research strategy that uses photography by putting cameras in

the hands of participants as a tool for bringing about social change. It is a process that gives people the opportunity to record, reflect and critique personal and community issues in a creative manner. Wang’s (1999) study involved working with Yunnan women farm workers in China, who documented their lives through photovoice. They captured their working conditions in the rice paddies visually, using photographs, and presented the findings to the policy-makers, who were then compelled to address their dire working conditions. This study is a good example of how research and policy-making can be ‘democratized’ to make a difference in a community.

Mitchell, Stuart, de Lange, Moletsane, Buthelezi, Larkin, *et al.* (2010) offer another example of photovoice at work with learners in *The Feeling Safe/Not so Safe* project in Swaziland. When the teachers viewed the photographs that the learners had taken, they were surprised at the depictions of danger, which the girls encountered daily, when going to the toilets at their school. This prompted the school to set into motion a process of monitoring the toilets in order to ensure a safe environment for the learners (Human Rights Watch 2001; Mitchell *et al.* 2010).

The educators in one of the rural schools with whom the researchers had been working in the project *Digitizing Data: Giving Life to Data to Save Lives* raised the issue of HIV-related stigma in the community, particularly among learners at their school. They suggested that the research team work with the learners. We, as the researcher team, were keen to use photovoice to understand how the learners viewed HIV-related stigma. Furthermore, the researchers wanted to create a space for the learners to reflect on how they themselves might address stigma in their school and community (Moletsane, de Lange, Mitchell, Stuart, Buthelezi & Taylor 2007). The research team decided to use cameras and photographs, bringing energy and a sense of fun to the research process, but keeping in mind that a sense of having fun must be balanced by serious research (Mitchell 2004). The findings showed that the participants had a deep awareness of HIV and AIDS in their community, HIV-related stigma, and its impact on the community, and also an acceptance of their personal agency and the need to take action (Moletsane *et al.* 2007). A collection of enlarged photographs was given to the school for public exhibition, thus bringing the findings of the study to the community. This enabled them to engage in a critical dialogue around the issue of stigma and to contribute to the necessary change.

Photovoice presents many exciting possibilities for community research, as can be seen by the work done with teachers and community healthcare workers in addressing the many challenges around HIV and AIDS in rural communities in KwaZulu-Natal (Mitchell, Moletsane, Stuart, Buthelezi & de Lange 2005). It is also illustrated in research conducted with educators in Motherwell, Port Elizabeth, in addressing the challenges in their lives as teachers in the age of AIDS (Olivier *et al.* 2009); in the research undertaken with staff in the department of agriculture at Jimma University, Ethiopia, in addressing issues of gender inequality and its link to HIV and AIDS; and in the research work at the Kigali Institute of Education, Rwanda, with new researchers, both male and female, in addressing the economic empowerment of girls and women (in 2009). The publication *Putting People in*

the Picture: Visual Methodologies for Social Change (de Lange, Mitchell & Stuart 2007), bears testimony to the photovoice work already conducted in this field.

Using participatory video in addressing gender-based violence

Imagine a group of 35 learners, teachers, community healthcare workers and parents arriving on a Saturday morning at a school in a rural community in the lower foothills of the Drakensberg. They are ready and willing to spend the whole day making short videos of issues that affect their lives in their rural community (de Lange 2008). None of them have used video cameras before. However, by the end of the day, by using a No Editing Required (NER)¹ approach, the first time film-makers have produced a range of three minute videos around selected issues affecting their lives. These are 'not-always-technically-perfect', but are sometimes 'more convincing, more true to life' (Weber 2008:47) than a professional video production. More importantly, the participants have had an opportunity to engage with issues that are difficult to discuss, such as incest, raping of school girls by teachers and male learners gang-raping school girls.

The participatory video process plays itself out in group work. It includes a brainstorming session to identify important issues affecting the lives of the participants, followed by a process of voting to find an issue that the majority of participants feel is critical to their community. They determine whether a video could and should be made concerning the topic. They then write a storyboard to plan how the video will be filmed. This is followed by the shooting of the video and finally the showing thereof to the whole group of participants. This enables them to see what issues the other participants have identified as important, and to engage in a discussion around them. The process itself is more important than the final video produced. The process is about who is invited to participate, the role each participant plays in the various phases of the exercise, the discussions during the video production phase, and also regarding who owns the video and what gets done with it (Mitchell & de Lange 2011).

Using participatory video is, therefore, not a 'once off' activity, but is part of a process of community engagement. The researchers work with the videos over time in order to involve a wider group of community members, beyond those who initially made the videos. Thus, dialogue and ultimately the possibility of social action are emphasized, particularly in the context of social issues, such as poverty and gender-based violence – problems that are prevalent in rural South Africa (Mitchell & de Lange 2011).

In one study, one of the issues that the participants brought into the research agenda, through participatory video, was gender-based violence (Moletsane, Mitchell, de Lange, Stuart & Buthelezi 2009). When five of the six videos made by the learners focused on gender-based violence, it clearly demonstrated that this issue was a key problem experienced on a daily basis. The researchers identified a need to engage with the educators in a workshop on gender-based violence, and in a participatory fashion developed a facilitator's guide to be used with the composite video²

entitled, *Seeing for Ourselves* (containing some of the short videos made by the learners) on ways of addressing gender-based violence in schools. Realizing that further research and intervention was required, it was necessary to obtain a deeper understanding of men and women teachers' constructions of gender-based violence, what kinds of gender-based violence are experienced at school and what the school did to address it. The findings of the study led to a further workshop on gender-based violence, which was conducted with the educators (Bhana, de Lange & Mitchell 2008). This clearly highlights the need to allow the focus of the research to emerge from the participants, making it not only meaningful, but also relevant to the communities where the research is undertaken. The publication, *Handbook of Participatory Video* (Milne, Mitchell, & de Lange 2012), intends to strengthen the theoretical underpinnings of participatory video.

Creating and using a digital archive to improve the health of the community

Living in an electronic era new technological innovations hold endless possibilities for research. The large volume of visual data accumulated from our rural community work included several hundred photographs, and some drawings and videos. Hence, it was very important that the data be stored in a digital archive in cyberspace. A digital archive is hosted on a website, and is designed to store data in a way that is accessible by software applications and that consists of a collection of data in a digital format (Pearce-Moses 2005). The visual artefacts are not only stored, but given an extended life, as was achieved through the *Giving Life (to Data) to Save Lives* project (de Lange *et al.* 2007). This digital archive opened up the possibility of using the visual data in different places and spaces, as well as re-inserting it back into the rural community, for further use in addressing HIV and AIDS. Mnisi's (2009) study illustrates how a digital archive can be re-used in the same community (see also Park, Mitchell and de Lange 2008), on the development of a digital archive). The researchers worked with a group of educators in a computer laboratory at a rural school, which had acquired Internet connectivity through the research project. The study explored how educators might access and use the digital archive, consisting of the visual data generated by them, in their teaching, in order to improve the health of the community. The findings showed that the digital archive was used as part of their pedagogical strategy, contributed to breaking the silence around HIV, allowed for the projection of feelings, influenced the school policy from grass roots and created a sense of agency (Mnisi, de Lange & Mitchell 2010).

In another study, the learners were engaged in an interactive way with the photographs in the archive, through a blogging activity, which allowed them to reflect on and respond to key issues individually, but also to produce knowledge, and to make known their messages in cyberspace, especially around issues of HIV and AIDS (Mitchell, Pascarella, de Lange & Stuart 2010). Community healthcare workers were also engaged in re-using the visual data of the archive, by getting them to add new analyses of the photographs. The digital archive, containing the visual data produced by them, contains visual artefacts that are both local and relevant,

and, therefore, meaningful in their context. Hence, digital archives can become a 'lifesaving' resource in communities where resources are not abundant. However, a key challenge is how to provide Internet access to the rural communities of South Africa.

Conclusion: what might our 'doing' do?

Drawing together the three parts of the article, and with Gladwell's tipping point in mind, I suggest the idea of geometric progression be used to start a 'positive epidemic of social change' through social science research, in the age of AIDS. To achieve this, it is necessary to abandon the 'expectation of proportionality' and to believe in the 'possibility that sometimes big changes follow from small events' (Gladwell 2000:11). The already abundant research in HIV and AIDS undertaken by academic researchers and postgraduate students in the social sciences should be sustained, but re-imagined in order to infuse elements of 'democratizing' research. It can largely be achieved by drawing on a wider range of research methodologies, including visual participatory methodologies, which have a strong emphasis on social change. A vibrant research culture at universities could, through small (and large), but meaningful projects, contribute towards making a difference in the age of AIDS. Therefore, an aggregate of these small research projects could constitute the 'masses of small projects', spoken of by McDermott (cited in Mitchell *et al.* 2005), that slowly add up to make a significant difference (de Lange 2011; Gladwell 2000).

It is against this backdrop that I posit that visual participatory methodologies have the ability to make an important contribution towards the 'democratization' of research. In this way, the 'ivory tower' of academia is brought closer to the communities that universities serve and simultaneously make a difference in the lives of the people in these communities. The urgent nature of the AIDS epidemic should push researchers towards new ways of thinking about and doing social science research. At the same time, social science researchers need to continuously interrogate the very critical idea of Michel Foucault that we must understand – as Dreyfus and Rabinow (1992) rephrase it – what 'our doing does' in taking up our social responsibility to ensure that in the age of AIDS the 'times they are [indeed] a-changin'.

Acknowledgements

I gratefully acknowledge the financial support of the National Research Foundation (South Africa) in the research projects referred to. The ideas expressed in the article are those of the author. I also acknowledge, in particular, the input of my mentor and friend, Prof Claudia Mitchell from McGill University, as well as the co-researchers at the Centre for Visual Methodologies for Social Change who worked on the projects with me, and the participants in the Vulindlela district. I also thank David Morton for his meticulous editing of the manuscript.

Footnotes

¹Claudia Mitchell and Monica Mak coined the term NER to refer to the use of 'in camera' revisions. Each scene of the storyboard is

shot only once, with the participants then moving on to the next scene.

²A composite video draws together video footage of the participatory video process as well as the participatory videos that were generated by the participants (Mitchell & de Lange 2011).

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