
Seeing with the body: educators' representations of HIV and AIDS

Naydene de Lange, Claudia Mitchell,
Lebo Moletsane, Jean Stuart and
Thabisile Buthelezi

Abstract

Within the social sciences generally, there is a burgeoning of interest and expertise in using visual and participatory elements for research designs which have a built-in 'research as a social change' orientation. Lister and Wells (2001) stress the unprecedented importance of imaging and visual technologies in contemporary society, and urge researchers to take account of those images when conducting research. A growing body of scholarship in education is incorporating certain image-based techniques into its research methodology. This article explores the use of visual and arts-based methodologies with a group of educators in a postgraduate programme at a university. Issues around HIV and AIDS are explored through creating photographic representations of the body, a natural site to begin exploring AIDS, trying to use photographic imagery to unpack understandings and experiences of AIDS, in so doing creating a context for action and social change. From their visual presentations a variety of themes, revealing the participants' understandings and experiences of AIDS emerged, but differences were also apparent in the way the selections were presented and in the stories that were told. Implications both for methodologies in education, as well as implications for addressing HIV and AIDS with educators are discussed.

Introduction

With respect to education and schooling, we must first accept that in the (post)modern era schools and classrooms – teaching, learning, assessment, policy, and so on – *are visual*, and that the relevant actors (teachers, students, administrators, parents, etc.) are meant to be *seen*. We must face, further, simply that watching and being watched does not automatically mean that we

understand what is being watched – what and who we are watching and being watched by (Vinson and Ross, 2003).

Like Vinson and Ross (2003), we are interested in the meanings of the *visual* – particularly in the context of HIV and AIDS. Within the social sciences generally interest and expertise in using visual and participatory elements for research designs that have a built-in ‘research as a social change’ orientation is on the increase. Schratz and Walker (1995) in their book *Research as social change* for example, map out a number of different tools and approaches including memory work, drawings, photographs and visual mapping. Notwithstanding the accessibility afforded by such approaches, and a democratising of research itself (Mitchell, 2004), it is worth highlighting the blurring of boundaries between and amongst the uses of visual texts as modes of inquiry, modes of representation, and modes of dissemination, as well as the blurring of boundaries in terms of ‘what counts as data’. Is taking a picture, the act of choosing and selecting a ‘shot’ in the first place, the narrative behind the visual text? Is the resulting artifact, the picture, the point and (for the researcher) the data? Or is it the story that is evoked by the picture, the narrative text that begets the story? Or is the story evoked years later, a photograph as an artifact ‘in history and with a history’? All of these are possibilities within the vast body of work on photography: photo-voice techniques (e.g. Wang, 1999), photo therapy (Weiser, 1999; Spence, 1988; 1995), photo elicitation (Walker, 1993), self-representation through photography, particularly through the eyes of a number of marginalised groups: children (Mitchell and Reid-Walsh, 2002; Ewald, 1992, 1996, 2001; Hubbard, 1994; Karlsson, 2001), women (Kun Yi, Cheng Li, Wen Tao, Ke Lin, Burris, Yi Ming, Yan Yun and Wang, 1995; Mateo, Sanches and Lykes, 2000; Spence and Solomon, 1995; Lykes, 2001; Wang, 1999); teachers (Mitchell and Weber, 1999; Weber and Mitchell, 2004; Krisman, 1986); rural communities (Rohde, 1998), memory work and photography (Mitchell and Weber, 1999; Spence, 1995); public memory (Coombes, 2003), working with family albums (Faber, 2004; Spence, 1995), or working with the visual texts to create a new text by way of staging and representation through arts-based media/cultural studies ‘tools’ (see, for example, Buckingham & Sefton-Green, 1994; Walton, 1995; Stuart, 2004).

In this article, we are particularly interested in this last category, of working with visual texts to create new texts, as an approach to explore themes and issues related to the body in the age of AIDS. Our interest in this area comes out of a concern for innovative approaches to involving educators in looking

at themselves and their own communities with the idea that, hereto, education has been more regarded as the problem, rather than the solution, in addressing the high incidence of HIV and AIDS amongst young people (Kelly, Parker and Lewis, 2001) and particularly the vulnerability of girls and young women in relation to unprotected sex, early debut of sexual experiences, and non-consensual sex. We are aware that educators, while occupying an important 'leverage point' in working with young people are themselves infected and affected by HIV and AIDS. We are, therefore, interested in two questions: How might educators explore their own perspectives through visual representation? Secondly what might their photographs reveal about some of the issues that need to be addressed within teacher education in South Africa more broadly? These questions come out of previous work with young people where it was found that participatory visual arts-based approaches were very effective in terms of facilitating a 'taking action' approach to looking at their own sexuality (see, for example, Walsh, Mitchell and Smith, 2002; Walsh and Mitchell, 2004). Much of the underlying work related to loveLife through their Groundbreakers programme similarly draws on this notion of activism through taking action (Lesko, 2005). In essence, then, we are interested in how the type of work that we had done previously with young people on 'seeing through the body in the age of AIDS' might work with a group of educators in a university classroom context, with the idea that learning as much as we could from one group would allow us to adapt the protocols for use in rural KwaZulu-Natal communities (De Lange, 2003). This article reports on a series of 'seeing through the body' workshops with educators and teacher educators with a particular focus on describing and analysing one set of data: a series of photo narratives produced in small group work during the workshops and analyses of the photo narratives produced by the various groups in the workshops.

About the design

The photo workshops drew on our experiences with a similar type of 'what can be done in a day?' approach (Mitchell and Motheba-Tapela, 2004). In this case the workshops took place over the course of two 3-hour sessions, and involved approximately 40 participants (teachers enrolled in an MEd module on research methodology, and researchers who were teacher educators interested in visual methodologies). Because of time and space considerations, all of the work took place 'on location' at the university campus. Logistically, the central issues in the previous photo-voice studies we had conducted,

included four main points: (1) some lead-in time both to the context for the work but also the technicalities of composing photographs and operating 'point and shoot' cameras, (2) space for dialogue when working with the photographs, (3) time for public display; and (4) time to get the stories behind the stories. Clearly, not all of these were equally possible in every instance, something we will also take up in the final section of this article. The overall procedures were as follows:

Session one: Taking the photographs

Participants were introduced to visual methodologies by showing *Unwanted Images* (Mak and Mitchell, 2000) and viewing a number of books on visual methodologies. An overview of the purpose of the research project, 'seeing through the body' was given, also referring to photo works such as Gideon Mendel's (2001) *A Broken Landscape*, which truthfully, but also powerfully, depicts the reality of HIV and AIDS. A brief introduction to the cameras and the protocol followed. The participants were asked to work in small groups and to focus on the body as a way to represent feelings, scenarios and ideas evoked by AIDS. They were instructed to choose a theme to work with, or to be the directors of 'images'. The participants were also required to keep brief field notes of the images they were making, and to specify what they were trying to get across in the images. The following prompt was given: *Construct images of HIV and AIDS through the body*. The groups, consisting of four to six participants, were then given 45 minutes to take their photographs. The films were developed in sepia in preparation for the next workshop.

Session two: *Seeing through the body* exhibition, presentations and discussions

The second session began with a 'walk about' where participants viewed enlargements of a sample of photographs that had been selected by the workshop facilitators. It is quite possible that the participants themselves might have made different choices and that the unequal power relations between the facilitators (teacher educators) and the participants (mostly MEd students) might have impacted negatively on the process and the discussions that followed. However, we did not reflect on the effects of this.

The further work in this session attempted to address this. This involved participants sitting in their small groups in which they together viewed their set of 24 photographs from which they had to select a set that they could use to ‘produce’ a photo narrative. The photo narrative was then presented and discussed with the larger group.

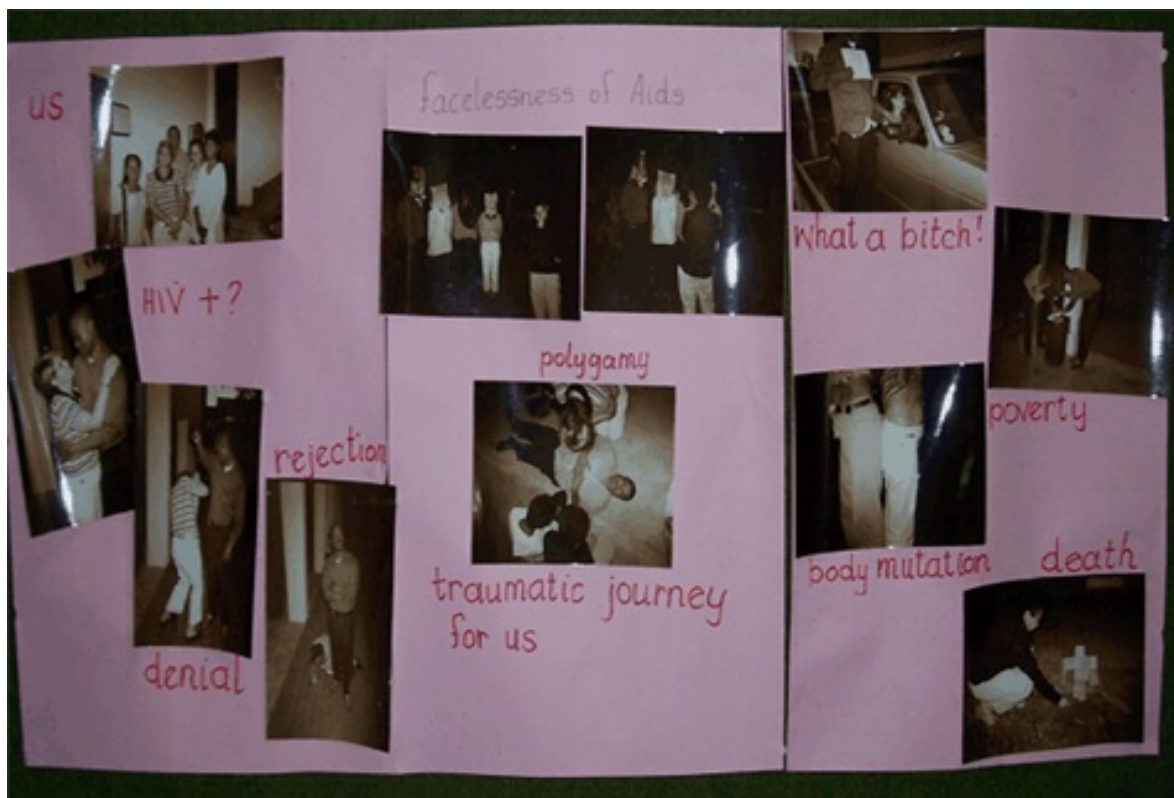
Working with the photo narratives

From the participants’ photo narratives a variety of themes, showing their understanding of HIV and AIDS, emerged whilst differences were also apparent in the way the selections were presented and the stories were told. These photo-narratives were the result of choices and decisions that the participants made when ‘directing’ their own photographs, and then selecting the photographs to compose the photo-narratives. Such data might then be seen as “the material for telling a story where the challenge becomes to generate a polyvalent data base that is used to ‘vivify’ interpretation as opposed to ‘support’ or ‘prove’” (Lather, in Jipson and Paley, 1997). We also “learn from spaces of silence as well as speech” (Hooks, in Jipson and Paley, 1997). Their chosen photographs became a starting point for dialogue and opened up possibilities for reflection and discussion, and it is such reflection, discussion and presentations that hold the possibility of research as social change. Like Mendel’s work, which is a call to action, challenging those who view it to take a position on the lives and deaths of those it represents (Kauffman and Lindauer, 2005), the participants were challenged to take action, to take a position through creating their images of HIV and AIDS using the body.

As researchers, we were aware of these choices, and the visual narratives then became the ‘visual text’ to explore patterns of understanding HIV and AIDS as a social reality, as a second layer of analysis. The seven photo-narratives are, firstly, described, referring to how the participants presented them, the headings and captions they included, and the content of their stories. The second layer of analysis occurred when the research team viewed the photo-narratives immediately after the presentation, reflected on the discussion of the participants and looked for emergent themes, which are presented as the headings in the following section. Using literature around HIV and AIDS to recontextualise the findings (Poggenpoel, 1998), in line with the emergent themes, we identify possible questions which might be raised by the photo-narratives.

Photo-narratives

Photo narrative 1: Behind the facelessness of AIDS there is a story



This narrative explored the possible ‘stories’ behind HIV and AIDS. Our analysis is that the phrases chosen by this group to speak and narrate about their selected photographs, such as ‘*traumatic journey for us*’, firstly reflected how the experience of working with the photographs to depict HIV and AIDS affected the participants as individuals. This was the only group that had included a picture of themselves, possibly highlighting the point that everybody is immersed in the HIV and AIDS dilemma. Different aspects (‘stories’) of HIV were then referred to, such as diagnosis, causes and consequences, as indicated by their verbal text, e.g. ‘*HIV + ?*’, ‘*rejection*’, ‘*polygamy*’, ‘*poverty*’, ‘*body mutation*’ and ‘*death*’. A smaller photo collection within the narrative depicted the now all too common dilemma in relationships of being unsure of whether a partner is infected. Partners deny that they are the source of the initial infection, followed by rejection of the other. Some consideration was also given, in the photo narrative, to specific cultural practices such as polygamy and its contribution to the current HIV and AIDS

pandemic. The reference to the '*traumatic journey*' experienced, tied the photo narrative to the South African context in that no one could escape the reality of HIV and AIDS. Just as beggars confront and invade spaces at traffic lights, so poverty impacts on the spread of HIV and AIDS, HIV and AIDS visibly mutilates the body, and finally the fragile human body succumbs to death.

For us, this photo narrative highlighted the fact that there are potentially many 'stories' behind the facelessness of AIDS, created by the complexity of the milieu of environmental and behavioural influences (Webb, 1997), as well as socio-economic and cultural influences (Kelly *et al.*, 2001).

Photo-narrative 2: From complacency and denial to finding solutions



The second photo narrative effectively used the body and physical space to portray the cycle of HIV and AIDS in communities. Firstly, this narrative referred to the notion that people generally refuse to acknowledge the presence of HIV and AIDS, choosing to displace it to other groups, particularly those that are seen as morally deficient and inferior. For example, one caption to a smaller collection of photographs read, *'Where is the humour? What images satirise the stupidity of ignorance, fear and hostility?'* Secondly, through the narrative, this group raised a number of questions: What if you are positive? What are the possible ways of coping with your positive status? What happens when you disclose your status to significant others and the community? The narrative developed from these pictures suggested that upon discovering a positive status, people feel anger, despair and fear, with one caption

suggesting that “*smiling inappropriately after discovering positive HIV status*”, was a way to avoid crying. It also suggested that the most common way in which the victim and significant others respond to an HIV positive status tended to be destructive. For example, victims are rejected, feared, stigmatised, and isolated by their significant others and their communities. However, while acknowledging this, the narrative also hinted at the possibility of dealing positively with the virus. In this vein, a collection of photographs within this narrative was captioned, “*Does he kill himself? Does he triumph?*” Elaborating on this response, the narrative illustrated that, for example, in some cases, victims and their significant others managed to work through the destructive feelings and responses and rediscover each other and themselves, and that communication, collaboration and a sense of community re-develops.

This narrative touched on understanding the ‘lived experience’ of HIV and AIDS (Rhodes, 1995), also highlighting community responses to HIV and AIDS and how it is conditioned in part by the macro-determinants of the HIV and AIDS epidemiology, the behavioural context of sexual activity and the heterogeneity within the social make-up of communities, expressed through the responses of individuals (Webb, 1997).

Photo-narrative 3: Power relations visible in provocative symbolism

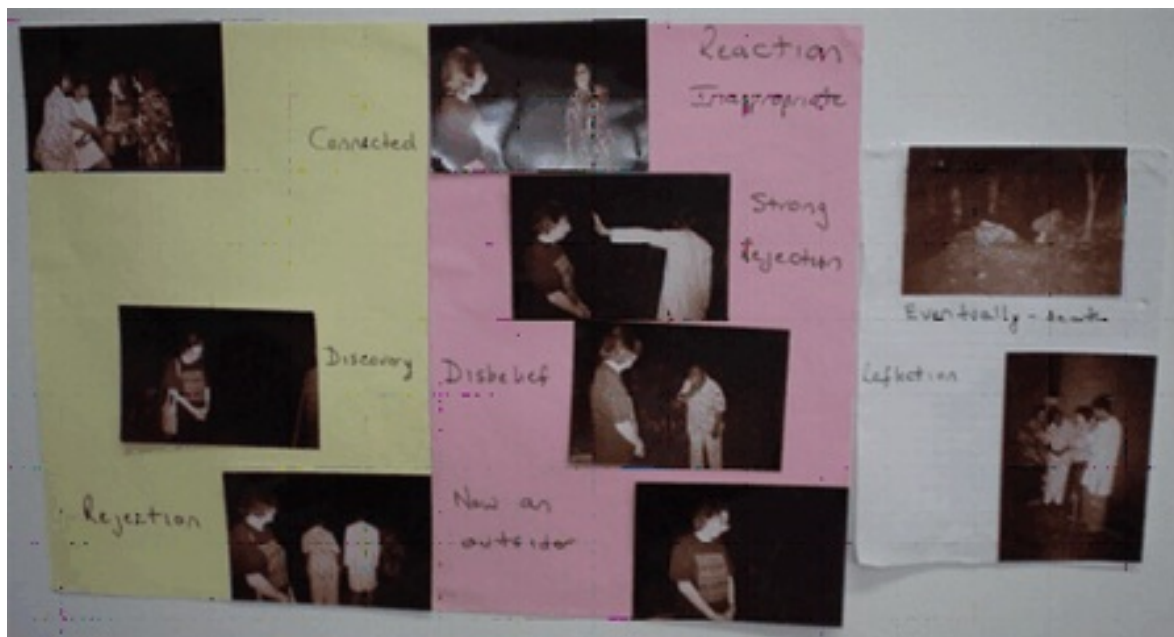


The third photo narrative explored domination, bondage and restrictive role expectations, particularly in male-female and intimate heterosexual relationships, symbolised by shackles and physical barricades in the selected photographs. The narrative raised the question whether causes for the high infection rates lie in unequal power relations between men and women in general, and between men and women in intimate heterosexual relationships in particular. It also raised the question of what would happen if these 'shackles' were broken and there was genuine gender equality. In the narrative, the body and the physical space were used to symbolise the isolation, despair, loneliness and confusion created by the shackles and bondage they create for the victims and perpetrators of inequality.

This is in line with research evidence in South African studies which indicate that HIV infection is negatively skewed against young women, with the ratio of young men to women between the ages of 15 and 24 years infected with HIV in South Africa estimated at 1:4 (Dorrington, Bradshaw and Budlender, 2002). Analyses of such findings suggest that gender relations, particularly among adolescents are unequal and are often defined by violence, including rape and assaults by classmates (Coombe, 2002). Webb (1997) also refers to the unequal gender relations as part of the complex milieu of environmental and behavioural influences on sexual activity, and subsequently the cause of HIV and AIDS. The universal issue of the relative lack of power for women to

negotiate sexual behaviour remains key to this issue (Ross and Deverell, 2004), behaviour apparently not determined at the level of individual agency and action (Kelly, *et al.*, 2001). Without addressing these issues, interventions against HIV and AIDS might be rendered ineffective (Kelly, *et al.*, 2001).

Photo-narrative 4: Human life cycle and the story of stigma



The fourth photo narrative developed around pictures that depicted the human life cycle through images of the body and the physical space, starting with birth and ending with death (from HIV and AIDS related illnesses). The narrative also depicted the deliberate anonymity of people living with HIV and AIDS, and the rejection and isolation of those who are open about their status. The narrative revealed the silence and absences created by death (of adults and children). For example, at many funerals it is stated that the person had died of “*unknown*” illnesses or the cause of death is not even mentioned. For us, questions that could arise from these pictures include: Do HIV and AIDS accelerate this life cycle, resulting in people completing it prematurely? Are there possible ways to disrupt this acceleration and slow the process and the cycle? This is closely linked to stigmatisation as many patients actually request that their own family only be informed of their HIV status when their health has deteriorated to the point at which they are on the verge of medical disablement (Webb, 1997).

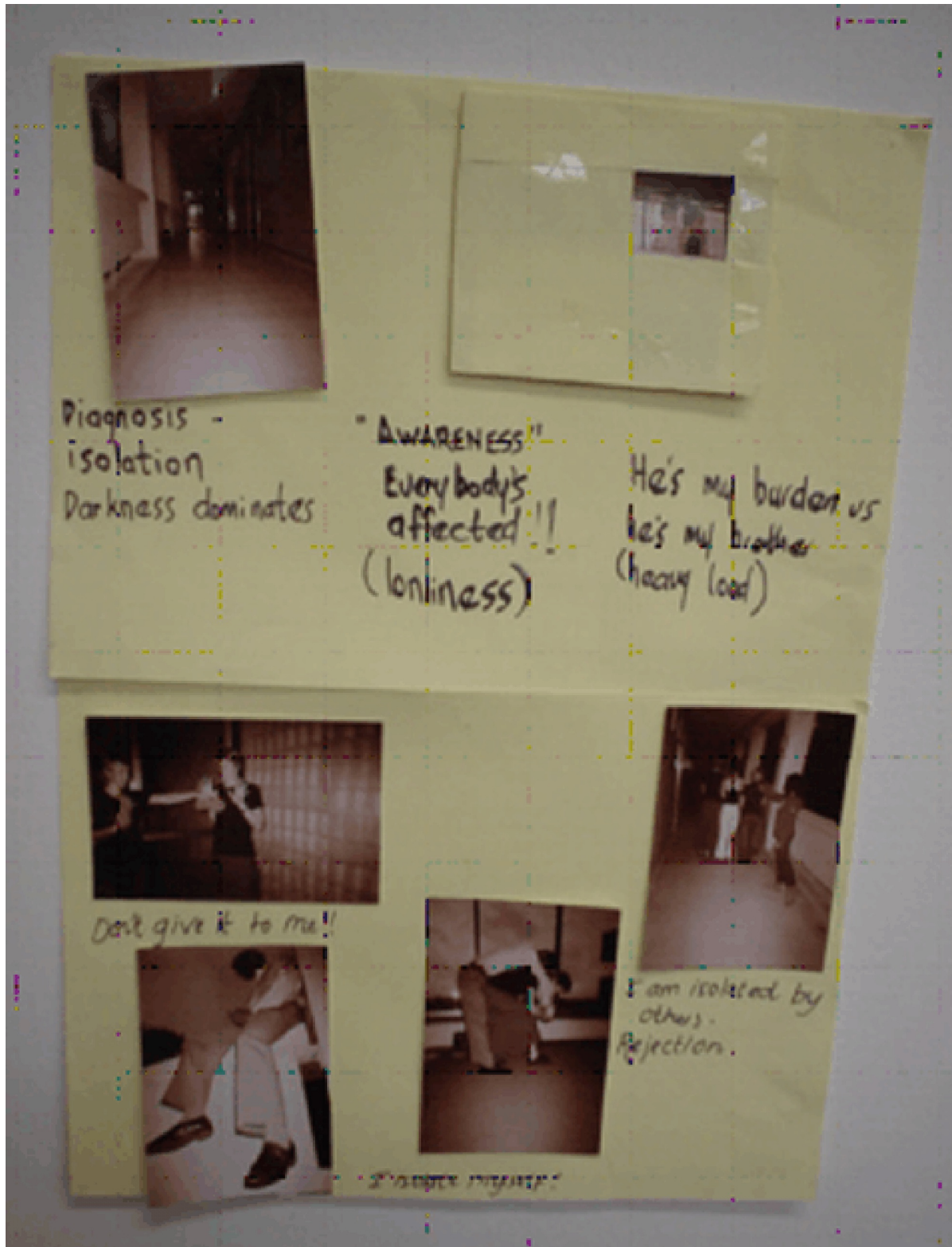
A second collection of photographs also engaged with the narrative of stigma. Some of the questions that were played out in the narrative include: What happens when you discover you are HIV positive? More importantly, what happens when you tell significant others (partner, friends, family, and so on)? The narrative used images of the body to tell a story of the break-up of relationships, rejection, disbelief, and of stigmatisation and banishment of the victim by significant others and community. It is disturbing to note that there still is a strong call for isolation of people infected with HIV, both socially and geographically, throughout Africa, West Europe and United States and that the difficulty still lies in removing the stigma attached to AIDS. Webb (1997) asserts that stigmatisation on such a scale is unprecedented and unusual. Some of the strategies for disrupting the acceleration of the natural life cycle include reversing these silences and taboos and removing the stigma around HIV and AIDS. There might possibly be more support (from all levels of society) for victims and their families if there was no stigma attached to being HIV positive, and it was treated like any other chronic illness. What strategies might be employed to remove this stigma? We continue to grapple with the latter question in subsequent work in our research.

Photo-narrative 5: The physicality of AIDS



It is interesting to note that the fifth photo narrative had no written comments or captions as the group fully utilised the prompt in exploring HIV and AIDS through the *body* by letting the photographs speak for themselves. This has implications for the methodology, an issue we return to later in this article. The body was used to boldly depict the physicality of HIV and AIDS, which could possibly relate to the reality that there is no meaningful way out of this disease unless there is acceptance and support from the significant others and the community as a whole. The narrative juxtaposed the physical and emotional suffering of the individual on his/her own and the physical and emotional support from others. The narrative suggested that sustaining relationships is seen to be crucial to the survival and quality of life of the individual, as well as the community as a whole. A lack of knowledge and understanding of the disease might render one helpless to help the other, due to the fear of being infected, and wipe out a whole community. Tobias (Green, 2005, p.11) takes this further, suggesting that unless “we get our hands around it . . . AIDS is really going to destroy the world”. A compassionate response (Webb, 1997) should not be neglected because of lack of knowledge about HIV and AIDS.

Photo-narrative 6: HIV and AIDS as a 'heavy load' for all



The sixth photo-narrative depicted the sombreness of HIV and AIDS. The adapted phrase '*He's my burden vs he's my brother (heavy load)*', borrowed from the words of a well-known song, "he ain't heavy, he's my brother" reiterated the notion of despair. The other phrases such as '*isolation*', '*darkness dominates*', '*don't give it to me!!*', '*I am isolated by others – rejection*' told the sad tale of the way in which significant others in the family and community experience HIV and AIDS and treat the infected. The narrative suggested that HIV and AIDS become a '*heavy load*' for everyone. Of interest to us was the fact that in this photo-narrative the body was carefully used to explore and express emotions not often expressed or which are difficult to express, and that the body is used as a release for expressing emotions, an issue we intend to explore in subsequent work with teachers and learners in schools.

Photo-narrative 7: A sense of hope



This photo-narrative consisted of a selection of ten photographs and contrasted the previous narrative in that there was a firm suggestion of hope in the title, "*Do not loose (sic) hope*". Unlike the other narratives, this one looked to the future and presented the future scenario as hopeful. Could the hope lie in being there for the other? That in togetherness there is strength? That attitudinal change often occurs when the epidemic has taken hold in a community (Webb,

1997). In this regard, it is interesting to note that Ross and Deverell (2004) suggest that the disease be attacked at a community, rather than individual level. It was this notion that prompted us to pursue this line of inquiry in our current work with teachers and community health workers in rural communities in KwaZulu-Natal.

Standing back: what do these photos mean? What meaning does the method have?

Following through on the two-fold purpose of the article, we offer some comments on the use of visual methodology itself as well as the narratives around HIV and AIDS.

Overall, the diverse messages created by the participants demonstrated the inclusiveness and flexibility offered by a method that provides tools to represent, often simultaneously, the needs and perspectives of the infected, affected and those resisting involvement. This seems significant considering recent research into a group of pre-service teachers that revealed that even in a small group of teachers the levels and entry points of engagement are very different, and can range from anxiety about ways in which the disease can be contracted to finding ways of living positively (Stuart, 2004).

The diversity of settings and range of symbols also hint at the playfulness and creativity that this arts-based approach seems to stimulate, allowing for spontaneous and relatively uninhibited exploration and representation of responses that can be difficult to articulate e.g. emotions such as fear. One of the aspects of the methodology to explore in the future is whether differences in responses relate to time given to participants to plan or shoot their photographs.

Requesting participants to review the photos in a subsequent workshop, and to create narratives to communicate the meanings of the images to others, gives opportunity for reflecting on the original intention of creating an image, and thus for self-reflection. The photographs therefore provided a starting point for dialogue between participants and, once out on display, this reach of dialogue extends to a wider audience. For this reason, it seems important to create exhibitions or displays of such narratives and to invite audience comment.

Working with primarily visual images has its challenges because of their polysemic nature. All but one of the groups narrowed down possible interpretations of their images by providing verbal anchors. Given the worldwide move towards embracing multi-literacies generally and the reach of visual images beyond particular languages, it seems important to develop a wider base for addressing HIV and AIDS.

Through the production and sharing of ideas related to HIV and AIDS, the participants can become active agents for change both by modeling engagement and envisioning possible solutions to problems. Although the photo narratives we have viewed do not go far enough in offering ways forward, it can be argued that changes of behaviour begin with consciousness and reflection on, for instance, the consequences of discrimination.

Conclusion

In this article, we set out to work with a group of teachers to explore issues around HIV and AIDS through creating photographic representations of the body, for us, a natural site to begin exploring issues related to sexuality and AIDS. The photo narratives indicated an engagement with these issues and raised a number of questions for us in the group as well as in our work. We also aimed to challenge the participants to take action and to take a position through creating their images of HIV and AIDS using the body. As Kelly, *et al.* (2001) suggested, people would respond more actively to HIV and AIDS if “contexts for change” could be created. Using a visual arts-based approach that allowed the participants to reflect on and explore and present their position through photo narratives, our work prepared participants for taking action. Whether they will sustain these lessons beyond the workshops and into the level of their own schools and communities is still unknown, and further inquiry is needed that specifically examines this aspect of the work.

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Naydene de Lange
Claudia Mitchell
Lebo Moletsane
Jean Stuart
Thabisile Buthelezi

Faculty of Education
University of KwaZulu-Natal

delangen@ukzn.ac.za
mitchellc3@ukzn.ac.za
moletsaner@ukzn.ac.za
stuardt@ukzn.ac.za
buthlezit10@ukzn.ac.za