Digital Storytelling to explore HIV- and AIDS-related stigma with secondary school learners in a rural community in KwaZulu-Natal

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DECLARATION

I, Thoko Esther Mnisi, student number 210250348, hereby declare that the thesis for Philosophiae Doctor Educationis is my own work and that it has not previously been submitted for assessment or completion of any postgraduate qualification to another university or another qualification. When referring to the work of other authors I have referenced it using APA 5th referencing style.

Thoko Esther Mnisi

ABSTRACT

This study explores, through digital storytelling, the experiences of HIV- and AIDS-related stigma of rural community secondary school learners. HIV- and AIDS-related stigma is seen as an impediment to a proficient response to HIV and AIDS in communities, also rural communities, and requires addressing. The rural community in which the research is undertaken is particularly hard hit by HIV and AIDS. Learners' experiences of HIV- and AIDS related stigma could therefore inform how school and community could engage with HIV- and AIDS-related stigma and how they could address it in a constructive way.

The study attempts to respond to two research questions:

- What can digital storytelling reveal about secondary school learners' experiences of HIV- and AIDS-related stigma in schools in a rural community?
- How can digital storytelling enable secondary school learners in school in a rural community to take action to address stigma?

This qualitative study is positioned within a critical paradigm, and employs a community-based participatory research strategy. Twelve Grade 8 and 9 male and female learners aged 15 to 18 years, from two secondary schools in rural Vulindlela district of KwaZulu-Natal, South Africa, who experienced, witnessed or heard about HIV- and AIDS-related stigma participated. Digital storytelling, a visual participatory method, was used to generate the data, and this was complemented by group discussion and written pieces completed by the participants in reflection sessions. The thematic analysis of the data made use of participatory analysis: the analysis of the digital stories was done by the participants while the overarching analysis was done by the researcher.

This study, located in the field of the Psychology of Education, is informed by the theoretical framework of symbolic interactionism. In terms of the experienced stigma, it was found that living with HIV and AIDS and the related stigma is perceived as a 'hardship'. The stigma is experienced on many levels: in the family, at school, and from friends and members of the community. It has an impact on the individual on an intrapersonal and interpersonal level. The young person is caught up in a vicious cycle of silent suffering since there are no reliable and trustworthy people with whom he or she can share these challenges. Some so-called traditional beliefs and customs such as not talking about sex, and practices like virginity testing, also fuel HIV- and AIDS-related stigma. The use of derogatory terms and the severe criticism of early sexual debut along with the gossiping which is used to spread the stigmatising statements further complicate the hardship experienced by young people. Digital storytelling was found to not only enable the learners' voices to be heard but also to enable their taking charge of the stigma and thus create the space for critical participation in this research.

The implications for the study are that the pervasive stigma that young people experience should be addressed at every level of the community. The stakeholders such as the families, school, educators, the King (Inkosi) and Chiefs (Indunas) of the area, relevant departments with that of Education taking the lead, must work hand-in-hand with the affected young people. Such collaboration may allow for the identification of the problem, for reflection on it, and also for the addressing of it.

HIV- and AIDS-related stigma, while it has changed since the emergence of HIV, still is an issue that many HIV-positive individuals have to contend with. This stigma is, however, contextual and how the individual is stigmatised fits in with the language, meaning and thought that a community constructs around stigma. While digital storytelling enables the uncovering of particular stories of stigma that learners experience in the context of a school in a rural community, the digital storytelling in and of itself enables a change in the language, meaning and thought around stigma in its drawing on the specifics of the stigma as experienced in the community. Also, digital storytelling is about sharing stories about, and experiences of HIV- and AIDS-related stigma and how these stories can be used as part of the solution. If such stories can be told, people can spread them just as gossip is spread, but in this case such spreading would work towards positive social change. I claim that in order to confront the challenges raised by the perpetuation of stigma, efforts must involve the communities and must tap into their own experiences of perpetuating or enduring stigmatisation. Suggestions by the very same people from the community who are at the front line of perpetuating and /or suffering the stigma must be considered. This may also become one way of instantly communicating the research findings back to the community involved in the research. Using digital storytelling can ensure getting self-tailored, contextual, specific views on how HIV- and AIDS-related stigma is experienced but also how it could be addressed.

KEY WORDS

Community; Community-Based Participatory Research; Digital storytelling; HIV- and AIDS-related Stigma; Learners; Rural KwaZulu-Natal School

DEDICATION

I dedicate this study to all those people who are suffering any form of stigma, a ‘silent killer’, which makes people feel less than others. I dedicate it in particular to those who suffered HIV-related stigma and who therefore were unable to access the available support and were thus denied life.

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ACRONYMS

AIDS	Acquired Immunodeficiency Syndrome
ARV	Antiretroviral
CAPRISA	Centre for the AIDS Programme of Research in South Africa
CBPR	Community-Based Participatory Research
CVMSC	Centre for Visual Methodologies for Social Change
DST	Digital Storytelling
FGD	Focus Group Discussion
HCT	HIV Counselling and Testing
HIV	Human Immunodeficiency Virus
KZN	KwaZulu-Natal
NMMU	Nelson Mandela Metropolitan University
UNAIDS	Joint United Nations Program on HIV and AIDS
UNICEF	United Nations International Children’s Emergency Fund
UNIFEM	United Nations Development Fund for Women

PREFACE

As an African woman who lives in a community affected by HIV and AIDS I, too, am not spared from its impact. HIV has an impact directly on most people's lives in my community and I am equally affected. While I am a permanent resident in South Africa, my extended family resides in Swaziland, a country which leads in HIV prevalence among the sub-Saharan countries (UNAIDS, 2013) and which has a higher than forty percent HIV infection rate (UNAIDS, 2012). Stigma exists everywhere (Holzemer et al., 2007) also in Swaziland and it, too, has a dramatic effect on my people.

HIV- and HIV-related stigma are real issues which African women are constantly confronted with (see Motalingoane-Khau, 2010). My personal experiences of how the illness is dealt with in my own family back in Swaziland while I was living in South Africa, made me reflect on my position as a researcher researching HIV- and AIDS-related stigma. In an instance where I had very close relative dying of HIV- related illness, we all referred to the cause of death as cancer with no mention of HIV. This is a common practice, according to Campbell, Gibbs, Maimane, Nair and Sibiya (2009). We empathized with my relative only after she had been diagnosed with cervical cancer.This indicated clearly to me that my experiences as an HIV researcher were not different from other members of the society who do not do research related to the disease.

Another close relative who lived with me in my house for 8 years, and who knew my area of research, died of HIV-related illnesses. After completing her tertiary education she left South Africa for Swaziland where she died. I was told that she did not access health care; she was purported to have said "I would rather die than to go for testing." For me this raised many questions. I write about HIV- and AIDS-related stigma, and she helped with typing my papers, and I assumed that she would have acquired the necessary information while working with me. I have always talked with my family about HIV but have come to realise that knowledge does not necessarily translate into action, as also noted by Campbell, Foulis, Maimane and Sibiya (2005a). It was a difficult time for me since I was aware of her HIV status, but could not share her story with my family for fear that they might stigmatise her. Upon her death, I told my family, whereupon *some became worried about whether they might have been infected from sharing the same space with her and eating what she had cooked.*

The worry that emerged from my family confirms that stigma is also about fear, especially because of the way this virus has changed its face since its beginning (Deacon & Stephney, 2007), and because there is still no cure. HIV-related stigma persists even though there is hope through the availability of Anti-Retrovirals (ARVs). The gossiping that goes around, however, makes people afraid of being tested, afraid of queuing for the medication in health centres, and afraid of other people knowing that they are taking ARVs.

These experiences constantly challenge me as a researcher in the field of HIV. I was afraid that my emotions would influence my research. However, the extra support from my supervisor who provided timely guidance, counselling and care during my emotional turmoil has helped me to keep focus and write about my research journey. I, too, am therefore implicated in the study.

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CHAPTER ONE

ORIENTATION TO THE STUDY

> *“We’re all living with HIV, whether we have the virus or not, real stories told by real people are the only way to get the community to understand how to break the cycle of shame. We can choose to perpetuate shame with our silence and judgment or we can choose to save lives with our love and compassion* (Asian & Pacific Islander Wellness Centre [Apiwellness.org], 2012, p.1)

1.1 INTRODUCTION

HIV and AIDS remain a concern and a health priority globally (UNAIDS, 2012), despite the significant developments towards HIV prevention and access to antiretroviral (ARV) treatment. The epidemic has a massive, persistent impact on individuals, families, schools, communities and public services — especially in sub-Saharan countries — and affects education and national economies in the whole region. Although the pandemic is a cause for concern worldwide, South Africa is most affected as it has the most people living with HIV and AIDS - in 2012 it was estimated to be 6.4 million people (Shisana, 2013). The estimated prevalence of HIV (the proportion of people living with HIV in the country) increased from 10.6 percent in the 2008 HIV Household Survey, to 12.3 percent in 2012 (Shisana, 2013). Another key finding of the 2012 survey was that over 2 million people were on ARV treatment by mid-2012. This dramatic increase in ARV treatment coverage in the country has had a major impact on the survival of people living with HIV (Shisana, 2013).

In 2007, 32 percent of all the new infections and AIDS-related deaths worldwide occurred in South Africa, and more than half of the infected South Africans lived in KwaZulu-Natal (UNAIDS, 2008), which is the South African province in which my research is situated. This led to South African President Jacob Zuma committing Government to achieving 80 percent access to ARVs and cutting new HIV infections by half by 2011. It proved impossible to reach this target. Although the strategy of rapid scaling-up of ARV treatment in South Africa is generating considerable public health gains, South Africa’s epidemic continues to outpace the response (UNAIDS, 2010). Looking back over the history of the response to HIV in South Africa, we can see that it was delayed by leaders who had doubts about the scientific facts behind AIDS and the effectiveness of ARV treatment (Palitza, Ridgard, Struthers & Harber, 2010). However, it is encouraging to note that in recent years, South Africa has become one of the successful countries in the world as far as HIV treatment roll-out is concerned (Karim, Kashuba, Werner & Karim, 2011). In spite of such success KwaZulu-Natal still has the highest prevalence, 27.6 percent of 15 to 49 year-olds are living with HIV (Shisana, 2013).

Perhaps one of the most complex psychological and sociological HIV- and AIDS-related phenomena is that of stigmatisation (Lorentzen & Morris, 2003; Onyebuchi-Iwudibia & Brown, 2013). The phenomenon of stigma is multi-dimensional and it evolves to take new forms over time (Foucault, 2006). HIV- and AIDS-related stigma is not static either — it, too, changes over time as infection levels and awareness of the virus increases, and as the availability of ARV treatment improves (World Health Organisation (WHO), 2008).

Something needs to be done to address HIV- and AIDS-related stigma from the school to the political level. In South Africa, Target Number 8 of the Ten Bold Targets set in the Political Declaration for 2015 is aimed at decreasing HIV-related stigma and related discrimination (Republic of South Africa Global AIDS Response Progress Report, 2013). There seem to be well-intended policies in place to protect HIV-infected and affected learners (Wood, 2008). However, it is unclear whether learners and educators are fully aware of the stigmatisation that occurs in the schools and whether they are able to engage with it in a constructive way so as to help prevent HIV-related stigma. Piot (2006) points out that, although stigma is considered an impediment to proficient response to the HIV and AIDS epidemic, stigma intervention programmes have not been a priority.

I draw on the exploration of HIV and AIDS in an earlier project where stigma was identified by the educators as an issue in the community in the “Learning Together: Towards an integrated participatory approach to youth, gender and HIV/AIDS interventions in rural KwaZulu-Natal schools” (Centre for Visual Methodologies for Social Change [CVMS], (n.d); De Lange et al., 2003), hereafter, the Learning Together Project. The educators revealed that while the study was of assistance in the school in terms of addressing HIV and AIDS, stigma impeded the success of these intervention programmes. In this rural district in KwaZulu-Natal 66.67 percent of pregnant women are HIV-positive, and most households are headed by children or by grandparents who raise the affected children (Mitchell, 2011). The families of the infected persons are deeply affected and are often stigmatised.

My earlier work (Mnisi, 2009) drew from the Learning Together Project in which a digital archive containing HIV- and AIDS-related stigma photographs was used to further explore stigma with educators in schools. Findings showed that the stigma that exists in the schools was related not only to HIV and AIDS, but also intertwined with stigma related to poverty, sexual violence, rape and teenage pregnancy.

1.2 RATIONALE FOR THE STUDY

HIV- and AIDS-related stigma is a life concern and one that affects child development (Deacon & Stephney, 2007). The othering of affected and infected learners in a way that implies inferiority and stereotyping requires a change towards accommodating diversity (including health differences) and supporting the learners (Donald, Lazarus & Lolwana, 2006). By this I mean that it is essential to be alert to physical, psychological and social factors that have an impact on the learners' holistic development, including the hampering of the learning process. "Because HIV- and AIDS-related stigma is such a complex psychological and sociological consequence of the HIV and AIDS epidemic and because it leads to the spread of the virus" it complicates care and prevention (Lorentzen & Morris, 2003, p.11; Campbell, Skovdal, Mupambireyi & Gregson, 2010). There is a vital need to understand this phenomenon.

While there is an increasing amount of literature on stigma on issues such as HIV, mental illness, obesity and stuttering, for example, (Singhal & Rogers, 2003), there is a paucity of studies — particularly of those that use the voices of the learners themselves – that focus on how young people experience stigma. Traditional social research methodologies used in much of the research on children and young people has often prevented children's voices from being heard (Fargas-Malet, McSherry, Larkin & Robinson, 2010). There is substantial research done by adults on the stigma directed towards HIV-affected children and there is also substantive amount of research on the intersection of stigmatisation, based on orphanhood, poverty, and street children (Campbell, Foulis, Maimane & Sibiya, 2005b; Deacon & Stephney, 2007). Another area of research on young people and children investigates the levels of knowledge concerning risk behaviours, for example, substance abuse and unsafe sex, that can lead to HIV contraction, and seeks to prevent these high risk behaviours (Goodwin, Kozlova, Nizharadze & Polyakova, 2004) but we need, too, to explore children's experiences of stigma. There is a need to comprehend the form of stigma as it is experienced by rural learners — through their own voices — without further stigmatising them. We need to establish steps towards solving the problems of stigmatisation in schools. The HIV- and AIDS-related stigma literature on childhood and youth experiences is under represented and this might be so because of methodological issues involved in researching young people and children from an adult perspective (Deacon & Stephney, 2007). This points to a need for the exploration of the stigma from the perspective of witnessed experience as well as lived experience given the effect stigma has on the lives of children and young people in the context of HIV and AIDS.

1.3 STATEMENT OF THE PROBLEM

Children and young people might be infected but they are also affected if their parents or family members are infected. This is in itself a challenge that is exacerbated by stigma. In spite of various HIV interventions stigma is still rife and it affects the implicated people at home, at school and in the community. Knowledge of what the experiences of stigma are for children and young people in school, and how they deal with the stigma is difficult to access. They are vulnerable and, as a researcher I would not want to make them more vulnerable, hence the need to try out participatory methodologies which serve not only to generate knowledge about experiences of stigma, but also enable the rural school learners themselves to become producers of their own knowledge and to become agentic in their own lives.

1.4 RESEARCH QUESTIONS

In line with the research problem, the research questions are formulated as follows:

- What can digital storytelling reveal about secondary school learners' experiences of HIV- and AIDS-related stigma in schools in a rural community?

- How can digital storytelling enable secondary school learners in school in a rural community to take action to address stigma?

1.5 AIMS OF THE RESEARCH

Although a growing body of studies provides significant primary direction for exploring HIV- and AIDS-related stigma, additional work is needed to explore how this stigma is experienced by learners in schools in a rural context. Drawing from the research questions, I undertook this study to explore:

- what digital storytelling can reveal about secondary school learners' experiences of HIV- and AIDS-related stigma in schools in a rural community and
- how digital storytelling can enable learners to take action to address stigma.

1.6 POSITIONING MYSELF AS A RESEARCHER

As a secondary school teacher in urban and rural schools in Swaziland and as an AIDS activist, and a MAC AIDS Leadership Programme Fellow, I have for several years studied and worked in formal and informal educational settings with children aged between 13 and 18 years. As the mother of two teenagers I realise the need to engage young people in the issues of HIV and AIDS but in a way that will interest them. Furthermore, in my studying of Psychology of Education, I have been fascinated by the notion of children and young people as thinkers and learners. My professional and personal experience in education and my interest in innovative ideas placed me in a position to explore digital technologies in addressing HIV and AIDS.

As an intern for the "Digitization and Data Management with visual Data in Social Research: Giving life (to data) to save lives Project, see CVMSC (n.d), I noticed that creative and participatory visual approaches such as photovoice and participatory video techniques (Mitchell, De Lange, Moletsane, Stuart & Buthelezi, 2005) used by the research teams in their various projects, such as the Learning Together Project (De Lange et al., 2003), the Every Voice Counts Project (see CVMSC, n.d) and the Youth as Knowledge Producers Project (Stuart et al., 2006) leveraged technology in communities in which participants may otherwise not have had access to it. I realised that this exposure to technology was important because it created opportunities for school community members to learn how to use technology, including computers and related software (Mnisi, 2009), giving space for the voice to communities of "teachers, learners, health care workers and parents in identifying the key issues and challenges affecting their lives" (De Lange, Mnisi, Mitchell & Park, 2010, p.162).

As an African woman growing up with the experience of storytelling as a method of communication amongst the indigenous people of Southern Africa, I opted to introduce technology with the aim of enabling the participants' production of digital stories. I tapped into the opportunity that digital storytelling allows for people to share their narratives using digital technology and media (Gubrium, 2009). I knew that methods for facilitating the production of digital stories could include photovoice and/or drawing — two methods to which the community had been exposed in the earlier projects.

1.7 CONCEPT CLARIFICATION

A concept, according to Steinberg (2007), is a word to which scientists in the field assign the same meaning so that they can understand each other. I offer a clarification of the following concepts used in this research.

1.7.1 Digital storytelling

This is a workshop-based practice in which people are taught how to use digital media to create short audio-video stories, usually about their own lives or experiences (Hartley & McWilliam, 2009). Digital storytelling is seen as an innovative community-based participatory research tool that increases community members' participation (Lambert, 2006). In essence, following Gubrium, (2009), it is a process of generating digital stories. For the purpose of this research, digital stories are 3-minute visual narratives, created by the participants that synthesise images and audio recordings of voice and text to create accounts of experience.

1.7.2 HIV- and AIDS-related stigma

This is a socially created construct which refers to all negative thoughts and feelings that people have about HIV and AIDS and those people living with the disease

(Ogden & Nyblade, 2005), their families, and even about discussing it (Campbell et al., 2005a). HIV- and AIDS-related stigma results from the “interaction between diverse pre-existing social and cultural sources of stigma and the fear of contagion, disease and death” (Lorentzen & Morris, 2003, p. 11). Stigma is perceived as a mark of shame where the carrier is blamed, devalued, and significantly discredited (Aggleton, 2000; Goffman, 1963). Stigma is therefore a powerful tool for social control; it is used to marginalise, discriminate, label, and at the same time cause fear (Alonzo & Reynolds, 1995; Deacon, Uys & Mahlahlane, 2009; Goffman, 1963).

For the purpose of this study, HIV- and AIDS-related stigma is viewed as a multifaceted phenomenon that emerges from the intertwinement of human motivations, social structures, social discourses, and power relations in the context of HIV and AIDS, and which is experienced contextually, imagined, witnessed or heard about by the participant learners in this study.

1.7.3 Learners

This refers to people engaged in a learning activity (Donald et al., 2006). In South Africa the term “learner” has replaced “pupil” and “student”. Learning is acquiring new knowledge, behaviour, skills, values, preferences or understanding, and may involve synthesising different types of information (Van der Horst & McDonald, 1997). Therefore, the terms “learners”, “children”, “young people” and “adolescents” will be used interchangeably in referring to secondary school learners in the South African context. For the purpose of this study, following Deacon and Stephney (2007) and Skinner et al. (2004) learners refer to rural school children, both boys and girls, in the age range of 13 to 18 years and who are in grades eight and nine, and who were peer educators.

1.7.4 Rural schools

A rural school can be described as basic educational institutions which form part of the wider community (Donald et al., 2006) and which are located in a remote area which is often informationally and infrastucturally underdeveloped (Pansiri, 2008), and associated with high levels of poverty, disease and “other social ills” (Chikoko, 2008, p.78). For the purpose of this research, rural schools refer to senior secondary schools in a remote area, which serve learners from grades 8 to 12.

1.7.5 Community

There are several easy ways of conceptualising community in line with Community-Based Participatory Research (CBPR): community as a setting; community as a target of change; or community as an agent of change (see 3.5.2). In this study the perspective from which the term "community" is used is that of working with the population within the specific geographical location where the study is based. By this I refer to working with the participants who are school-going learners. Learners are part of the school community and the school is an institution within the wider community. The participants may be also viewed as agents of change in that they better understand the struggles of their communities since they are part of them.

1.8 LITERATURE ON WHICH I DRAW

I draw on the literature around HIV- and AIDS-related stigma in general and then focus on HIV- and AIDS-related stigma and young people. I explore the term "stigma" as well as the ground-breaking and foundational work of Goffman's social theory to map the origins of stigma. I also focus on the various challenges that arise because of HIV- and AIDS-related stigma, which have an impact on the global and different local contexts, on the family, school, work, health centres, and on the community. Literature on the intersectionality of HIV- and AIDS-related stigma with its discourses of gender, sexuality, poverty and orphanhood is also discussed. I look at HIV- and AIDS-related stigma discourses such as those related to sexual activity in children, to innocence, gender, age, geographical context and poverty. I also look briefly at how visual and participatory methodologies have been used in addressing such issues in suggesting how to approach the topic. I have also highlighted a few studies which specifically use digital storytelling as a tool to provide some precedent.

1.9 THEORETICAL FRAMEWORK

As Beck and Kosnik (2006) point out, knowledge is socially and historically constructed. I choose to work in a critical-discursive frame and am interested in methodological innovation as well as offering a theoretical critique intended to give substance to the notion that qualitative methods are not (just) about particular techniques, but also about enquiring into the possibilities of methodologies for addressing HIV- and AIDS-related stigma.

In order to understand how adolescents experience HIV- and AIDS-related stigma, I chose to use symbolic interactionism to frame the study. The foundational work of “symbolic interactionism is mostly attributed to Cooley, Mead and Blumer, its most systematic enunciators” (Brickell, 2006, p. 417). Blumer (1969) puts forward the three principles of this theory which are meaning, language, and thought.

Broadly, this theory is used to “explore how *meaning* is created, assembled, negotiated and modified by members of a society” (Brickell, 2006, p.417). This theory “presumes meaning to be an emergent property of human interactions, not something intrinsic to an individual or a situation” (Brickell, 2006, p. 417). Accordingly, people construct the meaning of “their social world and ..[their] own lives through …[their] interactions with other people, gathering together and negotiating meaning as ..[they] participate in social life” (Blumer as cited in Brickell, 2006, p.417). Furthermore, meaning is not fixed; it evolves from interactions within an environment and with people. The second core principle is *language*, which gives people a means by which to negotiate meaning through symbols. Language is significant in thought and social action and is used to assign shared meanings and interpretations of significant symbols (Blumer, 1969). Language becomes equally important in the third core principle which is that of *thought*.

Human beings are thinkers, and symbolic interactionists describe thought that happens within a human being as an inner conversation (Rober, Elliott, Buysse, Loots & De Corte, 2008). Thought, therefore, is a process that happens when people are internalising their next actions. Human action is not only interaction among individuals but also interaction within the individual (Charon, 2004). What makes meaning within an individual does not simply randomly happen; “it results from ongoing social interaction and thinking” (Charon, 2004, p. 31). Charon (2004) argues that human action is the result of the present social interaction, present *thought*, and present definition.

Symbolic interactionism is the main explanatory model when it comes to questions of stigmatisation. This is because stigma, like all other social phenomena, is a product of social processes such as interaction and socialisation. This perspective will be used to make sense of the data in answering the critical questions (see also Chapter Two).

1.10 RESEARCH DESIGN AND METHODOLOGY

1.10.1 Qualitative, critical and contextual research design

In this study I chose to adopt a qualitative, critical and contextual research design. Qualitative research attempts to generate rich textual and descriptive data in respect of a particular phenomenon or context, with the intention of developing an understanding of what is being studied (Nieuwenhuis, 2007). It is for this reason that most studies on the nature, effects, and experiences of HIV- and AIDS-related stigma in South Africa use a qualitative research approach (Campbell, et al., 2005a; Campbell et al., 2005b; Campbell, Nair & Maimane, 2006; Campbell, Nair & Maimane, 2007; Campbell, Nair, Maimane & Nicholson, 2007; Greeff & Phetlhu, 2007; Greeff et al., 2008b; Hosegood et al., 2007; Niehaus, 2007; Petros, Airhihenbuwa, Simbayi, Ramlagan & Brown, 2006; Skinner & Mfecane, 2005). Therefore, I found qualitative research more suitable for exploring HIV- and AIDS-related stigma with learners using digital storytelling. The participants understand their context best and are able to reconstruct their worlds (Denzin & Lincoln, 2003) in an attempt to address needs which are best known to and by them.

Looking at a critical paradigm in particular, critical researchers assume that social reality is “historically created” and “reproduced by people” within the society (Nieuwenhuis, 2007, p.62). Critical theorists challenge the reproduction or maintenance of power relations to eliminate domination. Therefore, critical researchers offer a critique on social life to disclose the struggles of people. This shows, for example, how they are exploited or dominated, even if the people themselves are not aware of these struggles.

Considering the above, I use methods which create spaces for the voices of the HIV-affected learners to be heard. Qualitative studies blend with the critical paradigm as well: the digital stories are generated in a participatory way, and involve learners as active participants along with me as the researcher and as an active role-player (Aluko, 2006; Bowman, 2010). The method and the paradigm fit the purpose of obtaining rich data but also hold up the notion of social change which the critical paradigm assumes — in this case research as intervention. People actively construct their social worlds rather than being objects of research. They understand their contexts and are able to reconstruct their worlds in an attempt to address the needs which are best known to them. Description, understanding and taking action are the ultimate aims of qualitative research. These also blend in with the critical paradigm, which is why the data generation methods (participatory) must enable and create rapport, possible mutual trust, and honesty between and among the researcher and the participants.

1.10.2 Community-based participatory research as research methodology

This study draws on a community-based participatory research (CBPR) approach because of its efficacy in making findings readily available and able to be immediately disseminated to the community or participants involved (Miller & Shinn, 2005). CBPR has been defined as a collaborative approach to research that involves all stakeholders in the research process, and recognises the unique strength that each brings. CBPR begins with the community identifying a topic of need and importance to itself. The aim is usually to combine knowledge with action and achieve social change to improve well-being outcomes and eliminate health disparities (Meyer, Armstrong-Coben & Batista, 2007; Minkler & Wallerstein, 2003).

In this study I worked with the participants throughout the research process which gave them first-hand information on the findings and enabled them to act in providing solutions to the problems they identified.

1.10.3 Digital storytelling as method

Digital storytelling is used as the main data-generation tool. This method is growing in health and community education practice, although it has been used in primary education as a way to increase student access to alternative forms of literacy (Educause Learning Initiative, 2007; Kajder, 2006; Miller, 2008; Ohler, 2007). It is still an emerging method for community health promotion and practice. Using their own images and language, the participants reflect on, discuss, and present their knowledge through these user-generated digital stories produced using computers in a computer lab. Complementing digital storytelling, written reflections and discussions are used as data-generation tools (see my explanation of the methodology in Chapter Three).

1.10.4 Research setting and participants

The study participants are drawn from Vulindlela, a rural community in KwaZulu-Natal struggling with the HIV epidemic. Walford (2001) argues that gaining access and becoming accepted in the community is a slow process, and this is especially true when we are researching sensitive issues. In this research, purposive sampling is used for deliberately selecting two rural schools in KwaZulu-Natal because they have been involved in an earlier project so, as Rallies and Rossman (2003) point out, they are more likely to produce rich data. During the Learning Together Project the teachers identified stigma as a barrier to efforts towards combating HIV. The teachers also suggested that learners entering secondary school should be engaged in exploring and understanding stigma as they have several more years at school to feed back into the school what they had learnt from the research process (Moletsane, De Lange, Mitchell, Stuart & Buthelezi, 2007). Grade eight and nine learners from the two schools in the rural community, who were members of the peer educator programme, who were willing to participate, who were willing to talk about experienced, witnessed or heard about HIV- and AIDS-related stigma, and who were computer literate, were purposively selected to participate in this research. The purpose was to explore learners' experiences of HIV- and AIDS-related stigma and have them address stigma — through their storytelling — by identifying the problem and taking action by providing solutions.

1.11 DELIMITATION OF THE STUDY

This study is located in Psychology of Education, a discipline which has as its focus the development and learning of children. Schools, as education institutions, are critical in the development and learning of children: how their stigma experience affects their learning and development. The focus of the study, therefore, is to explore, through digital storytelling, how secondary learners experience HIV- and AIDS-related stigma in two schools in a rural community.

This is a small-scale study with only 12 grade 8 and 9 participants, both boys and girls, from two secondary schools in one rural district in KwaZulu-Natal. The findings therefore offer a snapshot of this small group of learners and hence they cannot be generalised. I will, however, provide a rich description of the context, participants, methodology and choices I made, placing the onus on other researchers to determine whether the findings can be inferred to their own context.

An analysis of the visual data can be done in various ways. In this study the participants were involved at all levels: storytelling; the reflection; and also the identification of common themes across their stories. The interpretation of visual images, therefore, comes directly from the participants — they state what they intended the images to mean. It would have been interesting to analyse the signifiers, that is, the visual content of the images. However, I do not attempt to do so since the study is not located in Media and Communication Studies. I am aware, though, of semiotics, the idea of the visual as empty signifier, and that images can mean different things to different people, which is relevant to understanding some of the participants' choice of visuals to illustrate their stories, and to understanding the visuals that include animals.

1.12 POSSIBLE CHALLENGES TO THE STUDY

Considering that this research would involve children and the topic of HIV- and AIDS-related stigma, it was possible that some members of the community might fear that, instead of helping solve their problems, critical data might (further) stigmatise their communities. They might have decided to withdraw when data was about to be disseminated, or even when it was already disseminated. I am, however, aware of the ethical issues that may be raised with regard to the publishing or display of sensitive or critical data (Minkler, 2004), and I negotiated sensitively with the participants. In working with the participants as sensitively as possible I endeavoured doing "most good" and "least harm" (Mitchell, 2011, p. 191) through my research.

1.13 UNFOLDING OF THE STUDY

Chapter Two, a literature review, provides an overview of the broad bodies of literature, i.e. HIV-related stigma discourses. I refer to the origins of stigma and highlight how it has been framed in different studies. I draw on local and international literature which informs the choice of the theoretical framework for the study.

In Chapter Three I outline the research design and methodology used. A description of the research setting, the selection of participants and their roles, and the researcher's role is provided. This chapter explains how the research process unfolds and how the data is generated and analysed.

Chapter Four puts forward the results of the study according to the first question presented thematically in the form of participants' stories, discussion and written reflections, and this is contextualised within the literature.

Chapter Five presents findings and a discussion of the second critical question. Findings are presented thematically and contextualized using the literature.

Chapter Six, the final chapter, sets out a summary of the findings, conclusions and implications of the study. I indicate some of the limitations of the study and offer suggestions for further research. Here I also theorise the contribution of the study.

1.14 SYNTHESIS

This study explores the use of digital storytelling in addressing HIV- and AIDS-related stigma with learners in two rural schools. This first chapter has provided an orientation to the study, which hopes to make the often silenced voices of learners heard on their experiences, lived or otherwise, of HIV- and AIDS-related stigma in a participatory way, and ultimately contribute to addressing stigma in the rural school and community in an innovative way.

CHAPTER TWO

AN EXPOSITION OF HIV- AND AIDS-RELATED STIGMA

2.1 INTRODUCTION

A literature review is an integral part of any research process since it lays the foundation for good research inquiry and endeavours (Fouché & Delport, 2005). I engaged with relevant intellectual voices in order to inform and contextualise my study, and do not suggest that it is definitive.

Local and related international literature on HIV- and AIDS-related stigma is thematically discussed, beginning with the origins and definition of stigma as a phenomenon, as well as looking at how the phenomenon presents itself in various contexts and at how different disciplines have interrogated it using different perspectives. I highlight efforts and intervention strategies to address stigma, including policies filtering through to the education system. While I also review literature on HIV- and AIDS-related stigma pertaining to adults I draw mainly on literature pertaining to children and young people.

2.2 THE ORIGIN OF THE TERM ‘STIGMA’

The original use of the term stigma was in reference to a tattoo mark that was branded — with a branding iron — on the skin of slaves or those who found themselves on the wrong side of the law. This was common practice during the days of early Greek civilisation (Singhal & Rogers, 2003). Because of the burn or scar, slaves or criminals could be easily identified wherever they went so that the general public could avoid the blemished individual. Stigma was thus seen as a mark of disgrace; a stain or reproach on one's reputation, later it became a sign of defect or disease (Kiefer, 2001; Wakana, 2005).

While HIV and AIDS is not necessarily a visible condition, there have been efforts to make HIV-infected persons visible. For example, in the 1980s Buckley openly proposed in *The New York Times* that anyone diagnosed with HIV must be tattooed (Herek & Glunt, 1988), while in the 1990s in Tanzania, children who were HIV-positive were expected to attach a red ribbon or a red star to their school uniforms (France, 2001). This still seems feasible to those who stigmatise people living with HIV. More recently in Swaziland, my home country, and the country which has the highest HIV prevalence rate in sub-Saharan Africa (UNAIDS, 2012), a similar suggestion was made in Parliament. Myeni, a then member of parliament, suggested that people who were HIV- positive must be branded to curb the spread of HIV and AIDS (Mabuza, 2009). Deacon, Stephney and Prosalendis (2005) allude to the reality that stigma has always existed in relation to many afflictions, for example, mental illness, disability and some terminal illnesses, but also to behaviour associated with sex. Stigma has always been used to exclude certain people from various social aspects of life and social interactions with the rest of society in various ways (Dovidio et al., 2000).

2.3 EVOLUTION OF STIGMA

2.3.1 Goffman's spoiled identity

In this section I take a closer look at stigma by exploring the notion of stigma as a 'spoiled identity' by drawing on the early work of Goffman before going on to explain it in the context of HIV and AIDS. Goffman's social theory (1963) has become a point of departure for many studies related to stigma. Goffman (1963) focuses on physical deformity, character blemish and tribal origin (prejudice stigma). According to Goffman (1963) stigma in terms of physical deformity refers to the discrepancy between what people accept as an ideal condition and the real physical condition which, for example, could include physical deformities and disfigurements. With regard to the character blemish type of stigma, he associates it with the behaviour and addictions that are thought to have been avoidable such as, for example, alcoholism and dishonesty. The third type (tribal in origin) originates when one group perceives features of race, religion, or nationality of another group as deficient compared with their own socially constructed norm.

Goffman (1963) describes these stigmatised people as individuals with spoiled identities who are rendered unworthy by others because they possess an "undesired difference" (Francis & Francis, 2006; Singhal & Rogers, 2003 p.249). Goffman (1963) further suggests that stigma is a deeply discrediting attribute which results in detaching a person or group from the whole because he or she is valued less than so-called normal people (Brown, BeLue & Airhihenbuwa, 2010; Dovidio et al., 2000). Goffman (1963) explains that stigma is not a fixed characteristic of the person; it becomes attributed to an individual through social interaction. In efforts to understand the stigma of medical conditions including mental illness, tuberculosis and sexually transmitted infections, including HIV, most researchers still use Goffman's (1963) social theory.

2.3.2 Discrimination and stigma

A clear distinction between the concepts of discrimination and stigma has proved to be rather difficult (Deacon, Uys & Mohlahlane, 2009). I however, found it important to separate the two concepts since this could possibly enable conceptualisation of stigmatisation for the purpose of this HIV- and AIDS-related stigma study.

Discrimination refers to treating people from the same membership differently — some getting worse treatment than others (Larson, 2012). This could be irrational decision-making such as not affording to members from the same group or community similar privileges available to another group with the intention of creating isolation and exclusion amongst the group (Giddens, Duneier, Appelbaum & Carr, 2009). "Defining stigma as something that results in discrimination reduces analytical clarity about the relationship between stigma and its effects" (Deacon, 2006, p.421). The reason for saying so is because it is not a certain class or group of people in a community that stigmatise. This can be applicable to anyone (Deacon, 2006; Deacon et al., 2009). For instance, poor and marginal groups can stigmatise people who are richer and who have more powerful status in their societies (Deacon, 2006; Deacon & Stephney, 2007; Deacon et al., 2009).

The argument put forward by Deacon (2006) is that discrimination and stigma are independent processes, one of which can happen without the other happening, so the two concepts cannot be used interchangeably. For instance, stigmatisation can happen where there is no discrimination happening as "even in the absence of any active discrimination stigma may have a negative impact on the self-concept and actions of stigmatised people" (Deacon, 2006 p. 421). Sayce (2003, p. 628) critiques the work by Link and Phelan as causing confusion on the use of the term, stigma, "to describe both the act of discrimination and the personal experience of being labelled." In the case of health-related stigma, there is a need to understand how it leads to disadvantage, not just through discrimination. For instance, internalisation of stigma can lead to "self-doubt, lower self-esteem, depression, immune-suppression and even premature death" (Deacon 2006, p. 422; Deacon et al., 2009). In the case of HIV and AIDS the stigma could prevent people from testing and accessing the necessary health care (Steinberg, 2008). As Deacon (2006) and Deacon et al. (2009) put it, using discrimination to define stigma constricts the conceptualisation and understanding of the variety of effects of stigma.

2.3.3 HIV-related stigma as a worldwide concern

The stigma related to HIV has been the greatest impediment to efforts to combat HIV and AIDS. There were early warnings from Herek et al. (1998), which were taken up by the theme *Live and Let Live* of the 2002-2003 World AIDS Day campaign, to address HIV- and AIDS-related stigma. The United Nations general assembly's special session on HIV and AIDS in 2001 also made a declaration of commitment in response to the need to address stigma (Lorentzen & Morris, 2003). HIV-related stigma, however, remains a subject of global concern. There is evidence of manifestations of HIV- and AIDS-related stigma globally, regardless of differences in countries, communities, and personal beliefs and ideologies (Ogden & Nyblade, 2005; Stuart, 2006). Then the 2011-2013 World AIDS day theme became *Getting to Zero: Zero Discrimination, Zero New Infections and Zero AIDS-related deaths*. Zero stigma could have been included here since stigma remains a global challenge.

According to Parker and Aggleton (2003) stigma is quite often not well understood and is overlooked both theoretically and programmatically. Stigma is, however, multifaceted and it is essential to understand contextually which type of stigma one is referring to. However, it is agreed that HIV- and AIDS-related stigma is usually linked to other forms of prejudice and discrimination — racial, sexual or those related to behaviours that are considered socially objectionable such as prostitution or drug use across all contexts (UNAIDS, 2008). Because of the complexity of stigma as a phenomenon, it is logical that its effects in different contexts are not straightforward and predictable. In South Africa, particularly, the prevalence of negative behavioural intentions towards people living with HIV is common (Maughan-Brown, 2006), while Buseh, Park, Stevens, McElmurry and Kelber (2006) established that in Swaziland gender is a major factor in predicting stigma since they found that boys were less sympathetic to People Living with HIV and AIDS (PLWHA) than were girls.

2.3.4 HIV- and AIDS-related stigma as a psychological and social phenomenon

The scholarly work of social psychologists usually addresses aspects of stigma: one is the perceptions of people; another explains the origins of stigma among humans; and a third one looks at the consequences of these perceptions on relations in society — what it does to the stigmatiser and what it does to the stigmatised (Dovidio et al., 2000). To understand this, one can draw from an example of individuals with chronic illnesses like HIV, cancer and diabetes. They are seen as presenting a deviation from what many people expect in daily social interchanges, and for that reason, they are stigmatised, as I will show.

In the last two decades research on understanding the psychological and social aspects of HIV and AIDS increased in spite of most resources being put into medical research (Parker & Aggleton, 2003). One related study by Parker and Aggleton (2003) considers HIV-related stigma to be a social phenomenon involving the interplay between social and economic factors in the environment, and the psycho-social issues of affected individuals. The stigmatisation related to HIV and AIDS has negative consequences on people both affected and infected, and also on children and their holistic development (Ogden & Nyblade, 2005). Research done by Santana and Dancy (2000) indicates that one can anticipate that enacted and/or internalised stigma would have a negative impact on the adult's self-esteem, leading to low self-esteem. This could also apply to children. To complicate matters further for children, HIV- and AIDS-related stigma weakens their support system (Deacon & Stephney, 2007). Clay, Bond, Nyblade, Chilikwela and Kafuma (2003) argue that children, whether infected or affected by HIV and AIDS, suffer a significant material and psychological disadvantage because of HIV- and AIDS-related stigma directly or indirectly (Deacon & Stephney, 2007). Furthermore, there is no clear cut measurement of the effects of stigma when compared with other effects such as parental death, poverty, and being orphaned (Deacon & Stephney, 2007). Put explicitly, HIV- and AIDS-related stigma intensifies the negative psychosocial and social effects of the disease on children, such as, for example, their self-esteem and their social interactions, also in school.

2.3.5 Understanding stigma in the context of HIV and AIDS

In the context of HIV and AIDS there are four types of stigma: self-stigma; stigma by association; institutional stigma; and public stigma (Bos, Pryor, Reeder & Stutterheim, 2013). Stutterheim, Pryor, Bos, Hoogendijk, Muris and Schaalma (2009) argue that self-stigma has to do with how a stigmatised individual acts in response to the condition that is being stigmatised without necessarily being stigmatised by the people. Campbell et al. (2005a) and Pryor, Reeder and Monroe (2012) regard stigma by association as the type of stigma which has to do with social and psychological reaction to people who are in one way or another related to a stigmatised person. Institutional stigma refers to the legitimisation of the stigmatised status which is perpetuated by society’s institutions and ideological systems (Chaudoir, Earnshaw & Andel, 2013). Public stigma is associated with the social and psychological reactions of people to someone with a condition that is stigmatised (Reeder & Pryor, 2008). For example, when someone has HIV, her or his stigmatisation by health care providers and employers would be classified as public stigma.

It is argued that the different types of stigma can influence the process of stigmatisation as well as the quality of interaction amongst individuals in different contexts (Lorentzen & Morris, 2003). In spite of the types being described separately they may overlap and reinforce felt/self-stigma and enacted stigma (MacQuarrie, Eckhaus & Nyblade, 2009).

Felt/self-stigma is the internalised perception of an individual of being devalued or feeling less good than others (Scambler, 2004). Enacted stigma refers to the behaviour of the other towards the individual who is viewed as being different and stigmatised (Scambler, 2004). In self-stigma the victim sees him/herself as a social outcast whereas in enacted stigma, society defines the victim as a social outcast. Stigma is latent (unintentional) or manifest (intentional) (Alonzo & Reynolds, 1995). The phenomenon of stigma under study here is thus a social construct which has a major bearing on the life experiences of stigmatised people (Dovidio et al., 2000). This is mainly because the carrier is subjected to shame by being blamed, cheapened, and significantly discredited (Aggleton, 2000; Goffman, 1963). For that reason, stigma can be internalised and carried out consciously and subconsciously by the supposedly stigmatised without their even being stigmatised by others. The types of stigma presented here may elucidate the reason why HIV- and AIDS-related stigma is such a powerful phenomenon and may also demonstrate how it gains power from its being so faceted (Bos et al., 2013). Campbell, Nair, Maimane and Nicholson (2007) observe that, across all contexts, the common factors motivating stigma are instrumental stigma (fear of physical contagion), symbolic stigma (judgements based on immoral behaviour), resource constraints (sick people not being deserving of support) and courtesy stigma (resulting from association with people living with HIV).

2.4 DIMENSIONS OF STIGMATISING CONDITIONS

Dovidio et al. (2000) and Lorentzen and Morris (2003) identify six dimensions of stigmatising conditions: concealability; course of the mark; disruptiveness; aesthetics; origin; and peril. The degree of the visibility or invisibility of the stigmatising characteristic, for example facial disfigurement versus homosexuality, is referred to as concealability. In the event of HIV, Alonzo and Reynolds (1995) illustrate the HIV-related stigma trajectory by showing that people are stigmatised differently depending on their condition. They explain that before you divulge your HIV status you are stigmatised in a different way from when you have divulged your status. Similarly, once you show symptoms of being ill you will be more stigmatised than when it is just known that you are infected. This shows that if HIV symptoms did not show, this disease would be less stigmatised. The issues of concealment and disclosure are intertwined. This explains the reason for people concealing HIV under the umbrella of other diseases which have similar clinical symptoms, but which are less stigmatised, such as diabetes, cancer, or tuberculosis. In the South African context, in KwaZulu-Natal, most isiZulu-speaking people would say a person has *idliso* (Govender, 2006) implying that a person has been poisoned. Those whose illnesses are invisible and not made known will be spared social rejection (Dovidio et al., 2000). People living with HIV have been shown to conceal their HIV status at the cost of foregoing social support and medical treatment (Rintamaki & Weaver, 2008; Steinberg, 2008).

Another element relates to whether the ‘mark’ becomes more salient or progressively debilitating over time (Robinson, 2009). This is referred to as the course of the mark and is related to HIV stigma in that HIV is still seen by many as a terminal illness leading to death (Rimantaki & Weaver, 2008). HIV infection has degenerative effects and passes through several stages before it turns into Acquired Immune Deficiency Syndrome (AIDS). The stages differ from one individual to another and the outward symptoms may be frightening and associated with death. Some people may have several bouts of illness before they die and some may be ill only once and die, which makes the duration of AIDS unpredictable. Some people can lie in hospital beds for months, with families and friends no longer wanting to be associated with them. Sometimes this extends to even leaving the bodies unclaimed in the morgue (Campbell et al., 2005a).

Disruptiveness has to do with the extent to which stigma interferes with social interaction (Lorentzen & Morris, 2003). The “dimension of disruptiveness is often present in the definition of stigma, as stigmatisation involves the exclusion of certain individuals that have certain attributes” (Lorentzen & Morris, 2003, p.17). Consistent with other studies, Nyblade, Stangl, Weiss and Ashburn (2009) argue that fear of casual contact and the association of HIV with immoral behaviour is the cause of stigma. Individuals with illnesses perceived to be contagious and threatening to physical health, like AIDS, will also be a threat to group functioning since groups rely on good health to function properly (Lorentzen & Morris, 2003). Stigmatisation creates a barrier between the healthy and the unhealthy, the ‘good’ and the ‘bad’, those who conform to certain attributes and those who do not. This is well known as the ‘us/them’ barrier, which is designed to guarantee the maintenance of the healthy, effective group (Lorentzen & Morris, 2003). Cottrell and Neuberg (2005) regard this distancing strategy as an integral part of stigmatisation.

Aesthetics relates to the personal and subjective responses to the viciousness of the stigma (Lorentzen & Morris, 2003). Since its outbreak, the HIvirus has been associated with “disenfranchised” social groups including gay men, drug users, and, to some extent, African and Latino Americans (Rintamaki & Weaver, 2008, p. 69). The perception that the disease is unique to ‘deviant’ groups may be misinforming and may thus expose other people to the danger of contracting the virus.

The stigmatising mark’s origin (congenital, accidental, or intentional) can also involve the person’s role in the creation of the mark. People living with HIV sometimes have to endure being accused of being responsible for having contracted HIV (Francis &

Hemson, 2006) and associated with behaviours performed of their own free will, such as, for example, sex workers and drug users (Rintamaki & Weaver, 2008). In some societies the disease is associated with behaviours such as prostitution and homosexuality and, as a result, these people are more stigmatised because the behaviour is not considered to be accidental. It is also seen to be a result of personal irresponsibility and it is believed that it could have been avoided (Avert, 2008). Unlike other diseases like cancer or diabetes, HIV and AIDS are associated with immorality (Moletsane, 2003; Zhou, 2007). However, Alonzo and Reynolds (1995); Dinos, Stevens, Serfaty, Weich and King (2004) note that not all individuals with the illness experience the same degree of stigma; there are also some who are regarded by society as ‘innocent’ victims of HIV and AIDS. This includes babies who are born HIV-positive, blood transfusion recipients, and rape victims, and thus they may be stigmatised less harshly.

Another dimension involves what is sometimes thought to be the danger to others of the stigmatising condition. People are afraid of contracting this life-threatening disease. Misperceptions about how the disease is contracted have existed since the beginning of the epidemic and this, too, perpetuates the stigmatisation of the illness (Alonzo & Reynold, 1995; Moletsane et al., 2007; Parker & Aggleton, 2003; Qian et al., 2007). Although some people now know that HIV can be spread only through blood transfusion, needle-sharing, mother-to-child transmission, and through unprotected sex, HIV remains scary for most people. From time to time caregivers of HIV-positive patients contract the disease from assisting their patients without protection from contact with their blood and bodily fluids (Govender, 2006; Tanner & Parkinso, 2006). A study conducted by Francis and Francis (2006) illustrates that people are afraid of HIV, often irrationally: in their study they found that whenever an HIV-positive learner went to the toilet the other learners would use Jeyes Fluid (a powerful disinfectant) to ‘clean’ the AIDS. Stigmatisation, therefore, also results from the perceived danger of the disease. Studies show that some families chase away their infected family members or do not allow them to use common utensils, while some couples break up (Avert, 2008).

In addition to the dimensions of stigmatising conditions already referred to, Dovidio et al. (2000), Quinn and Earnshaw (2011) and Earnshaw and Quinn (2012) argue that visibility and controllability are the most significant dimensions of stigma for the stigmatiser and for the stigmatised person. In the guidelines for addressing the root of stigma (UNAIDS, 2008), three key causes of stigma are clearly outlined; they must not be understated: first, linking people with HIV to behaviour that it is considered to be improper and immoral; second, the fear of HIV, including the myth that HIV can be acquired through everyday contact with infected people; and third, the lack of awareness and knowledge about stigma and its effects. This refers back to the suggestion by Campbell et al. (2005b) that the issues of HIV and stigma should be addressed simultaneously. A discussion of what could contribute to HIV- and AIDS-related stigma and the dimensions of stigma, provides insight into how these dimensions influence the processes of stigmatisation which, in turn, lead to further facets of stigmatisation. Understanding the dynamics of HIV and its effects could perhaps show which dimensions of stigma have to be addressed. Alonzo and Reynolds (1995) and Mill, Edwards, Jackson, MacLean & Chaw-Kant (2010) conclude that HIV and AIDS are a manifestation of an extraordinary illness in terms of its potential for multidimensional stigmatisation. From the above discussion we can see that there is a correlation between stigma related to HIV and AIDS and the fears about contagion and the disease itself that is associated with death, as well as pre-existing assumptions about HIV.

2.5 CATALYSTS FOR THE SPREAD OF HIV- AND AIDS-RELATED STIGMA IN SOUTH AFRICA

Various personal, social, economic and cultural factors act as a catalyst for the spread of HIV and AIDS as well as HIV-and AIDS-related stigma (Lorentzen & Morris, 2003; Singer, 2009). South African individuals differ with regard to ethnicity, language, religion, gender, sexuality, age, level of education, economy, and other important cultural traits (Airhihenbuwa et al., 2009; Mkhize, 2006). However, it seems that the stigma attached to these factors has not been much researched in South Africa.

2.5.1 Ethnicity

In the South African context there are several ethnic groups, categorised as White, Coloured, Indian and African. Although I am aware of HIV- and AIDS-related stigma in other ethnic groups, the focus of this study is on young Africans from a rural context and hence on literature pertaining to this group.

Africans are hugely affected by HIV and AIDS when compared to Whites, Coloureds and Indians (Airhihenbuwa et al., 2009; Bhana, 2007). Stigma is “an expression of belonging and relationships, institutional and familial value that influence” the groups’ “perceptions and interpretations” of implications of acceptance and rejection as they relate to HIV and AIDS as a stigmatised disease (Airhihenbuwa et al., 2009, p. 411). While stigma can emanate from an individual level (self-stigma and internalised stigma), it is argued that stigma in Africa, including South Africa, cannot be assumed as “an individual deviance or societal difference” but fundamentally “as a question of affirmation of identity or lack thereof” (Airhihenbuwa et al., 2009, p. 411). In terms of stigma, for example, in South Africa, just as in The United States of America, more black people are HIV positive than any other group, and hence being black is thus associated with the HIvirus.

2.5.2 Avoidance of the term HIV

It is evident that in researching and addressing HIV and AIDS, it is crucial to observe the unique socio-cultural contexts (Selikow, 2004; Visser & Sipsma, 2013). How HIV and AIDS are contextually termed and expressed can reveal how it is conceptualised in a specific context (Lorentzen & Morris, 2003; Undie, Crichton & Zulu, 2007). Language, an important part of culture, is not often researched in relation to how it influences the spread of HIV (Selikow, 2004; Mitchell & De Lange, 2011). Language terms are seen to be a contributing factor to continued HIV- and AIDS-related stigma; they indicate the way in which HIV is conceptualised in different contexts.

In some places in Nigeria, for example, AIDS has been termed *agolochen* (separation from people or isolation) and *ngu a igba ga* (person without kinsmen) (Alubo et al. as cited in Lorentzen & Morris, 2003, pp. 13-14). A common metaphor in Swahili for contracting AIDS translates as “stepping on the electric fence” (France as cited in Lorentzen & Morris, 2003, p. 14). In South Africa, depending on communities and context, HIV is referred to by different names to avoid saying HIV, such as “Umlazi 3” (which refers to a section of a well-known township in Durban, KwaZulu-Natal, which has sections numbered from 1 upwards but here the 3 refers to the 3 letters of HIV), “House In Verulam” (the initial capitals referring to the 3 letters, HIV). Verulam is a sub-urban area in KwaZulu-Natal, *Amagama Amathathu* (which means three names' i.e. HIV) (Francis & Francis, 2006), and "this animal" and the "three letter plague" (Steinberg, 2008). The avoidance of the term HIV and the use of other terms perpetuate stigma in that the terms are discriminatory and some are derogative.

The South African study by Selikow (2004) also shows that young people, for example, have their own special language to talk about sex and sexuality. In the township being what is known as a real man is portrayed by sexually assertive male behavior and by having many sexual partners. The study revealed that the language used to capture "a real man" is the term *ingagara* which was developed to show respect for such man. The "extreme opposite of an *ingagara* is an *isithipa*" — one who "does not have many girlfriends" (Selikow, 2004, p. 104). Clearly, the use of language influences the sexual behaviour of young people. This is shown in how the "youth have developed a specialised language to talk about sex and sexuality and this language has become part of the daily discourse, so that unsafe sexual practices become norms and are justified" (Selikow, 2004, p. 102). In the case of this study, the language works to reinforce unsafe and unhealthy sexual practices where concurrent partnership is presented as the norm, "women are seen as objects" and "there are double standards for men and women" (Selikow, 2004, p.106).

Conversely, "as language always occurs in a material context, it is also necessary to work towards changing the material environment, such as alleviating poverty" (Selikow, 2004 p.102). This kind of environment not only promotes "the development of a particular language but it also encourages unsafe sexual practices" such as concurrent partnership and "transactional sex" (Selikow, 2004, p. 102). If male youth gain respect from having many sexual partners, and those who do not have many girlfriends are labelled as stupid, it is more likely that young people may opt for this unhealthy sexual practice so as to earn respect.

2.5.3 "Disenfranchised" social groups

HIV has been associated with "disenfranchised" social groups including gay men, drug users, and to some extent Africans (Rintamaki & Weaver, 2008, p. 69; Reddy, 2009). HIV- and AIDS-related stigma strengthens stigma related to sexually transmitted diseases, sexual practices and sexual identities which do not conform to the norm

(Lorentzen & Morris, 2003; Reddy, 2009; Serner & Wagner, 2005). It is vital to note that the perception that the disease is unique to disenfranchised groups is misinforming and it may expose other people to the danger of contracting the virus. Also, the stigmatising of certain groups leads to fear of accessing care and support that is gradually becoming available.

2.5.4 Low level of education

Studies aimed at addressing HIV- and AIDS-related stigma reveal that the level of education influences stigma and discrimination (Hargreaves et al., 2008; Rao, Kekwaletse, Hosek, Martinez & Fodriguez, 2007). A study carried out by Phaswana-Mafuya and Peltzer (2006), for example, shows that those who were educated to at least grade 12 were less stigmatising towards others. In rural areas education levels are often low and the HIV rate high, hence the rate of stigmatising attitudes is high. This could be because of limited literacy which has been linked to patients being “more sensitive to matters of shame and stigma as a result of their co-existing concern for social stigma” (Waite, 2008, p. 1367).

2.5.5 Religious judgementalism

South Africa also has diversity of religion (Religious Intelligence, 2006). Most of the religions are consistently judgmental when it comes to HIV contraction and how people living with HIV are treated. This is more so because many of these religions, such as Christianity, Hinduism, Islam, Judaism, Buddhism and the Bahai faith, to mention a few, (International Religious Freedom Report, 2006) advocate for sexual abstinence before marriage.

Christianity is the dominant religion in South Africa with 73.54 percent of the population belonging to the Christian faith (International Religious Freedom Report, 2006; Religious Intelligence, 2006). Christianity, the oldest religion after the African religions, greatly influenced schooling by teaching people how to read and write, but also by entrenching its values.

Religion enacts a significant role in the lives of many South Africans (Elkonin, Brown & Naicker, 2012) and HIV- and AIDS-related stigma has clearly been influenced by religious beliefs and practices, which place a code of norms on people; these have an impact on the understanding of HIV and AIDS (Kalichman et al., 2006). While religious groups are perceived to be doing something to address HIV-related stigma in South Africa, they are also contributing to stigmatising attitudes “through conflating issues of sexuality and morality, and through associating HIV and AIDS with sin” (Keikelame, Murphy, Ringheim & Woldehanna, 2010, p. 63). HIV is then viewed as a punishment from God, for example, for failing to comply with the norms of sexual morality (Kalichman & Simbayi, 2004).

All this suggests that HIV is stigmatised because of the moral denouncement of behaviour through which the virus is mainly transmitted — sex. In areas where religious institutions have a big influence, for example, in rural communities, greater stigmatisation is reported (Kalichman & Simbayi, 2004; Paruk, Mohamed, Patel & Ramgoon, 2006). A related study shows that there is silence in Christian churches about the issue of HIV and AIDS and the stigma that surrounds the illness. There is also little knowledge available on what the church is doing about stigma with the exception of the study, *When the body of Christ has AIDS* by Van Klinken (2010). It is quite encouraging, though, to note that churches are gradually becoming comfortable with discussing issues of HIV and AIDS (Van Sickle, 2003), and in so doing, enabling the reduction of the incidence of HIV and AIDS.

African traditional religion existed in Africa before other ‘imported’ religions came into play. Unlike the other religions, African tradition religion does not have a founder and also does not have scriptures (Mbiti, 1970; Mbiti, 1990). African religion includes ancestor worship, ubuntu, and includes the sacrifice of animals for special events to honour the spirits of the ancestors. Beliefs are held by communities and they are more communal than individual (Mbiti, 1970; Mbiti, 1991). Individuals are celebrated from birth and after death, when they are regarded as ancestors. The African traditional religion believes that if a person rejects religion this would mean disassociating himself or herself from the total life of his or her people. In the African religion, HIV and AIDS is associated with spirits and supernatural forces attacking those who have disobeyed the ancestors and are being punished by ancestors for their wrongdoings (Kalichman & Simbayi, 2004; Visser, Makin, Vandormael, Sikkema & Forsyth, 2009). Also, some African beliefs such as witchcraft are incongruent with the scientific facts about HIV and likely to perpetuate stigma (Visser et al., 2009). Stigma is, again, perpetuated through the moralistic beliefs and the reinforcement of conservative gender ideologies.

2.5.6 Cultural practices of refraining from talking about sex issues

African communities in particular are guided by cultural practices (Cross & Carpentier, 2009; Owuor, 2008). Studies indicate that some cultural beliefs could also impede HIV prevention strategies and exacerbate stigma (Kalichman & Simbayi, 2004; Kalichman et al., 2005). Pekarsky (2009) concurs in that culture structures behaviour and shapes the attitudes of its members. With regard to sexuality and HIV education, the cultural norms are often a barrier to discussing these issues (Stuart, 2006). Hoff and Tian (2005) argue that in every culture there are conversational rules governing who can speak certain kinds of words. In many sub-Saharan African countries cultural practices make it taboo to discuss sex issues with children (Pattman & Chege, 2003). In the case of HIV, which is contracted mainly through sex, talking about it is circumvented, exacerbating stigmatisation and increasing the chances of young people contracting it.

2.5.7 Women as the face of AIDS in Africa

Women have been the face of AIDS since the early conception of HIV (Hackl, Somlai & Kelly, 1997), and HIV and AIDS is perceived as a female problem (Campbell et al., 2005b; Duvvury, Prasad & Kishore, 2006; United Nations, 2006; Wechsberg, Parry & Jewkes, 2008). First, women have been considered to be at greater risk of HIV than men (Rohleder & Gibson, 2006), irrespective of age since young girls are at risk of being raped because of the myth than men can be cured if they have sex with virgins (Kalichman & Simbayi, 2004). With married women the challenge is to negotiate safer sex within the restraints of the gender power imbalance (Deacon & Stephney, 2007). The state of women as the face of AIDS and this, linked to the background of violence in South African society is threatening the safety of elderly women, known as Gogos; there is widespread Gogo rape in KwaZulu-Natal. It has become common to see newspaper reports on old women having been raped by young men (see “Action Urged”, 2013). The old women also face the risk of contracting HIV. In the case of a woman being HIV- positive she often experiences the dual challenge of being a caregiver and a patient (Hackl et al., 1997). This applies to women of all ages.

The issue of school children teasing the affected and infected also has a gendered dimension (Bhana, 2008; Deacon & Stephney, 2007). Chase and Aggleton (2001), for example, reveal how HIV-affected children were taunted by their peers who said that their mothers were prostitutes. As for adolescent females, the stigma is aggravated since they are often positioned as being sexually active and are then vulnerable to more stigmatisation that is attached to HIV infection.

In older female populations, the effect of HIV is more pronounced because of the fact that females are often culturally, socially, and economically disadvantaged and dependant (Avert, 2008). Women are often abandoned and left with children, while the male spouse is likely to be excused for the behaviour which led to the infection in the first place (Avert, 2007; Ogden & Nyblade, 2005). The parents-in-laws blame the woman for infecting their son and sadly this prejudice is exercised by other women, like the mothers-in-law (Avert, 2007; Fleshman, 2004).

Testing is the only way to discover your HIV status. Since women will negotiate access to voluntary testing and counselling, and are necessarily submitted to HIV testing at antenatal visits, their chances of being identified as HIV-positive are heightened and thus they are seen to be the main transmitters of HIV (Avert, 2007; UNAIDS, 2007). In the case of expectant women, if a child is born HIV-positive, the label of ‘mother-to-child’ also stigmatises women without considering the origin of the infection. This is also related to the issue of how language perpetuates stigma.

A study in Zambia, Tanzania, and Ethiopia, indicated that both women and men are stigmatised for breaking the sexual norms of their gender (Nyblade et al., 2003). While many differences emerged from the views of the participants, women still appeared to be more stigmatised than men.

Other forms of stigma are reserved for women, like sex workers, who are thought to be responsible for their infection (Campbell et al., 2005a; Rintamaki & Weaver, 2008; Singhal & Rogers, 2003). Notably, sex-workers are not only worried about stigma but also about the loss of clients who might know their sero-status (Campbell, 2003). The fear of rejection, the loss of clients, and the loss of the love they get from their regular partners, always prevails. Women, as can be seen, are highly stigmatised and are indeed as Fleshman (2004) indicates, the face of AIDS in Africa.

2.5.8 HIV- AND AIDS-related stigma discourses

I now turn to the HIV- and AIDS-related stigma discourses and in so doing, I will draw from researchers, some whom explained stigma discourses before HIV and AIDS was known. (This explains why some older references are used.)

The meaning of the concept discourse has not been stable over time. For some scholars, discourse is a term that is often used synonymously with ideology and as such constitutes ideas, concepts, beliefs, and language which together create what becomes knowledge or an accepted world view (Bilton et al., 1996; Grimshaw, 2007; Wood, 2002). Another separate route of development which the concept of discourse has taken stems from post-structuralism and semiotics (Haug, 2005; Revell, 2009). Foucault (1972) was the major scholar behind the transformation of the concept of discourse from its linguistic formulation so that it could be applied in the generality of the social sciences. Foucault (1972) sees discourse as a synthesis of knowledge, social practices, forms of subjectivity and power relations such that knowledge cannot be separated from the latter three aspects since they are inherent in it (De Saussure, 2011; Haug, 2005). Therefore what it means is that if knowledge is subjective it creates discourses which are not just limited to ways of thinking and producing meaning.

The bulk of Foucault's work can be linked to history, although he was in a way opposed to orthodox historical explanation and preferred to work with what he characterised as the 'archaeology' or 'genealogy' of knowledge production (Ball, 2013; Grimshaw, 2007; Pinkus, 1996). Using these approaches he was able to analyse how knowledge was produced and given meaning over time frames that he termed 'epistemes.' According to Foucault, each episteme is characterised by particular continuities and discontinuities and thus it becomes a knowledge system within a specific time frame which then influences how people living within that time frame think De Saussure, 2011; Revell, 2009; Wood, 2002). Therefore the epistemological age becomes the social context within which certain knowledge and practices are either affirmed or discontinued (Pinkus, 1996; Willcocks, 2004). In contemporary times, we claim to be in an epistemological age in which certain knowledge and practices have been produced and affirmed in relation to HIV and AIDS and related stigma. In Foucault's view there is no way in which knowledge can be separated from power, such that even in writing it can be referred to as power/knowledge (Markula-Denison & Pringle, 2006). It is evident that Foucault was not merely concerned with the origin of discourses, but their effects because if they are linked to power they can then be involved in the institutionalisation of knowledge (Ball, 2013; Pinkus, 1996; Ramazanoglu, 2002).

Foucault applied the concept of discourse to examining and analysing many sets of knowledge and one example is on the discourse of “madness” (Foucault, 2006). In this example he demonstrates how the understanding of madness changed through different epistemes over centuries. A madman during the middle ages, for instance, was perceived as someone blessed by God, or under the influence of Satan. With the developments in science and medicine at the beginning of the enlightenment and modernity, the discourse on madness was framed from a medical point of view with the interpretation that madness represented a biological weakness involving either genetics or neurochemicals. As Wood (2002) suggests, the final meaning of ‘madness’ involved viewing it at the interface of biology, experience and social context. As is the case with HIV and AIDS, all these different understandings lead to affirmations of social attitudes which in turn influence social action – such as exorcism, burnings, locking mad people away, or giving them drugs and therapy (Wood, 2002; Haug, 2005). Similarly, there are social practices and social actions related to HIV and AIDS.

A discourse does not represent any universal truth —it actually constructs what people see as representing what is real (Blommaert, 2005). In that way people end up having a certain way of saying things and even the way people think is influenced. So, a discourse is an institutionalised way of speaking that determines not only what we say and how we say it “but also what we do not say” (Johnson, 2005, p. 1). DiAngelo, (2010, p. 3) puts forward that “Discourses provide a unified set of words, symbols, and metaphors that allow us to construct and communicate a coherent interpretation of reality.” Of course, discourses vary across cultures as well as time, and even vary within cultures (Labov, 2011). It is therefore the reason why I foreground discourse in this study: it has implications for HIV- and AIDS-related stigma.

2.5.8.1 Moral and social discourses

Moral and social discourses that have to do with the stigma associated with HIV and AIDS in children is not structured in the same way as is the stigma that adults experience (Deacon & Stephney, 2007). For example, HIV and AIDS are viewed to be consequences of deviant behaviour as measured by social constructions of sexual and moral behaviour (Visser, Makin & Lehobye, 2006). A central understanding is that of HIV and AIDS as revenge for moral recklessness, thus supporting the relationship between the attitudes of contagious disease and moral impurity (Campbell et al., 2005a; Gladden, Welch, Figueredo & Jacobs, 2009; Lorentzen & Morris, 2003). HIV- and AIDS-related stigma towards adolescents is associated with discourses of sexual activity. The sexual experience of the adolescent, determines the nature and extent of stigmatisation exerted around HIV and AIDS (Brownet al., 2010; Deacon & Stephney, 2007). Adolescents who have HIV or AIDS are more likely to endure stigma, compared to younger children and adults, based on the assumption that they acquired HIV through their violation of norms set by adults. The same applies to rape, which, in spite of being condemned, results in the stigmatisation of rape-survivors so many victims prefer to remain silent (Mnisi, 2009). The reality is that adolescents are most vulnerable to HIV infection (Kunnuji, 2013; UNAIDS, 2008) and young women in Southern Africa are in more danger of contracting the disease than anywhere else in the world.

2.5.8.2 The discourse of othering

Conceptions of the other can be positive or negative and these are researched in different fields such as philosophy, psychology, sociology and education (Rule & John, 2008, p. 79). According to Rule and John (2008, p. 80), “the verb ‘othering’ picks up on the sense of difference and takes it further to mean a process of making alien, of separating and denigrating in some way”. From these differences it depends on whether the philosophers want to construct the other in a negative way or a positive way.

Although the discourses of othering have been evident in different circumstances and contexts, they have been prevalent in HIV and AIDS issues from their very early history (Rule & John, 2008). For example, the first name that HIV was known as “was GRID, Gay-related Immune Deficiency”, and, in its use of ‘Gay-related’ had obvious othering meanings (Flowersas cited in Rule & John, 2008, p. 84). In this procedure of othering, those who thought they were not HIV-positive were able to attribute othering to the disease of a “small, marginal and stigmatised community” (Rule & John, 2008, p. 84). Even after the change of name, there was not much change in terms of the attitude of people who regarded themselves as HIV-negative (Henderson, 2010).

The studies on HIV-related stigma shows that the harassment of the people affected and infected by HIV occurs in settings such as homes; in institutions of learning such as schools; health care institutions such as the hospital and clinics; the community as a whole and the media, too. There is also a form of internalised oppression: even those infected have attitudes against each other. The oppression can manifest itself in many forms such as overt violence, isolation, discriminatory practices and labelling. All these forms and systems of oppression of people who live with HIV is referred to as “HIVism” by Francis (2004, p. 66). This author argues that at the foundation of HIVism is the strategy of othering through which people are identified, differentiated, subordinated and discriminated against. In othering people with HIV and AIDS, the perpetrators link it and its spreading to distanced social groups such as women, homosexuals, blacks and foreigners (Rule & John, 2008). Campbell (as cited in Rule and John, 2008, p. 85) maintains that “this process of ‘othering’ often serves as a mechanism whereby groups distance themselves from taking any responsibility for seemingly overwhelming problems”.

2.5.8.3 The discourse of age

Of all infectious diseases, no other in this era has presented such a disturbing impact on children and young people, globally, as has HIV. Because of HIV- and AIDS-related stigma young people are subjected to sadness and social isolation whether their parents are alive or not (United Children’s Fund [UNICEF], 2006a). Stigmatising people varies according to age. Young children, who contracted the virus through parent-to-child transmission, are less stigmatised than adolescents who might be suspected to have contracted the virus through engaging in sex (Deacon & Stephney, 2007). Adolescents are more stigmatised because of the association of early sexual debut with immorality and actions which as seen as avoidable. The meaning some societies give to youth who contract HIV is related to immorality and a lack of self respect. This points to the fact that stigmatised behaviours such as early sexual debut are regarded as a personal choice, and perceived to be degrading and avoidable (Roura, Urassa, Busza, Mbata, Wringe & Zaba, 2008).

While the foregoing discussion shows how sex at an early age is demonised, the issue of age is overlooked when it comes to some Nguni customary practices such as *kwendzisa* (arranged marriage), in SiSwati culture, and of *ukuthwala* (abduction of a girl for marriage) in Xhosa culture (Phasha & Myaka, 2009). These are practices in which families arrange marriages for young girls to men of any age — commonly older men. This usually does not require the consent of the young girls but their parents' consent is sought. Other females would be responsible for the facilitation of this marriage and once the girl is accepted by the groom's family a message that the girl has been taken, accompanied by a cow, will be sent to the girl's home (Wood, 2005). Thereafter, the girl may have sex with that old man, and if she resists, force is used (Phasha & Myaka, 2009). "She may even be held down by other women for penetration to take place" (Phasha & Myaka, 2009, p. 6). This form of sexual experience is neither treated as rape nor as immorality nor is it cursed as an 'early sexual debut'.

The same is the case in Swaziland, where the King, His Majesty Mswati III, still lives according to the traditional Swazi formal procedure that embraces polygamous practices (Forsyth-Thompson, 2011). He can be commended for initiating HIV prevention programmes such as declaring HIV and AIDS a national disaster in 1999 as documented in Whiteside, George, Barnett and Van Niekerk (2003). In the early 2000s, King Mswati III invoked a time-honoured chastity rite (*Umcwasho* — the wearing of tassels) and urged all young women to abstain from sex for five years (Okuonzi & Epstein, 2005). This Swazi custom was observed by other girls to honour Her Royal Highness Princess Sikhanyiso who was about to come of age, so that, together with her age mates, they could learn responsibility for their behavior (Ogunleye, 2006; Kumalo, 2013). To respect this means that all Swazi girls should remain virgins and not engage in sexual relations for the duration of the term. Any girls who married or had sex were heavily fined. In spite of this initiative, pioneered by the King, he married a 17 year-old woman. King Mswati III continues to marry young women, some of whom are far younger than his own children. These young girls then join the sexual network along with older, middle-aged and very young women all of whom are married to the King (Borgsund & Stureson, 2005). This illustrates how some discourses are used to suit particular situations, and illustrates what is seen to be correct by a certain group of people. Also, we can see how such practices can encourage the spread of HIV and its related stigma.

2.5.8.4 The discourse of innocence

Another discourse used in the context of HIV and AIDS and in relation to children is that of innocence. Children are considered to be innocent; even when they are infected they are innocent victims (Bhana, 2007; Bhana, 2008; Deacon & Stephney, 2007). As Holland (as cited in Bhana, 2008. p. 727) observes, “discourses of childhood innocence are used to stigmatise and disregard the children who do not conform to the ideals of innocence”. In that way innocence then functions to replicate the impression that children are regarded as detached from the socio-cultural environment they live in (Bhana, 2008, Jewkes & Morrell, 2012; Oduro, 2012; Oduro & Otsin, 2013). While children are expected to be sexually innocent and where teen sexual agency is viewed as dangerous and an impediment to the academic purpose of schooling, learners still “construct sex and sexuality as a positive development that enables active, self-aware, pleasure-seeking agents to negotiate their identities” (Mathe, 2013, p. 1). The same ‘innocent’ children express their view that high school years are the time “for sexual fun, sexual identity constructions, sexual exploration and sexual freedom” (Mathe, 2013, p. 1). Therefore, it sounds like an understatement to suggest that being young equates with innocence, knowing nothing and having nothing to say (Thomson, 2008). The notion that being young means being too immature to be taken seriously needs to be challenged. Thomson makes it quite clear that children are capable of providing expert testimony about their experiences, associations and life styles: “children can offer expert testimony, specific and unique insights” (2008, p. 1).

2.5.8.5 The discourse of poverty

There is a lot of documented evidence that many people affected by HIV and AIDS in southern Africa also experience poverty (Campbell, 2003; Francis & Hemson, 2006; Parker & Aggleton, 2003). It is these already underprivileged people who are most exposed to HIV and AIDS (Lorentzen & Morris, 2003; Wood & Webb, 2008). Rural communities, often poor, are at high risk of HIV because of the difficulty in accessing education as well as prevention programmes and health facilities. Malnutrition and vulnerability to other diseases also contribute to making societies more exposed to HIV

(Lorentzen & Morris, 2003; & Rajapakse, 2010). Poverty plays a part in increasing the vulnerability of the young people to HIV and AIDS, and this, in turn, exacerbates poverty — a significant factor in the spread of HIV.

Although poor people are seen to be more stigmatised, Bond (2006) suggests that high status people are not spared from the stigma, and more stigma is exerted on them if they are infected. This is because they are expected to know better and to be more careful. However, that can be debated since high status people are able to escape the stigma by using their resources and money to keep the stigmatised matter a secret (Deacon & Stephney, 2007). For instance, it is possible for wealthy people to make appointments with private health centres rather than go to public clinics and hospitals, to get tested and get treatment early. Wealthy people are in a position to avoid stigma and can send their pregnant girls away along with any who are HIV-positive, "to avoid loss of social status in their community" (Deacon & Stephney, 2007, p. 7). This confirms that although people of a higher economic status experience stigma, they may be less stigmatised in that the cost of stigmatisation is not the same and the consequences are different but this is not to suggest that the effect of being stigmatised is less intense.

According to Deacon and Stephney (2007) and Mahajan et al. (2008) there are four ways in which poverty can be associated with stigma. Deacon and Stephney (2007, p. 38) suggests that "poor people are more vulnerable to contracting HIV" because of risky sexual behaviour perpetuated by material needs. At the same time, they are likely to advance quickly from an HIV-positive status to having AIDS. Second, HIV infection may lead to a cycle of increasing poverty as breadwinners become ill and eventually die. Also, because HIV- and AIDS-related stigma is often associated with stigmatising beliefs about poverty, this very poverty could be the reason for the different treatment of HIV-positive people within families. The poor, therefore, are more exposed to HIV and AIDS, more likely to suffer its effects publicly at a household and personal level, and are more vulnerable to discrimination (Deacon et al., 2005; Ogden & Nyblade, 2005). Deacon and Stephney (2007) also explored the interconnectedness between discourses about poverty, orphanhood and HIV- and AIDS-related stigma. They observed that while there is an evident decrease in the overt HIV- and AIDS-related stigma against children, the stigmatisation of HIV-affected children for their poverty is maintained. These findings are in the same vein as those of Thielman, Ostermann, Whetten, Whetten and O'Donnell's (2012) study on the correlation of poor health among orphans and abandoned children in less wealthy countries. It does not come as a surprise, then, to note that HIV- and AIDS-related stigma is often coupled with stigma around poverty, lack of a formal home, and orphanhood.

There is a greater likelihood that children of African ethnicity, living in poor households, and in informal settlements would be HIV-positive compared to other children (Brookes, Shisana & Richter, 2004). The link between orphanhood and poverty and how the challenges which accompany poverty have an impact on orphans is also bemonstrated by Clayet al. (2003). The effect of stigma and poverty could be seen in the context of other factors like loss of parental care or other forms of stigma (Deacon & Stephney, 2007). While it has been proven that stigma exacerbates negative material effects, what is not as clear is the extent of the negative impact it has on children and youth. The extent of material poverty experienced by AIDS-affected children and youth which is exacerbated by the related stigma is also not known.

The more recent forms of disadvantage such as HIV- and AIDS-related stigma is dynamic, and not just a replication of existing forms of marginalisation or structural disadvantage such as poverty; it is an interaction with other exclusionary othering discourses and practices like sexism and racism (Deacon & Stephney, 2007). As I have already said, it evolves and is multifaceted in that it presents itself differently in different contexts and times. Therefore, different forms of social stigmatisation or social exclusion are likely to affect people irrespective of the link with these other forms of social stigma or disadvantage (Deacon & Stephney, 2007).

2.5.9 Intersectional stigma (HIV, sexuality, gender, culture, levels of education and age)

The discussions in the preceding sections substantiate the existence of a link between and among HIV, sexuality, gender, culture, levels of education and age. Therefore, issues of sexuality, gender and culture cannot be separated in addressing those of HIV. As alluded to earlier, the HIvirus itself was first associated with gayness and sex, and the constructs of gender have made females more vulnerable than males (Campbell, 2003; Stuart, 2006; UNAIDS, 2008). Shisana (2013) demonstrate, clearly, that females have a higher rate of infection than males.

HIV- and AIDS-related stigma is termed a dual humiliation in that it was initially identified in a group already marginalised before any of its members contracted HIV (Campbell et al., 2005b). Women, young people, gay people, people who sell sex, drug users, and the poor often fall into the category of the socially disadvantaged and marginalised. This has promoted the view that decent people do not contract HIV (Dageid & Duckert, 2008). Despite the fact that females are more vulnerable to HIV (Campbell, 2003) and that they are more stigmatised, when they carry condoms to protect themselves they are perceived to be ‘hunting’ for sex. Reports of violence are associated with the fact that women are unable to negotiate safe sex (Leach, 2002) so they experience violence at the hands of their partners for requesting safe sex, refusing sex or being tested; this includes married and unmarried women. UNAIDS (2012) concurs that women experience more stigma and discrimination than men, and that, furthermore, it is usually the most damaging kind of stigma: it includes violence (Earnshaw & Kalichman, 2013; Nyblade et al., 2003). It is paradoxical that women who are not well positioned to negotiate safe sex should be more stigmatised.

2.6 STIGMA IN DIFFERENT ECOLOGIES

Seedat, Duncan and Lazarus (2001) write on ecologies in terms of a fit between person and environment, and they emphasise that both social and physical environments and the individual’s relationship to them are important in establishing the optimal match between the person and the setting. This approach — an ecological perspective — moves away from linearity in its focus on the wholeness, interdependence, and complementarity of systems (Wahl & Lang, 2003). Individuals, families, small groups, organisations, communities, societies, and cultures can be viewed as systems, all of them interdependent (Donald et al., 2006; Hill & Thomas, 2011). Donald et al. (2006) describe the interaction of ecologies and systems in different levels of social context.

Stigma as a phenomenon is complex and its effects in diverse contexts are not straightforward and predictable. Based on this premise, in this section I describe various levels of stigma affecting children in different contexts. Consistent with other studies, that by Phaswana-Mafuya and Peltzer (2006) reveals the existence of stigma across all ages and in different contexts like family, school, work, health centres, and at community levels.

Stigma is not only a challenge to the stigmatised or the stigmatiser but also a challenge to humanity (Dovidio et al., 2000). The person who is stigmatised is devalued and his or her social identity is spoiled. Dovidio et al. (2000) conclude that stigmatisation is personally, interpersonally, and socially costly. Deacon et al. (2005) suggest that understanding the role played by the stigmatising person in the process of stigmatisation is far preferable to defining stigma as the problem of an individual. It is therefore vital for me to examine how HIV is stigmatised personally, interpersonally and socially, and in so doing I draw on some cases as evidence of stigma.

2.6.1 Stigma at individual level

An individual is positioned at the centre of her or his own world, requiring active involvement through her or his own interpersonal relationship with family and peers at school and the wider community (Donald et al., 2006). Manifestations of stigma, according to Campbell et al. (2005a) are rooted within the individual irrespective of whether the person is HIV-positive or HIV-negative. At the level of the individual who is HIV-negative or assumes that he or she is, it takes the form of behaviour, thoughts and feelings that express prejudice against people infected by HIV as well as their families (Campbell et al., 2005a). An individual, who knows that he or she is HIV-positive, according to Aronstein and Thompson (1998), registers panic, anger, shock, fear, shame, denial, and suicidal thoughts. These are brought about by the fear of not knowing how long he or she will live, fear of a painful death, fear of stigma, disbelief regarding his or her status, and a desire to protect the family from the pain of prolonged illness. Linsk and Mason (2004) add sadness, isolation, and uncertainty about the progression of the illness. They further state that the affected individual's family faces feelings that are akin to those of the infected member. The fear, isolation, and the attempts to avoid personal stigma spread from the level of the individual to every other member of the family.

2.6.2 At the level of the family

The family is the most important institution in which children are nurtured. The significance of the role played by the family in providing care and support for people living with HIV and AIDS cannot be denied. In the South African context it is mainly the family members who provide primary care to sick members (Avert, 2007; Avert, 2008; Singhal & Rogers, 2003), since African traditions emphasise and draw on complex family and community relations of support. Not all families adhere to this because of what Herek et al. (1998, p. 4) term “secondary AIDS stigma,” where those who are close to the HIV-infected person — the family members who are expected to give support — are also targeted Consequently, infected family members may find themselves not getting adequate social support and may even experience stigmatisation within the family. Campbell et al. (2005a) concur and report that stigma also manifests in the family, and reveal that families stigmatise their members, gossip about their children who have the disease, calling them evil. Moreover, family members do not want people to know that there is a sick person in the house, so will hide the person and prevent anyone from helping.

Stigma can also hamper the normal grieving process in that when a family member passes away because of AIDS-related illness, the cause of death is kept secret (Campbell et al., 2005a). In reaction to the anticipated stigma, the family adopts a conspiracy of silence which slows down the healing process and isolates the family further from traditional forms of support (Linsk & Mason, 2004). Landry, Luginaah, Maticka-Tyndale and Elkins (2007) and Zwemstra and Loxton (2011) assert that the affected youth, for example, are unable to mourn the death of their parents openly, and they often experience psychosocial problems like behavioural changes in the form of withdrawal or aggression. This is caused by the fact that when they are mourning the demise of their relatives they have to keep the cause of the death secret.

However, it is encouraging to see respected African statesmen like former president Kenneth Kaunda of Zambia (Singhal & Rogers, 2003) and former president, the late Nelson Mandela of South Africa lead the way when they publicised the cause of the death of their sons. Public disclosure, made by highly regarded persons provides one highly significant way of reducing the stigma since it humanises HIV and the AIDS epidemic.

2.6.3 At the level of health care settings

Health care settings, especially where primary health care is offered, are said to be key in addressing HIV and AIDS. Research, however, shows that HIV- and AIDS-related stigma is rife in health care settings and may deter people from accessing medical support (Nyblade et al., 2009). In the early years of the HIV pandemic in India, patients' beds would be marked "HIV-positive" (Singhal & Rogers, 2003) and their medical charts marked in red as a warning to hospital staff. In the South African context, Deetlefs, Greeff and Koen (2003) found that South African nurses' attitudes towards HIV patients were negative. A similar study of HIV-related stigma in health care settings in four other African countries —Swaziland, Lesotho, Malawi, and Tanzania — also showed that there is stigmatising in health centres (Holzemer et al., 2007).

While there is enough evidence that stigma exists in health care settings, Nyblade et al. (2009) claim that studies show that HIV-related stigma in health centres is also caused by the lack of awareness of the damaging effects that stigma has. Specially allocated HIV Counselling and Testing (HCT) and HIV and AIDS treatment rooms contribute to stigmatisation (Population Council and Health Systems Trust, 2006). Steinberg (2008) asserts that people prefer to die at home rather than to go for free anti-retroviral out of fear of being stigmatised in the very same health care centres where support can be obtained.

2.6.4 At the level of the schools

Schools are important spaces of socialisation where teaching and learning take place (Donald et al., 2006). This is a space of socialising, learning to engage with others, share with others and have fun together. Research suggests that children stigmatise each other, and that educators stigmatise learners, in particular the adolescents (Macleod & Austin, 2003).

The prevalence of HIV stigma is evident in South African schools as well as in schools in other countries. In the rural contexts of Mali and Botswana, for example, children's attitudes towards HIV-positive people of any age were stigmatising (Castle, 2004; Letamo, 2004). Some studies show that in the absence of educational intervention very few learners would be comfortable with HIV-positive learners in the same classroom

(Maritz & Coetzee, 2012). Gender also plays itself out in the children's teasing at school; HIV-affected children had their mothers referred to as prostitutes and they were taunted by other children (Chase & Aggleton, 2001; Deacon & Stephney, 2007). Adolescence is a critical period of development and identity formation. Adolescents need affirmation and they need to conform to their peer norms (MacLeod & Austin, 2003). Therefore, they are likely to experience more internal conflict around feelings of difference than do younger children. Children's stigmatisation of each other at school can have a negative impact on their wellbeing, and it can affect teaching and learning.

Learners are also stigmatised and discriminated against by educators (Francis & Francis, 2006). These researchers refer to an educator asking an HIV-infected learner to share with the class how she got infected, and warning the class not to get close to her. Disclosure is not easy, and much less so, surely, for this learner as for anyone if revealing her or his HIV status is regarded in a negative way. It is clear that both learners and educators do participate in stigmatisation of other learners.

2.6.5 At the level of the community

Communities are usually made up of people who have shared characteristics, interests or goals which bind them and keep them together in a belonging way. A community is seen as a "social grouping of people, often having values, customary practices, interests and concerns in common" (Donald et al., 2006, p. 3). Therefore, a community with a strong sense of community can be an excellent support to the people who are affected by HIV and AIDS. When a community grapples with HIV- and AIDS-related stigma, for example, in not knowing how to deal with it or with HIV itself, much damage is done to individuals, families and friends, and to the school. In Columbia, South America, for example, people were forced to undergo an HIV test and those who were found to be HIV-positive were evicted from the area (Singhal & Rogers, 2003). This is similar to the findings from the Populations Council and Health Systems Trust (2006) that people feel uncomfortable using HCT services where local community members are employed, fearing the compromise of confidentiality, which could lead to stigmatisation and exclusion from the community. In Brazil, too, people choose not to register for free anti-retroviral drugs out of fear of being stigmatised (Sighal & Rogers, 2003). Closer to home, there is the extreme example of Gugu Dlamini who was murdered by members of her community after divulging her HIV status (Francis & Hemson, 2006; Moletsane et al., 2007). While Gugu's death came at a time when there were no ARVs in place, it is essential to note that stigma still exists even though there is more support in place. Steinberg (2008), in his book, *The three letter plague,* describes how a rural community stigmatises those who go for HIV tests. The author shows how the people in the rural community gauge the time spent in consultation as a measure of whether or not the person is HIV positive. When a person takes less time in the health care institution, the person is presumed to be HIV-negative with no need for a long counselling session. In 2008 the newspapers and radio stations reported the case of a 37 year-old woman in the Eastern Cape who killed four of her children and then committed suicide after being continuously harassed by the community for her assumed HIV status (Booi, Ngcukana & Pather, 2009). While it can be agreed that HIV-related stigma continues to be a challenge, the increased uptake of HIV counselling and testing is an indication of the significant inroads made in reducing HIV-related stigma and associated discrimination (Republic of South Africa AIDS Response Progress Report, 2013). A community should be the environment in which HIV- and AIDS-related issues are talked about openly and addressed without fear of being further stigmatised (Deacon & Stepheny, 2007).

The stigma associated with HIV also interferes with the gathering of accurate information about the extent of the infection, and effective treatment and care, and it is seen to be a barrier to prevention (Deacon et al., 2005; Singhal & Rogers, 2003). Campbell (2003) writes that those who disclose their status often become victims in communities where HIV is frowned upon. In the past, national surveys in South Africa showed the pervasiveness of the stigmatising of people infected by HIV (Shisana & Simbayi, 2002). Research on stigma and children is becoming more available as researchers such as Bhana (2008); Campbell et al. (2010); Campbell et al. (2012); Deacon and Stephney (2007); Shu-Acquaye (2010); and Zwemstra and Loxton (2011) explore this important area.

2.7 EFFORTS IN ADDRESSING HIV- AND AIDS-RELATED STIGMA

It is more than 30 years now since the beginning of the HIV crisis but there is still no cure and far too little has been done on HIV-and AIDS-related stigma prevention programmes. UNAIDS (2012) concurs with Campbell et al. (2005b) and Deacon et al. (2005) that intervention strategies should deal with stigma as well as with HIV and AIDS since stigma has been identified as an 'illness' on its own. When he started his work, Piot, the then Director of UNAIDS made efforts by calling for programmes to address the issue of pervasive silence resulting from stigma (Brown, Macintrye & Trujillo, 2003; UNAIDS, 2008). In South Africa stigma still remains a concern. Efforts were first made to address the confusing messages about eating healthily to cure HIV which were sent to the public by the then Minister of Health, Manto Tshabalala-Msimang, and later, ARVs were rolled out far too slowly, causing the untimely death of a large number of South Africans (Kalichman & Simbayi, 2003). However, currently support and medication are becoming more available such that HIV, once seen as a terminal illness, is now regarded as a chronic but manageable illness. On that note, more efforts are required since the persistence of stigma related to HIV disrupts the social interactions of the infected person with other people.

In spite of the advances made, more research is needed to systematically address HIV- and AIDS-related issues. In order to do so, stigma needs to be understood in relation to HIV and AIDS, starting with understanding the early HIV infection dynamic and what has been done to address this issue. To this end, I highlight the need for doing research that can be translated into policy.

2.7.1 Policies

There are various policies in place which are designed to combat the pandemic globally. The Millennium Development Goals is one such policy: the sixth goal is to halt and reverse the spread of HIV and AIDS (United Nations, 2006).

The Children's Bill of Rights (1996) is also of relevance. Children have been silent witnesses to AIDS (UNICEF, 2006a) and while access to education — a fundamental human right — must be guaranteed for children who have been infected or affected by HIV and AIDS, we must also ensure, as educators and researchers, that we reduce the children's vulnerability to HIV and AIDS. Article 3 of The Children's Bill of Rights (1996) is explicit that all organisations concerned with children, for example, schools and the health services, should work towards what is best for each child. Article 12 also points to the rights of children to give their opinion when adults are making decisions that will affect them. In so doing, they could say what they think through speaking, writing, and drawing, unless it violates the rights of others as pointed out in Article 13. All children also have the right to information from television, radio, newspapers and the Internet. Policies must ensure that the information is understood by children, that the content is useful, and that the language is understandable, as stated in Article 30, so that they can apply the information in their daily HIV- and AIDS-related challenges.

In South Africa the Education White Paper 6 Special Needs Education, Building an inclusive education and training system (Department of Education, (DoE), 2001), in particular, is explicit that no learner must be discriminated against for his or her HIV-positive status. The DoE (2001) also proposed the integration of HIV and AIDS within life skills education to mitigate the effects of stigma surrounding people living with HIV and AIDS. Kader Asmal, the then Minister of Education, recommended that life skills programmes needed to include values, the context of the community within which schools operate as well as the broader community so as to mitigate the effects of the stigmatisation of people living with HIV and AIDS (DoE, 2001). The Education White Paper 6 addresses not only the issue of including HIV and AIDS infected and affected children in South African schools, it actually draws on and is informed by international thinking as in the Salamanca Statement on Principles, Policy and Practice in Special Needs Education (UNESCO, 1994).

Through the available anti-discrimination legislation, too, there is hope and promise that the public stigma directed towards people with HIV and those with AIDS can be reduced (Campbell et al., 2005a; Kalichman & Simbayi, 2003). But “manifestations of stigma are often too subtle to be immediately apparent, rooted within individual psyches, families, and communities and beyond the reach of the legal system” (Campbell et al., 2005a, p. 808). Hence, it is clear that addressing stigma goes beyond policies on goals, rights, inclusion and legislation.

2.7.2 Education

There is an increasing body of literature on how HIV and AIDS issues could be dealt with in the classroom using various methodologies, but still the stigma around HIV and AIDS persists. Francis (2004) shows evidence on how the oppression of people living with HIV includes negative treatment they receive from other people who might not be aware of their own HIV status. Francis and Francis (2006) conducted research on how HIV-related stigma and its related prejudice in addition to discrimination can be addressed in the classroom. Francis and Hemson (2006) explored a participatory visual arts-based method to challenge HIV-related stigma. Their key argument is that progress in addressing the epidemic can only be made if shame is replaced with solidarity, fear with hope and some of the language used in addressing HIV, for example the war imagery in the 'fight' against HIV (UNAIDS, 2011), is dropped. Moletsane et al. (2007), through the use of photovoice as a tool for activism in response to HIV and AIDS stigmatisation, argue that stigmatisation can be eliminated when new understandings about HIV-related stigma are successfully developed and also when new ways of taking action by individuals and groups, teachers and learners, are in place.

To date, education has had a crucial role to play in addressing HIV and AIDS (Griessel-Roux, Ebersöhn, Smit & Eloff, 2005; Stuart, 2006). Researchers recommend that a holistic approach to HIV and AIDS education continue to be a critical component in any strategy to reduce stigma (Francis, 2008; Francis & Francis, 2006; Hankins & de Zalduondo, 2010; Moletsane et al., 2007; Sengupta, Banks, Jonas, Miles & Smith, 2011). The Education Labour Relations Council (2005) emphasised that adequate strategies to address the complexity of the HIV and AIDS pandemic must be in place in educational institutions. In rural communities, stigmatisation continues to be, amongst other things, a stumbling block. It is therefore necessary to use approaches and methods that involve the community members and also tap into their voices. Thus, while education and legal safeguards (policies) may "arguably be necessary conditions for fighting stigma, they are certainly not sufficient ones" (Campbell et al., 2005a, p. 808).

Peer educators have established school-based programmes, which are usually clubs formed by learners in which participation is voluntary. These programmes are normally run outside the school timetable and are facilitated by peers who are usually capacitated to do so, and supervised by a teacher. Peer education is becoming an increasingly popular method of promoting behaviour change among adolescents. It involves the training and use of individuals from the target group to educate and support their peers. Peer-based approaches are based on the assumption that behaviour is socially influenced and that behavioural norms are developed through interaction (Visser, 2007). In the age of HIV peer educators are also trained to educate their peers.

2.7.3 Anti-stigma programmes

Deacon et al. (2005) observed that few anti-stigma programmes were successful in the early 2000s. Some programmes were information-based awareness programmes designed to reduce ignorance about people with AIDS (Campbell et al., 2005a). However, while ignorance often played a key role in perpetuating stigma, “providing people with factual information about the contagiousness of illnesses did not lead to widespread stigma reduction” (Campbell et al., 2005a, p. 808). Anti-stigma campaigns have also created positive environments for enacting policies to protect the human rights of people living with HIV and AIDS (Campbell et al., 2005a). Community mobilisation and social activism programmes also have broad positive effects on AIDS-related stigma. At the global level, UNICEF (2005, p. 5) launched “UNITE FOR CHILDREN” that is, “UNITE AGAINST AIDS, a global campaign bringing together UNICEF, UNAIDS co-sponsors, bilateral donors, non-governmental and faith-based organisations and civil society members”. The focus was and still is on ensuring that children have a central place on the global HIV and AIDS agenda including that of addressing HIV- and AIDS-related stigma, throught the Global Movement for Children in 2006 (UNICEF, 2005; UNICEF, 2006b). In South Africa, ribbons and symbols on T-shirts which signify HIV and AIDS have become iconic symbols for anyone who openly advocates and supports people living with HIV thus contesting stigma publicly and proudly with love and encouragement. Energies to lessen HIV- and AIDS-related stigma are sustained in South Africa “through mass media campaigns and public demonstrations and should be sustained to ultimately achieve success” (Campbell et al., 2005b; Kalichman & Simbayi, 2003, p. 446).

Reidpath and Chan (2005, p. 425) concur that “reducing HIV stigma is an integral component of a comprehensive approach to the control of the HIV and AIDS epidemic.” In the early 2000s the focus in Africa was on HIV and AIDS in general and the politics around HIV and AIDS (Deacon et al., 2005). However, there is a growing body of literature showing that the importance of programmes that are based on a culture-centred analysis are fundamental to understanding the nature and context of HIV- and AIDS-related stigma in South Africa (Airhihenbuwa et al., 2009; Campbell et al., 2010).

2.7.4 Visual participatory methodologies

Studies from different fields such as medicine, sociology, psychology and education using different methods have been conducted in an attempt to address stigma (Campbell, 2003; Campbell et al., 2005a; Deacon, 2006; Deacon & Stephney, 2007; Deacon et al., 2009). The use of visual and participatory methodologies such as drawing, collage, photovoice, participatory video, image theatre and a digital archive containing visual artefacts have been employed in various projects in KwaZulu-Natal to challenge HIV-related stigma (Francis & Hemson, 2006; Moletsane et al., 2007, De Lange et al., 2010). Francis (2010) also examined how drama, in the Boal tradition, could be used to engage students in communication about HIV at a school in KwaZulu-Natal. In Zimbabwe, a study framed by social representation theory used drawings and short stories to explore how Zimbabwean children represent AIDS-affected peers. This was done to ascertain whether children stigmatise each other or not, with the aim of crafting stigma-reduction interventions. The study, in identifying non-stigmatising representations, and informed by a theory of change, “accords a central role to community-level debate and dialogue in challenging and reframing stigmatising representations” (Campbell et al., 2011, p. 975),

Recent studies show that success has been achieved in using visual participatory methodologies such as photovoice, drawing, and collage with young people to study the social factors of HIV and AIDS (Francis, 2004; Mitchell et al., 2005; Stuart, 2006; Moletsane et al., 2007). Francis and Francis (2006) agree that the issue of HIV- and AIDS-related stigma can be addressed with learners, which confirms Griessel-Roux et al.’s (2005) findings that learners want teachers to deliver HIV and AIDS education in a more practical way. This is an indication that urgent attention should be given to how HIV is addressed with youth.

Another international study which adopted visual methodology and addressed the gendered dimension of HIV is that of Berger (2004), whose research explored the experiences of women of colour in Michigan living with HIV and AIDS from 1986 to

1996. The experiences of the women in the study included drug abuse and conflict with the law, while some were involved in commercial sex. The significance of this study was its demonstration of how visual and participatory methodologies enabled participation in complex issues. The use of digital storytelling as well enabled the women to recall their experiences while exploring the link between marginality and stigma. It also, at the same time, investigated how these women later assumed different roles as agents of change in their communities. The significance of Berger's (2004) work lies not only in its managing to collapse disciplinary boundaries, but also in its foregrounding of the digital stories of individuals whose voices are not usually heard in society. Sonke Gender Justice Network in South Africa, too, used digital storytelling and the findings concur that digital stories are of immense importance since they can inspire, educate, and move listeners deeply (Reed & Hill, 2010; Sonke Gender Justice Network, 2007). The effect of listening to, and being touched by, someone else's digital story is that people can make connections between their own experiences and those of others (Gubrium, 2009). In relation to complex issues like stigma, such connections enabled by the digital stories accompanied by the visual, can help bridge the differences that often divide people, and encourage them to act with compassion and conscience.

2.7.5 Digital storytelling and its social uses

In a quest to see any methodological gap, I further reviewed how other people have used digital storytelling. I read literature on miscellaneous uses of digital storytelling in social science research. I recognised that other researchers explored the social potential of digital storytelling in strengthening democracy thus demonstrating the democratic potential of participatory research (Burgess, 2006; Couldry, 2008; Lambert, 2013; Lundby, 2008). Digital stories have also been used as an evaluation tool to determine if they could be a potentially operational media tool for achieving positive community change while others have used them to assess the influence of the process of digital storytelling on the completed product of digital stories (Vivienne, 2011).

Digital storytelling has been used in the classroom context for educational purposes and it has shown a potential to give voice to a number of quiet students (Banaszewski, 2002; Ohler, 2006). Ohler (2013) further asserts that digital storytelling caters for the students whose skills might not fit into the traditional academic mode. Miller (2004) exposes challenges in using digital storytelling but Robin (2006) emphasizes that it increases multiple literacies in a classroom context. Hull and Katz (2006) specifically used digital storytelling for teaching in an English class. Digital storytelling is seen as a deep learning tool (Barrett, 2006; Bull & Kajder, 2004). It also can assist young struggling writers in this age of digital technology (Sylvester & Greenidge, 2009).

In a village in the Eastern Cape of South Africa an exemplar of digital storytelling was localised to suit the needs of the participants in this rural context in addressing HIV (Reitmaier, Bidwell & Marsden, 2011). Frohlich et al. (2009) used digital storytelling to address HIV-related issues. A feminist perspective on knowledge production on HIV issues was used and a corresponding digital storytelling approach was used by Gubrium and Difulvio (2011). In the South African context, digital storytelling has been used to address gender based violence by Reed and Hill (2010) who were working with young people. Higgins (2011) used digital storytelling to address issues of domestic violence and awareness of HIV. Digital storytelling has been also used as a psychological intervention as has been used by Davis and Weinshenker (in press) and for AIDS orphans (Pillay, 2009).

The *Let's Stop HIV Together: Innovative Implementation to Fight HIV Stigma and Complacency Project* (Mallalieu, 2013) addressed HIV and AIDS-related stigma, using traditional storytelling methods but these were not digital stories.

2.7.6 HIV- and AIDS-related stigma: children and young people

In terms of studies done to address HIV- and AID-related stigma, the focus has been on addressing stigma at the community level with young people and children. Although some studies did not focus solely on young people and children, efforts were made to address HIV- and AIDS-related issues. The studies that I refer here to were not necessarily conducted in South Africa but they are studies that focused on stigma and youth in their communities. Issues such as the lack of protective relationships in communities because of stigma were studied and here a few researchers are acknowledged (Baptiste et al., 2006; Betancourt et al., 2011; Buseh et al., 2006; Campbell et al., 2005a; Campbell et al., 2005b; Campbell et al., 2006; Campbell et al., 2009; Cook & De Toit, 2005; Hong, Anh & Ogden, 2004; Kidd, Clay & Chiiya, 2003;

Mahajan et al., 2008; Nyblade & MacQuarrie, 2006; Skinner & Mfecane, 2005; Stephenson, 2009; Wright, Naar-King, Lam, Templin & Frey, 2007).

In the biomedical field of research, a substantial amount of work has been done on HIV- and AIDS-related stigma experienced by young people and children in health care centres. A great deal of research with the same target group focused on challenges such as adherence and other stigmatising issues like transition from child to adult care in the health settings. Local and international researchers are commended for such work which informs us about youth and children in the area of HIV-related stigma (see Bond & Nyblade, 2006; Campbell et al., 2011; Dietz et al., 2010; Dowshen & D'Angelo, 2011; Fair, Sullivan & Gatto, 2010; Guttman & Salmon, 2004; Mellins et al., 2011; Rao et al., 2007).

Some studies have targeted young people’s and children’s HIV- and AIDS-related stigma behaviour and attitudes (Borgsund & Stureson, 2005; González-Rivera & Bauermeister, 2007; Nöstlinger, Bartoli, Gordillo, Roberfroid & Colebunders, 2006; Nyamukapa et al., 2008; Simbayi, Chauveau & Shisana, 2004; Stein, 2003).

Although the relationship of poverty to the contraction of HIV is not a simple one, there has been some research done with children on homelessness, poverty and HIV- and AIDS-related stigma (see Bond, 2006; Evans, 2005; Kidd, 2007; Strickland, 2004).

Researchers such as Cluver and Gardner (2007); Cluver, Gardner and Operario (2008); Cluver and Orkin (2009); Cluver, Bowes and Gardner (2010); Li et al. (2008); Robson and Sylvester (2007); Strode (2001); Thurman, Snider, Boris, Kalisa, Nyirazinyoye and Brown (2008); Zhao et al. (2010) have done research on orphans and stigma.

Children are often care-givers to their ill parents or family members infected with HIV and in that way they are affected. They also experience the HIV- and AIDS-related stigma of association and secondary stigma, all of which makes the issue of stigma a challenge since disclosure also triggers stigma (Butler, Williams, Howland, Storm, Hutton & Seage, 2009; Fair & Brackett, 2008; Fielden et al., 2006; Fielden, Chapman & Cadell, 2011; Hutchinson, Mahlalela & Yukich, 2007; Lam, Naar-King & Wright, 2007; Lee & Rotheram-Borus, 2002; McKay et al., 2007; Rotheram-Borus, Lee, Lin & Lester, 2004; Santamaria et al., 2011; Skovdal & Ogutu, 2009; Vaz, Eng, Maman, Tshikandu & Behets, 2010; Wiener, Mellins, Marhefka & Battles, 2007).

I also recognise that work has been done in the field of education with young people and children (Bhana, 2008; Bhana et al., 2004; Brown et al., 2003; Campbell et al., 2010; Goodall, Van Der Riet, O'Neill & Killian, 2011; Moletsane et al., 2007; Rule & John, 2008). Also, valuable international research on children and young people and stigma is disseminated through UNAIDS Stocktaking reports (UNAIDS 2008; UNAIDS, 2013).

While there is a growing body of literature on HIV- and AIDS-related stigma, literature on age-appropriate technology that provides the children and young people with spaces to deliberate on HIV- and AIDS-related stigma is in short supply. It must be noted that depending on their developmental stage, children may experience HIV- and AIDS-related stigma differently (Deacon & Stephney, 2007; Campbell et al., 2010) so they should be appropriately addressed. When we are dealing with children and youth some responses must be carefully analysed: what could be understood as a stressor to an adult, may not be perceived as such by children and their ability to respond to it could be different from that of adults. It is therefore important and essential to understand “how children experience and respond to [HIV- and AIDS-related] stigma in order to reduce its impact on their development, health and well-being, through appropriate efforts to address stigma with them” (Deacon & Stephney, 2007, p. 43).

Deacon and Stephney (2007), in exploring HIV- and AIDS-related stigma and children, adds another important aspect when she argues that it is crucial to understand the essence and social context around stigma. Children’s experiences of HIV- and AIDS-related stigma are influenced by factors such as sexual experience, poverty, orphanhood, gender and also ethnicity. This implies that stigmatisation reduction efforts should be looked at across different socio-economic contexts, taking into account the cultural differences. Hence there is still a need for more research.

The literature review allowed me to shape the theoretical framework which guided this study.

2.8 FRAMING THE STUDY

Stigma has a long history and yet there is still no clear definition of the phenomenon. The stigma attached to HIV and AIDS has further complicated the understanding of health stigma which is seen neither as separate from the existing stigma related to race, poverty, gays and lesbians, nor as replacing other forms of stigma, but one that adds to the complexity of this issue (Parker & Aggleton, 2003). I begin by identifying and critiquing some theories on the subject and highlight how some studies on HIV- and AIDS-related stigma have been framed. This assists in identifying and formulating a theoretical frame for making meaning of rural secondary school learners' experiences of stigma, whether these are real or imagined, witnessed or heard about. I also bear in mind the two questions guiding the study which, as I have said before, are: What can digital storytelling reveal about secondary school learners' experiences of stigma in schools in a rural community? How can digital storytelling enable secondary school learners in school in a rural community to take action to address stigma?

I subscribe to the notion that knowledge is socially and historically constructed (Beck & Kosnik, 2006) and "[w]hat counts as worthwhile knowledge is determined by the social and positional power of the advocates of that knowledge" (Cohen, Manion & Morrison, 2007, p. 27). I also align myself with the idea that valued knowledge changes over time since it is dependent on the social context in which it is created, and that power, be it oppressive or discursive, has effects on the content and process of knowledge production (Stoddart, 2007). I work within a critical-discursive frame and have an interest in methodological innovation, not only in theoretical critique. By this, I mean that I aim to give substance to the notion that qualitative methods are not simply about application of certain techniques, but also about inquiring into the possibilities of such methodologies in addressing HIV- and AIDS-related stigma. I consequently draw on theories from education, psychology, sociology, communication, public health, and other traditions.

2.8.1 Theory and theoretical framework

Any attempt at scientific understanding of a phenomenon in any discipline should be based on the body of knowledge or theories (Steinberg, 2007) available on the particular subject. A theory is considered a way of making sense of a phenomenon or situation in order to explain how and why it occurs (Steinberg, 2007). Vithal and Jansen (2004) add that a theory provides a perspective on events and that it exists in the context of competing theories, and “often represent[s] tentative solutions to a problem” (Steinberg, 2007, p. 30). Anfara and Metz (2006) argue that the social sciences have many theories that compete with each other and that it is up to the researcher to find the theories that offer the best explanations and to discard the rest. Anfara and Metz (2006) further argue that the use of multiple theories allows for the phenomena being studied to be viewed from multiple perspectives. However, it is important that whatever views a theory offers, it should stand the test of scrutiny when it is applied to research. In order to find an appropriate theory or theories to frame my study, I explored selected studies in the field of stigma and what follows is my critical analysis of some of the theories which have been applied to understand HIV- and AIDS-related stigma.

2.8.2 Towards finding a frame

I framed my Masters of Education study, *Beyond data generation: Exploring the use of a digital archive in addressing HIV-related stigma with educators from two rural KwaZulu-Natal schools* (Mnisi, 2009), within psycho-social theory underpinned by the continuous interface between the person and the social environment, throughout his or her development (Newman & Newman, 2006). Dovidio et al. (2000) explain how the psycho-social approach emphasises the effects of the immediate social and situational context of the stigmatiser on the stigmatised, on their interaction, and ultimately on the personal, social, affective, cognitive, and behavioural consequences of these transactions. I also considered and drew on the principles and values of community psychology, that is, the encouragement of health and well-being, caring and compassion, self-determination and participation, respect for diversity and human dignity, and social justice (Visser, 2007). When one is using community approaches, the social interactions between persons, settings, and systems are seen to be key and therefore community approaches analyse all levels of community, emphasise prevention, and are meant to be methodologically flexible (Lorentzen & Morris, 2003). Community psychology provided a suitable framework for involving members of the community since it emphasises local adaptation, empowerment, reflection and action, and speaks to the necessity of involving all community stakeholders when one is conducting studies of issues which directly affect the community, such as the HIV-related stigma (Donald et al., 2006). Central to the approach of community psychology is multidisciplinary collaboration and the belief in self-help.

When it comes to the issue of HIV- and AIDS-related stigma, gender is seen as a concern, as pointed out in the study *Stigma, gender and HIV: Case studies of inter-sectionality* (Campbell & Gibbs, 2009). These researchers used intersectionality as a way to study the relationship between stigma and gender and the implications of this relationship in programmes that address HIV- and AIDS-related stigma. As referred to earlier, the argument put forward is that in order to have effective HIV and AIDS programmes there is a need to understand stigma. HIV-related stigma deprives infected and affected people of confidence, and agency is therefore needed to access treatment, participate in programmes and increase self-efficacy (Campbell & Gibbs, 2009). The intersectionality perspective allows one to go deeper than to a simply descriptive level, emphasising the impact of agency, and going so far as explaining the complex psycho-social roots of stigma. The interest in gender and stigma is drawn from the fact that gender inequality coerces and exacerbates HIV and AIDS (UNIFEM, 2003). Therefore if this cycle is to be broken, as Campbell and Gibbs (2009) put it, there is a need to understand the connection between HIV, stigma and gender. Gender is a social construct, and what Campbell and Gibbs (2009) try to accomplish in their study, is an exploration of what Cornish (2006) and Howarth (2006) describe as the way in which the social world shapes and sets the contexts for construction of social identities and agency which are central to the ways in which stigma is internalised or resisted. Such a sharp theoretical lens cannot be ignored when one is doing HIV- and AIDS-related studies with either the young or the adult population.

The study by Lorentzen and Morris (2003) on Africa, *The Enigma of HIV/AIDS-related Stigma: A theoretical exploration of HIV/AIDS-related stigma in Sub Saharan Africa,* aimed at understanding HIV- and AIDS-related stigma from a conceptual point of view, and also employed community psychology and community counselling as appropriate frameworks. They found that these enhance the involvement of the local people, in terms of adaptation, empowerment, practical action and further studies. This demonstrates how researchers can respond in a manner that involves all community stakeholders when they are dealing with stigma (Donald et al., 2006).

Airhihenbuwa et al. (2009) conducted a study on *Stigma, culture, and HIV and AIDS in the Western Cape, South Africa: An application of the PEN-3 cultural model for community based research,* and studied the meaning of HIV- and AIDS-related stigma in families and health care using a cultural perspective. The study focused on socio-cultural and institutional contexts of stigma by exploring the question of belonging and differences as expressions of identities. The study concluded that culture-centred analysis relative to identity is central to understanding the nature and the contexts of HIV- and AIDS-related stigma in South Africa. It is further argued that stigma cannot be understood without considering culture. Although the study draws on affected participants, it fails to suggest a possible methodology for involving the community in providing solutions, or the notion of self help.

Another study based in KwaZulu-Natal used photovoice, a participatory visual methodology, to study HIV and AIDS as a barrier to learning (Muthukrishna, 2006). A paper published from that study, "*Unbinding the other in the context of HIV/AIDS and education"* by Rule and John (2008, p. 80) used the concepts of the other and othering in the context of HIV and AIDS to explore "the discourse of groups involved in education (learners, teachers, parents, caregivers, school governors, and other participants"). They were interested in how othering those affected and infected by HIV becomes a barrier to learning. Rule and John "argue that 'othering' offers an important perspective on social relations in the context of HIV and AIDS" (2008, p. 80). While the data from this study provides evidence that those children perceive and reflect on the fact that HIV- and AIDS-related stigma exhibits itself in a deep-seated othering of those affected or infected by HIV, there are no suggestions about how action could be taken to address this issue.

Deacon and colleagues have contributed much to the research on HIV- and AIDS-related stigma (2005; 2006) and have specifically focused on the literature on children and HIV- and AIDS-related stigma (Deacon & Stepheny, 2007). However, Deacon is grappling "towards a sustainable theory of health-related stigma" and suggests "limiting the definition of stigma to the process of othering, blaming, and shaming" (2006, p. 418). She further suggests the need to separate stigma and discrimination because stigma is conceptually inflated if it is defined in terms of discrimination (Deacon, 2006). While her contribution is valuable, Campbell et al. (2010) argue that trying to understand stigma only is limiting and that studies should also include interventions. Deacon (2006, p. 418) also states that:

> It is crucial to have a sustainable theory of stigma, which would begin with a coherent model of the process of stigmatisation that can help us to understand both its origins and its effects, and provide a way of bridging the divide between research models, evidence and interventions.

In an effort to address the scarcity of scholarship around children and stigma in southern Africa, a study, *Exploring stigmatisation of AIDS-affected children in Zimbabwe through drawings and stories,* was undertaken (Campbell et al., 2010). Using social representation theory (SRT) as its theoretical framework, the study explored how Zimbabwean children represent AIDS-affected peers, whether or not they stigmatise, what forms the stigma might take, and the existence of non-stigmatisation that might serve as a resource for interventions. Campbell et al. note that “SRT has been used to explore stigma in relation to the ‘othering’ of the mentally ill, notably in Jodelet’s classic study of interactions between the mentally ill and people who take care of them (French villagers were paid to lodge psychiatric patients in their homes)” (2010, p. 976). This theory provides an important framework and a productive perspective for examining the sense people make of their social worlds. Moscovici defines social representations as

> … systems of values, ideas and practices with a two-fold function; first, to establish an order which will enable individuals to orientate themselves in their material and social world and to master it; and secondly to enable communication to take place among the members of a community by providing them with a code for social exchange and for naming and classifying the various aspects of their world and their individual and group history (as cited in Campbell et al., 2010 p. 976).

Its key premise is that social representations are dynamic rather than static systems of social knowledge which are continually negotiated and renegotiated in daily interactions between individuals, groups, and institutions, through dialogue and communication as people go about their lives. The process of representation involves constant tension between stability (the possibility of reproducing traditional understanding) and change (the possibility of transforming these through constructing novel ways of making sense of the world). SRTs are relevant because they focus on the possibility of challenging and transforming “stigmatising representations through stigma-reduction programmes and place emphasis on the potential for representations to change” (Campbell et al., 2010, p. 976).

After much research and reflection on studies dealing with stigma, HIV- and AIDS-related stigma, and intervention programmes aimed at addressing stigma both internationally and locally, I conclude that challenging and transforming stigmatisation points to a need for theories that go beyond only understanding stigma in communities, and that involve communication towards change.

I frame my study in a participatory research approach to initiate community engagement from the bottom up, beginning with issues identified by the community, and the stage at which they saw themselves (see Horowitz, Robinson & Seifer, 2009). The school community was introduced to using visual participatory methods (see De Lange, 2003; Moletsane et al., 2007; De Lange, Olivier & Wood, 2008; Mnisi, De Lange & Mitchell, 2010). It is critical to draw on theoretical approaches that initiate a mode of action or provide a way of comprehending how participants can actively participate in the creation of new content, co-create relevant and contextual content, and even modify some. It is also important to see how such content can then be used and diffused, particularly in rural contexts, and by doing so, push the boundaries (Horowitz et al., 2009) of participatory methodologies in addressing HIV-related stigma.

In this study the idea was to explore how secondary school learners in two rural schools, using visual participatory methodologies, could create digital stories of HIV- and AIDS-related stigma, use the stories to understand stigma, and explore their use in addressing HIV-related stigma in the community. The learners actively participate in the creation of the stories, analyse the stories and provide solutions for the challenges they identify. Towards this end I decided to draw on Blumer’s symbolic interactionism to frame the study.

2.8.3 Symbolic interactionism

The intellectual roots of Herbert Blumer’s symbolic interactionism can be traced to John Dewey’s social-psychological theory (Lindsey, 1998) which posits that human beings cannot be understood in isolation of their context (Society for More Creative

Speech, 1996 in Lindsey, 1998). Symbolic interactionism is a study of “human group life and human conduct” (Blumer, 1986 p. 1) and involves the interactions that people engage in as they try to make sense of their world (Hier, 2005). The nature of this social interaction assumes that people are active agents “who take account of what each other is doing or about to do…. to direct their own conduct or to handle their situations” (Blumer, 1986 p. 8). This interaction takes place in a world that is socially constructed. What I understand from this is that people who live in a particular context would understand their constructed meanings better than outsiders. Blumer (1986) identifies three premises on which symbolic interactionism rests. These are meaning, language, and thought. It is believed that these premises influence self-perceptions as well as the extent to which one can be socialised into a larger community (Griffin, 1997; Kuwabara & Yamaguchi, 2013). What a person considers to be ‘bad’ and ‘good’ is dependent on what a particular community regards as good or bad (Plunkett, n.d.).

2.8.3.1 Meaning

In consideration of the first core principle which is *meaning*, Blumer (1986) states that humans act towards people and other situations, “on the basis of the meanings that the things have for them” (p. 2). This suggests that meaning making is central to human behaviour. In particular, the meaning ascribed to objects, events, or behaviours emanates from the understanding and interpretation people have of the world around them. If this is the case, then the interpretation of the meaning of the world is not fixed, but rather varies according to culture or context as people interact with their environment and with other people. Symbolic interactionism regards an “individual, a family, a school, a church, a business firm, a labour union, a legislature, as a unit of interaction” and that “any particular action is formed in the light of the situation in which it takes place” (Hier, 2005, p. 99). One primary condition is that action takes place in and with regard to a situation. A family is considered a unit of interacting personalities. The interaction that happens within the family unit is primary; it comes before interactions that take place amongst peers and other people on other levels of community. Symbolic interactionism sees the family as a social group in which individuals can develop both a self-concept and an identity through social interaction. It is through this self-concept and identity that people can make sense of events. Consequently, Margaret Mead (1934), a famous cultural anthropologist, concluded that human beings do not react directly to events, but, rather, their reactions are influenced by their interpretations of the meaning they give to events.

To make sense of their world, human beings develop a complex set of symbols (LaRossa & Reitzes, 1993). As people interact in their environments, they subjectively interpret through existing symbols. This is important when one considers the issue of stigma, and it points to the importance of understanding the symbols that are used so as to understand why people present certain behaviours. It is also important to note that meaning making is not a linear process. Rather, interactions with larger societal processes influence individuals to act, while at the same time individuals influence societal processes.

The rapist who insists that some women (hitchhikers for example), cannot be considered victims, because they are ‘looking for it’ is a good example of how people interpret social phenomena based on their understanding of the world and the pre-existing frames of reference. Here, hitchhikers are regarded as people looking for sex (Scully & Marolla, 1984). This shows that people interpret each other’s behaviours and act based on symbolic meanings which they give to situations within given situations.

As a consequence, Nelson (1998), marks symbolic interaction as a theory that can be used to analyse the interactions in society given that it addresses the subjective meanings that people ascribe to objects, events, and behaviours. The interest in subjective meanings arises from the fact alluded to in preceding sections that the behaviours of people are based on what they believe and not on what is objectively true. Thus, society is thought to be socially constructed through human interpretation (Nelson, 1998). For instance, why do people smoke cigarettes when there is objective medical evidence that highlights the dangers of smoking? To illustrate the subjectivity of the meaning making process, (Andersen & Taylor, 2007) suggest that this kind of behaviour is influenced by the way in which the situation is defined. Although cigarette packages clearly inform one about the risks of tobacco, popular culture has predisposed people to think that smoking is cool (Crossman, n.d; Researchgate, 2012). Therefore, the symbolic meaning of smoking overrides the actual facts regarding smoking and risk.

2.8.3.2 Language

In terms of the second core principle which is *language*, it is clear that language provides a way through which humans can negotiate meaning using symbols. Like Mead (1934) Blumer (1969) argued that naming assigns meaning to objects; accordingly, naming is a fundamental aspect of human society and the extent of knowledge (Plunkett, n.d.). It is through symbolic interaction with others that humans develop discourses they use in referring to the world (Searle, 2008). People's language is itself symbolic, and is used to attach meanings to symbols. De Saussure (2011) speaks about this when he says that the linguistic system is made up of signs, which are comprised of a mental image and an idea. We use words (linguistic signs) to refer to a conceptual sign, an idea or mental picture. That is what makes language symbolic.

Through language, we act towards others based on the shared meanings resulting from the interactions we have with them in our environment. This process is iterative in the sense that we create meanings internally based on our own experiences, cultures and social processes and then we verify these meanings externally in interactions with other members of our societies (Andersen & Taylor, 2007; Plunkett, n.d.). This shows that people develop concepts, including their self-concept, through interactions with others. In creating these meanings, people are influenced by culture and social processes such as social norms and social structures, which are worked out through social interactions with others.

2.8.3.3 Thought

Language influences the thought process and vice versa. This is because to comprehend the mental image, one needs the linguistic signs (words) to validate its existence. Human beings are thinkers and symbolic interactionists describe the thought that happens within a human being as an inner conversation (Rober et al., 2008). In other words, human action does not only emanate from interaction with others, but, also from interactions with the self-and from frequent social interaction and thinking (Charon, 2004).

Human action can also be regarded as an outcome of one's current social interaction, thought, and interpretation of meaning. Blumer (1969; 1986) explores the relationship between thought and language further and states that the thought process is a mental conversation or dialogue that requires participants to enact particular roles and to imagine different points of view (Blumer, 1969). According to Macionis and Gerber (2010), social roles are the expected actions of particular individuals guided by the shared norms and values of particular groups. Thus when people's actions are outside of the shared norms and values the possibility is that these actions are seen as being other to those which are shared by the social group. Douglas and Waksler (1982) contend that stereotyping occurs when complex human activity is explained by simply categorising and classifying it, or a group, as the other. There are both negative and positive stereotypes. When a person conforms, a positive stereotype is attached to that person, but if a person does not conform to norms, a negative stereotype, one that attracts stigma, is attached. Symbolic interactionists emphasise that deviants are likely to be stigmatized because they do not conform: some behaviours are privileged while others are criticised.

From my perspective, and after having engaged with sociological theories such Goffman's social theory and the labelling theory, I realised that there are similarities between social interactionism and these theories which come from different traditions such as psychology and sociology. However, symbolic interactionism is the chief explanatory model for me when it comes to questions of the source of stigmatisation. This is because stigma, like all other social phenomena, is a product of social processes such as interaction and socialisation. What make interaction possible are symbols which are shared and interpreted in the same way in a particular context by a particular group or community. Stigmatisation is understood to be a result of negative and undesirable stereotypes attached to the social roles that one is labelled with. People choose to group someone negatively depending on the meaning they give to the behaviour or situation presented. Interactionism focuses attention on the way that people interact through symbols, words, gestures, rules, and roles.

"Interpretations about what constitutes 'reality' are worked and reworked within multiple interaction orders: the domains of face-to-face interaction between people in given contexts," and "domains" in which "communications are governed by particular rules and conditions" (Goffman as cited in Brickell, 2006, pp. 417-418).

Although symbolic interactionism has been criticised for placing more attention on the self, I find it useful in understanding human experiences and interaction around HIV- and AIDS-related stigma. Critics of this viewpoint assert that symbolic interactionism ignores the influence of social structure and by so doing neglects the macro level of social interpretation. This criticism suggests that “symbolic interactionists may miss the larger issues in a society by focusing too closely on the ‘trees’ rather than the ‘forest’” (Zgourides, 2000 p. 11). Some theorists criticise symbolic interactionism as focusing on the diamond on the ring rather than on the diamond ring. Moreover, the theory is also criticised for overlooking the “influence of social forces and institutions on individual interactions” (ibid). For me, focusing on the learners, a small group, was to have them function as an entry point to the entire community. While acknowledging these criticisms, this study is premised on the idea that people are constantly in a process of interpretation and re-definition of their life experiences (Aksan, Kısac, Aydın & Demirbuken, 2009). This is how they derive meaning from everyday interaction. It is the meanings that people derive of self, that have an impact on the group meaning making and in turn influence their interactions at the macro level. Through interaction within social groups, information can be shared. Hence, while symbolic interactionism does not address the issue of social structure it pays particular attention to the intersubjective human components involved in the construction and maintenance of social life (Aksan et al., 2009). Role theory is used as the main counter-argument to the criticism that symbolic interactionism neglects social structure: basically it bridges individual behaviour and social structure and assumes that roles, which are dictated by social structure influence individual behaviour.

Having explained the theory in use, I now turn to how I will use it as a perspective on making meaning and answering the research questions. So, bearing the three pillars of symbolic interactionism in mind —meaning, language and thought — my expectation is that any representations produced by the learners regarding their experiences of HIV- and AIDS-related stigma would demonstrate symbolic interactionism. In this study I gave serious thought to the learners’ experiences and/or understandings of HIV- and AIDS-related stigma and then used their interpretations to find meanings that individuals assign to such stigma. I had to use the same learners since the symbolism may mean something different to different people coming from different contexts. In this case, the same information given by the learners about their community was interpreted by them to assign the meanings. The experiences — real or imagined, lived or witnessed —of the learners would give glimpses of the meaning, language and thought of HIV- and AIDS-related stigma. Their own rationale and reflection on the digital storytelling would throw light on any further meaning, language and thought, drawing directly from themselves as those affected, in some way or another, by HIV- and AIDS-related stigma. It would also explain how digital storytelling could enable them to change the meaning, language and thought around stigma through taking action. It is important to focus on the smaller groups to get the bigger picture about the community and then focus on what communication can be carried out to reach the wider community.

2.9 SYNTHESIS

I presented foundational work and insight into HIV- and AIDS-related stigma in this chapter. The chapter also shows how HIV- and AIDS-related stigma interacts with existing social and psychological structures. Intervention strategies have been discussed and the methods adopted have been looked into. Studies on stigma in the context of HIV and AIDS and how it has been conceptualised and theoretically framed have been reviewed. This assisted in my deciding on the theoretical framework that guides the study. In the next chapter I discuss the research design and methodology I chose to explore the research questions.

CHAPTER THREE

RESEARCH DESIGN AND METHODOLOGY

3.1 INTRODUCTION

In chapter two I discussed the literature on HIV- and AIDS-related stigma and the theoretical framework that guides this study. In line with my commitment to community-based participatory research, I am conscious of the processes that are involved in the data generation that leads to knowledge making.

In summary, this chapter is divided into three parts: in the first I discuss the design and methodology along with a consideration of the theoretical basis underpinning the methodological choices I made; in the second I talk about the preparations that were necessary; and in the third I outline the process of doing the research.

In part one I describe the research setting, the participants and their roles, my role as researcher, and I offer details of my methods, and the rationale for the choices I made. In addition, I present the sampling technique, selection criteria, sample size and the contexts of the selected participants in the study. Creswell (2009) posits that issues of ethics run throughout the research process. I therefore show how I have observed ethical considerations in formulating the research problem, the research questions, the data generation and analysis, and also in writing and disseminating the research.

In the second part of the chapter, I present the process of doing the research along with the procedures that I employed to generate data and analyse these with the participants. As Clark, Prosser and Wiles (2010) suggest, it makes epistemological sense to be explicit about how visual data (whether drawings, still or moving images) are created and the kinds of technology used to produce them and how it was analysed. This, therefore, is intended to make clear the complex process of working with participants to generate the data with them. The third part is on the actual data generation.

3.2 AIMS OF THE RESEARCH

This study was undertaken to explore:

- what digital storytelling can reveal about secondary school learners' experiences of HIV- and AIDS-related stigma in schools in a rural community, and;
- how digital storytelling can enable learners to take action to address stigma.

3.3 RESEARCH QUESTIONS

- What can digital storytelling reveal about secondary school learners' experiences of HIV- and AIDS-related stigma in schools in a rural community?
- How can digital storytelling enable secondary school learners in school in a rural community to take action to address stigma?

3.4 PART ONE: RESEARCH DESIGN AND METHODOLOGY

3.4.1 Research design

In this study I adopted a qualitative, critical and contextual research design (see Merriam, 2009) which is described in the sections that follow.

3.4.1.1 Qualitative research

Qualitative research not only attempts to generate rich textual and descriptive data in respect of a particular phenomenon or context, it also attempts to develop an understanding of what is being studied. Qualitative approaches allow for deliberation with, and creativity of, participants as they "make meaning in and through their activities" (Cohen et al., 2007, p. 20). Qualitative research allows for interaction among the participants and strives to record multiple perspectives of concepts, situations and events (Cohen et al., 2007). In qualitative research the researcher takes an "insider view" and is seen to be the "main instrument" (Babbie & Mouton, 2004, p. 270). In this way, Babbie and Mouton (2004) regard qualitative research as fluid, flexible, data driven and context sensitive. Behaviour is bound by the context in which it occurs.

Following Aluko (2006), I therefore provide a clear description of the context in which the research took place.

A qualitative approach was considered suitable for exploring HIV- and AIDS-related stigma experiences and understandings with learners using digital storytelling. Qualitative researchers view reality as “socially constructed” (Denzin & Lincoln, 2003, p. 271) and this enabled me to explore, with the learners, their social contextual experiences — lived or otherwise — of HIV- and AIDS-related stigma. Qualitative research also enables the generating of data which can reveal patterns, themes and categories, and is therefore suitable for revealing the complexity of HIV- and AIDS-related stigma. Since this is what I wanted to explore along with considering how the research with the participants could enable them to take action, I chose to work within a critical paradigm.

3.4.1.2 Critical research paradigm

De Vos (2005) argues that a researcher needs to go beyond understanding the nature of the research paradigm selected, and needs to spell this out in order to keep communication with the reader clear and unambiguous, so as to assist with establishing the coherence of the study. In the succeeding section I attempt to do so in a brief discussion of other paradigms and the reasons for my opting for the critical paradigm.

A paradigm is a set of assumptions or beliefs about essential aspects of reality (Nieuwenhuis, 2007). For Mertens (2012) paradigms are “philosophical frameworks that delineate assumptions about ethics, reality, knowledge, and systematic” enquiry (p. 256). Paradigms serve as “the lens or organising principles” for looking at how reality is constructed (Nieuwenhuis, 2007, p. 48). A paradigm is actually a model for observing and understanding, for shaping what we see and how we understand it (Babbie & Mouton, 2004). The understanding I have is that paradigms differ in the way they answer ontological, epistemological, and methodological questions (Nieuwenhuis, 2007; Taylor & Medina, 2013).

From the above it is clear that paradigms are crucial to research since they inform and hold together the practice and direction of inquiry. The paradigms therefore also influence the choice of research methodology and methods. In the next section I will look briefly at three key paradigms or ways of seeing the world, namely positivist, interpretive and critical to show how they differ from each other and I will then discuss the critical paradigm in detail since this work is located in it.

Researchers working within a positivist approach believe that reality is stable and that there are patterns and order that can be discovered in what they are researching. They subscribe to the notion that reality exists out there and therefore relationships between things can be easily measured. Positivists' epistemological assumption is that knowledge can be viewed "as hard, real and objective" (Maree & van der Westhuizen, 2007, p. 31) and can be accessed by using quantitative methodologies and quantitative data collection methods. This paradigm is mostly often used by researchers in the natural sciences.

An interpretive paradigm views knowledge as subjective, "which might lead to a more participatory role [and] often rejecting standard methods of natural science" (Maree & Van der Westhuizen, 2007, p. 32). Researchers in the social sciences research people's behaviour, attitudes, beliefs and perceptions, which are often not measurable. Interpretivists believe that the world is changeable and that it is people who define and construct the meaning of a particular situation or phenomenon, and that these meanings and constructions can be explored by using qualitative methodologies and qualitative data generation methods. They believe that it is not possible to discover all the rules and laws of the social world, but it is possible to understand how people make sense of the context in which they live.

In this study, I made the assumption that there is HIV- and AIDS-related stigma that is experienced by secondary school learners in schools in a rural community and that digital story telling could uncover these experiences of stigma and could empower participants to take action. This assumption informs the research questions which informs, in turn, the choice of a critical paradigm. Critical research draws on five constructs which are central to the paradigm and to the study: the marginalization of the powerless; power dynamics; social change; the historical construction of reality; and the existence of multiple realities.

The first construct I discuss is the marginalisation of the 'powerless'. Critical research is aware of the unequal and discriminatory way in which the social world is organised. Critical research moves beyond what the interpretivists do in understanding and describing how the world works and strives, rather, for a more equal and democratic place for everyone (Cohen et al., 2007). The critical paradigm identifies the forces or interests that place a social group in relative powerlessness and questions the legitimacy of this. The paradigm therefore seeks to emancipate the disempowered, and subvert excesses of power (Cohen et al, 2007; Mahlomaholo, 2009; Nieuwenhuis, 2007). Simply put, it aims to critique, emancipate and transform. Researchers in this paradigm, therefore, have a clear agenda which is to work towards an equal society which does not discriminate based on gender, race, and age. In this study the seldom heard voices of the secondary school learners in a school in a rural community about the stigma they experience in one way or another are heard.

Critical researchers are also concerned about power dynamics, which might manifest in several ways, including between the outsiders/researchers and the participants. Power dynamics play themselves out in traditional methods of research with outsider researchers seen as the powerful experts who take the lead (Creswell, 2009; Steinberg, 2007). Thus, critical researchers play an important role when they work with participants to research their (the participants') own situations and to understand the ways in which they are oppressed. In essence, the critical researcher aims not just to describe or understand, but to change society so that it can become just (Cohen et al., 2007). Research in this paradigm focuses on bringing about some kind of social change that will benefit those groups who are understood to be helpless or that are seen to have few opportunities or choices open to them, by bringing about social change. The critical paradigm reviews excess power and argues that such power is the outcome of dominating repressive factors that operate in the general interest of one group over another group's freedoms (Cohen et al., 2007). The critical paradigm sees reality as shaped by social, political, cultural, and economic power: it requires that we understand the ways in which power works in society and that we recognise how certain voices, such as those of children and young people, are often silenced.

Another construct of the critical paradigm is that reality is "historically created" and "reproduced by people" within a society (Nieuwenhuis, 2007, p. 62) (c.f. section 2.5.8 on discourses). Critical researchers aim to deconstruct the structural, historical and political aspects of reality in order to introduce changes of an emancipatory nature. This paradigm is critical of unequal power and the discriminatory ways in which the social world is organised (Mahlomaholo, 2009). If social reality is reproduced by people, it is clear that the groups of people who hold the power create the reality, and that those who are oppressed, like women and children do not (because they cannot) contribute to the social reality (see Campbell et al., 2005b; Deacon et al., 2005).

A critical paradigm also assumes that multiple realities exist. The assumption is that participants reveal these multiple realities and the researcher represents these multiple realities only as revealed by the participants as effectively as possible (Krefting, 1991). In this paradigm the reality is assumed to come from data produced by the participants who are conversant with the context and the actual phenomenon being researched or studied. The presence of multiple realities means that there is no “benchmark” through which universal truth can be obtained (Lincoln & Guba, 1985, p. 295).

What people claim to know is always subjective, influenced by social, political, cultural, and economic values, and history. Our place in society and our values informs how we construct our realities: there is neither universal truth nor universal reality. The critical paradigm assumes an independent rapport between the researcher and the participants whereby the researcher becomes submerged in the research through shared knowledge and social action (Healy & Perry, 2000). Critical researchers offer feedback that discloses the struggles of people, even if they themselves are not aware of how they are exploited or dominated. Usher (1996) affirms that no researcher can be neutral or disinterested because everyone has a particular position in society. Critical researchers recognise that their starting points are informed by their own values. In the subsequent section I highlight how the critical paradigm also informed my methodology, and how I use it in the analysis.

For me, the critical paradigm included dialogue with the participants and others, within a democratic framework (Cohen et al., 2007) which then enabled these marginalised groups to have their voices heard so as to be enabled to redress inequalities. I focused on doing critical educational research: this allowed me, together with the learners, the opportunity to examine and interrogate the learners’ stories of stigma and the solutions provided by them. This premise guided my study insofar as children’s voices are seldom heard in the field of HIV- and AIDS-related stigma (Bhana, 2008; Campbell et al., 2010; Deacon & Stephney, 2007). Considering this, I also used data generation methods which created spaces for the affected learners to express themselves.

One stream of critical research aims to bring about change through the product of research (Schratz & Walker, 1995). The other stream focuses on the process of the research, that is, how it is conducted, what methods are used, how participants are involved and the kind of skills and knowledge that the participants gain as a result of their involvement. In this study, both the process and the product are important in that the study extends beyond the acquisition of new knowledge and skills (such as technical and social skills gained by the participants through digital storytelling) in also addressing the challenges of HIV- and AIDS-related stigma with the learners.

I considered it important that the participants in the study become ‘co-researchers’ who also made decisions in the research process. In this model, instead of an outsider coming in to research a particular school or community, the educators and learners in the school and the members of the community become ‘researchers’ or ‘co-researchers’ in dialogue with the outside researcher (Flicker, Travers, Guta, McDonalds & Meagher, 2007). This reflects an understanding that the problem identified by the participants and the data is best generated by informed insiders — people who know and understand the situation and context. In this research I wanted participants to have a sense of ownership and responsibility and to take the lead in issues which affect them in their own community. In doing so, participants had the opportunity to critically reflect on and question social realities in relation to HIV- and AIDS-related stigma and also to generate possible solutions (see Du Preez & Roux, 2008).

Pragmatically, disciplines face the challenge of bridging the gap between research and practice (Rogers, 2003) and many research findings are not guaranteed successful translation into practical strategies. This gap between theory and practice is constantly emphasised by many scholars (Flicker et al., 2007; Israel, Eng, Schul & Parker, 2005). As a result of this disparity, much research becomes inconsequential and redundant and is not used by concerned communities or practitioners. Neither is the research useful in informing further research in the same field. It is therefore of concern to scholars that they make research relevant to communities (Bradley, Sexton & Smith, 2005; Campbell et al., 2005b). Bradley et al. (2005) proclaim a great need to fuse research with the practical world and this means research that allows for self-tailored, relevant, and context-based findings of participants and researched communities. In the context of the central tenets of critical research — the emancipation of the voiceless — I believe that if research is not translated into practice, it is of little use. In the next section I outline the research methodology, using a critical approach to make a case for research which brings about social change that is participatory in nature.

3.4.2 Research methodology

Authors such as Steinberg (2007) highlight the difference between the concepts of methodology and method. There is concern that these two concepts not be used interchangeably (Swann & Pratt, 2003). Methodology refers to the general approach of data production and data analysis while the term method refers to the actual way or technique of data production (Cohen et al., 2007). There is a clear difference between methodology as an approach and method as a technique or way of producing data, as noted by Swann and Pratt (2003).

3.4.2.1 Participatory research methodology

Participatory research methodology has evolved over the years. Since its inception it has always been used with the aim of including excluded voices in research (Kapoor, 2001) and for advocacy that focuses on bringing about change or emancipation (Creswell, 2009).

Babbie and Mouton (2004) describe participatory research as that which enables the production of knowledge in active partnership with affected participants. Participatory research allows participants to understand the intention of the research, and to feel confident that they have ownership of the study. Participatory research recognizes the participants as researchers, and allows them the opportunity to share their experiences and to make their voices heard. However, there are interesting debates about including excluded voices. Some researchers, such as Cornwall (2008), critique the notion of being involved in a research process, arguing that being involved in a research process is not equivalent to having a voice or having your voice heard. Therefore, the notion of working with the people and not on the people, which is critical to achieving authentic participation and enabling social change, is emphasised.

Olivier, Wood and De Lange (2009) describe participatory research as research that facilitates the process of knowledge production in ways that other research methodologies fail to do. However, Francis, Muthukrishna and Ramsuran (2006) argue that successful use of participatory approaches lies in the process rather than simply the technique used, since it involves the ongoing process of information sharing, dialogue, reflections and actions. Langhout and Thomas (2010, p. 64) believe that children can benefit from participatory research and "can become advocates for themselves and others". This brings me to the point that although participatory research may be critiqued, it does provide agency and audience, as well as the opportunities for voices which have been silenced to be heard (Lundy, 2007). This participatory research encourages participants to express themselves fully and engage with issues of HIV- and AIDS-related stigma. Since most of them are "sick of AIDS" in the sense of being bored by talk on this subject (Mitchell & Smith, 2003) and suffering from HIV and AIDS fatigue (Shefer, Strebel & Jacobs, 2012), using a participatory methodology is key. Hence the challenge for me in adopting participatory research with the aim of social change was to think through how best I could provoke action, and focus on social change. This ultimately brought me to the choice of community-based participatory research as described and discussed in the next section.

3.4.2.2 Community-based participatory research (CBPR)

I used a community-based participatory research methodology (CBPR) in this study. O' Fallon, Tyson and Dearry (2000) define CBPR as an ongoing research process which engages the community fully, in reflection, recasting and action which is a cyclical process within the community. Community members and researchers work together to bring together knowledge and action for social change with the aim of capacitating the community with self-help (Heaney, Wilson & Wilson, 2007). However, there is still little acknowledged about the amount of potential that CBPR has for sustainability, which is always a challenge to researchers doing research for social change. CBPR has been effective in producing high-quality research data to inform and guide the future, and that in turn, can maintain long-term university-community partnerships (Viswanathan et al., 2004; Heaney et al., 2007). CBPR brings together researchers' understanding of research using the members of the community as partners who bring their 'home-grown' experiences and the understandings of their own context, including its problems or challenges that need to be addressed (Borgart & Uyeda, 2009; Jones & Wells, 2007). “Community partners provide researchers with [relevant] insights into the local context, such as information about local policies or norms, or methodological considerations” (Borgat & Uyeda, 2009, p. 2). “These insights potentially lead to more effective interventions with more sustainable effects or to innovative approaches that otherwise may not have been considered” (Lasker & Weiss as cited in Borgart & Uyeda, 2009, p. 2).

Mc Leroy, Norton, Kegler, Burdine and Sumaya 2003, p. 529) provide an interesting way to conceptualise the different approaches of CPBR: “community as a setting; community as a target of change; community as resource; and community as an agent of change.” Community as a setting is referred to as the geographical location in which interventions are implemented (Mc Leroy et al., 2003). Interventions which focus on community as setting may be district-wide and may use any possible approach which suits the community and available stakeholders such as the schools and other organisations (Mc Leroy et al., 2003). Also, a variety of points of intervention can be adopted to ensure involvement of organisations such as the schools, families and individuals in HIV and AIDS education programmes so as to inform the community’s policies (Mc Leroy et al., 2003). In addition, the targeted community-based interventions could possibly seek community input through community structures or community organisations which are involved in HIV research programmes to ensure that relevant and suitable intervention programmes are implemented in the community, and, moreover, that they suit the intended target group.

The community as target of change refers to the aim of creating healthy community surrounding by systematically disrupting and challenging the community policies which affect the well-being of the community (Mc Leroy et al., 2003). Although the model here pertains to healthcare issues, it is possible to extrapolate from this to one that involves overall community health in the sense of social well-being. Sickness and the social ills of the community become the main area of focus for research as intervention, and for research for social change. This approach is used to address a number of community health programmes especially in relation to changes thought to be related to well-being and the remedying of other social ills (Mc Leroy et al., 2003).

A third approach to community-based participatory research is to view the community as a resource. This approach is usually practiced in community based research programme because it can enhance community engagement which, in turn, promotes the sense of ownership through the participation. Community participation is essential for sustained success in community based research programmes (Mc Leroy et al., 2003). These research programmes are targeted at harnessing a "community's internal resources or assets, often across community sectors, to strategically focus their attention on a selected set of priority health-related strategies" (Mc Leroy et al., 2003, p. 530). The community ascertains its priorities, and "these kinds of interventions involve external resources and some degree of actors external to the community that aim to achieve health outcomes by working through a wide array of community institutions and resources" (Mc Leroy et al., 2003, p. 530).

Finally, a fourth approach of CBPR is community as agent of change*.* Although closely linked to community as a resource, the importance in this approach is on valuing the assets the community has, respecting and reinforcing what the community brings by also developing and strengthening the capacities of communities (Mc Leroy et al., 2003). This makes epistemological sense since the communities are more knowledgeable about their daily challenges and at all times are responsible for resolving them. Mc Leroy et al. (2003, p. 530) say that "[t]hese naturally occurring units of solution meet the needs of many, if not most, community members without the benefit of direct professional intervention".

In this study the approach to CBPR used is that of community as agent of change within the specific geographical location where the study was based. By this I refer to my working with the participants who were secondary school learners in schools in a rural community. As I have pointed out, learners are part of the school community and the school is an institution within the wider rural community. The participants may also be viewed as agents of change in that they better understand their own struggles within the communities of which they are part.

CBPR from an agent of change approach is thus viewed as a joint research methodology to equitably involve stakeholders in the research process, each of whom offers something unique (Israel, Eng, Schulz & Parker, 2005). By involving the learners as participants, CBPR increased the relevance of the study in the context within which it was conducted. The primary community partners were two schools in the Vulindlela district of KwaZulu-Natal. The community partnership involved only learners as stakeholders of the school in its focus on their real or imagined, heard about or witnessed HIV- and AIDS-related stigma experiences. Community insights about the local school-based context for HIV- and AIDS-related stigma that I gained from my previous study (Mnisi, 2009) allowed me as a researcher to work with the participants to gain further insights into their experiences which I could then use to facilitate solutions. It made epistemological sense (Flicker et al., 2007) to draw on the group that was affected but also marginalised and in this instance (at least potentially if not actually) stigmatised, such as the affected school children and young people.

It is argued, by some critics, that when we opt to use CBPR in a study, all elements of CBPR such as the full engagement with the community must be used (Israel et al., 2007). But, rather than concentrating on covering all CBPR components in this study, I engaged in a dialogue with community members who were learners to realize the aims of this study, considering the time and resource constraints as Borgart and Uyeda (2009) suggest.

CBPR is also criticised for using weaker and compromised research methods (Resnicow et al., 2009). Some health psychologists, for example, are “concerned about conceding any control of the research process to community members who are not schooled in research methodology” (Borgart & Uyeda, 2009, p. 3). It may be challenging to work in rural community settings such as two schools, for example, because although the schools might be in the same context they will not be exactly the same and they will differ from other schools in the same area, and this may present challenges when it comes to generalising and trustworthiness. Increasing trustworthiness and the generalisability of the findings to other rural settings, where, for example, a substantial impact on individuals’ well being can be shown, is not always possible. In this research I try to argue the point that CBPR can result in successful and sustainable research which might otherwise not be possible where there is no community engagement. Such success may possibly yield effective, community tailored programs which are possible to sustain since they will be talking to the community’s priorities (Borgart & Uyeda, 2009).

De Lange (2012, p. 3) points out that “social science research should be framed within a participatory research paradigm, foregrounding participant engagement and process, which simultaneously has a ‘research-as-intervention’ focus”. So, the partnership between the community and the researching academic is fundamental to successful research as intervention programmes (Reniscow et al., 2009). Academic partners need to know the context very well in terms of the community structures, infrastructure and policies, (Borgart & Uyeda, 2009), and “partnerships should be built on relationships of trust, shared vision, mutual capacity building, and with genuine community engagement at multiple levels” (Uyeda, Bogart, Hawes-Dawson & Schuster, 2009, p. 1). If researchers do not have a backdrop to, and insight into, the community they work with it might not be possible to design a sustainable research intervention that pushes the agenda for social change in the community. Therefore, “identification and change of ecological factors, including public policies, may be best supported by research emanating from within communities, backed and promoted by respected community leaders,” and conducted in partnership with community members such as the learners (Borgart & Uyeda, 2009, p. 4).

3.4.3 Research setting

3.4.3.1 The rural community

The study took place in Vulindlela in rural KwaZulu-Natal, South Africa. KwaZulu-Natal is the province with the most HIV-infected people in South Africa (Gaym, Mashego, Kharsany, Walldorf, Frohlich & Abdool Karim, 2007). In 2010, research showed that more than fifty percent of the Vulindlela district’s young females were HIV-infected, by the age of 24 (Karim & Karim, 2012). In 2012, KwaZulu-Natal was still the province leading with 27, 6% HIV prevalence of men and women in the age group 15 – 49 years (Shisana, 2013). Findings from the Centre for the AIDS Programme of Research in South Africa (CAPRISA) also indicates than 17-18 year old girls from the same district have a 7.9% prevalence rate compared to 1.2% among boys of the same age group (National Strategic Plan for HIV and AIDS, STIs and TB (NSP), 2011, p. 22).

The CAPRISA website is updated with the information that this particular sub-district has 7 Primary Health Care clinics where nurses provide comprehensive primary care, including family planning services, voluntary HIV counselling and testing, sexually transmitted infection (STI) treatment, antenatal care, treatment of opportunistic infections and minor ailments (CAPRISA, n.d). The clinics are linked by ambulance to the regional referral hospitals, Grey's Hospital (about 30 minutes away), and Edendale Hospital (about 20 minutes away) (CAPRISA, n.d). In addition, there are about 60 community-based organisations in the district representing a variety of civic interests such as youth, women, religion, politics, and housing (CAPRISA, n.d). Several of these organisations are currently providing HIV prevention and home-based care services to this community and have links with the CAPRISA Vulindlela Clinical Research Site (CAPRISA, n.d). There is also a One-stop clinic which provides comprehensive treatment and which issues food parcels to people living with HIV. This is closer to Khuleka secondary school.

The Vulindlela community is mostly poor and without the resources of big cities. Many learners live in impoverished homes. There is a high rate of unemployment in this area such that only one tenth of the men here have a formal job. Many of the people have jobs which provide them with meagre incomes because the kind of jobs available is domestic work, truck driving and farm labour. Numerous family members, including grandparents, aunts and uncles, often share homes and household facilities. They have few recreational activities. Most learners walk to and from school, with distances of up to and sometimes greater than 2 km. The community is predominantly African and isiZulu speaking and is home to about 230,000 residents. It is divided into several wards and each ward has its own *Inkosi* (King) and *Induna* (Chief) who lead their 'own' people in their ward. For managing the education, the *Ubumbano* Circuit Management Centre in the Vulindlela-district is divided into five circuits (each with its own manager). Each circuit is comprised of several primary and secondary schools.

3.4.3.2 The schools

Walford (2001) argues that gaining access to a site to negotiate doing research and becoming accepted and trusted is a slow process, especially when one is researching sensitive issues. The two schools that I used had been engaged in several research projects lead by researchers from the education faculty of a nearby university since 2004, and so a relationship of trust had been built, and access was easily negotiated (see also De Lange et al., 2010). The two schools were therefore purposively selected because one of the schools had pointed out that issues of stigma were challenging in the school and the community of which both schools are part.

Thandaza School

The first secondary school I worked with is, for ethical reasons, referred to here by the pseudonym Thandaza School. Thandaza is close to other schools. Hardly any extra-mural activities are provided at the school. There are 1090 (male and female) learners. The school has thirty educators of whom fourteen are male and sixteen female, most of whom do not live in the community around the school. The school management team consists of a principal and a deputy principal. In this school there is also a Life Orientation teacher who addresses HIV, and a committee who looks after vulnerable children.

The school is fenced and a male guard keeps watch at the gate. A fence also separates the school from a pre-school and day care centre which is about 50 metres away. The school has an administration block housing the principal's office, the deputy principal's office, the secretary's office and the staff room. There are two blocks of classrooms opposite each other and between them there is a lawn. Most of the classrooms are swept and clean but the lawn is strewn with sweets papers. There is water and sanitation provided although not enough for the school's needs. The school has electricity, a well-equipped computer laboratory with more than twenty computers — a tribute to the principal's dedication and fundraising, and connectivity to the Internet thanks to the *Digitization and Data Management with visual Data in Social Research: Giving life (to data) to save lives* project (see CVMSC, n.d). The computer laboratory was used for one of the data generation sessions with the learners.

Khuleka School

The second secondary school, Khuleka School (here, too, I use a pseudonym) is some ten kilometres from Thandaza School but in the same Vulindlela district. There are 433 learners (male and female) at the school. The school has sixteen educators, seven male and nine female, most of whom are from the local community. The school management team consists of a principal, a deputy principal, and a head of department. There is one Life Orientation teacher who teaches HIV-related issues.

There is no committee to look after the needs of vulnerable children.

This school is also fenced but the fence and the buildings are in need of repair. There is an administration block with three offices housing an administrator, the principal and the deputy principal. There are three blocks of classrooms. One external wall has art on it showing Zulu warriors, a reminder of University of KwaZulu-Natal (UKZN) student teachers who were part of the Rural Teacher Education Project (RTEP). There is water and sanitation available. Electricity is supplied only to the administration block. There are only two computers available in the school — that of the administrator and one that was donated by the *Digitization and Data Management with visual Data in Social Research: Giving life (to data) to save lives* project (see CVMSC, n.d).

3.4.4 Selecting the participants

In this research, purposive sampling was used. Purposive sampling is a selection of those participants who will yield the most information or rich information about the topic studied (Leedy & Ormrod, 2005). Creswell (2009) suggests that for purposive sampling, researchers select participants in the context they understand for studies so that they can purposefully inform on the understanding of the research problem and phenomenon studied. Rallies and Rossman (2003) put it as simply deliberately selecting the participants. In this study, learners from two rural schools in KwaZulu-Natal who have been involved in earlier projects in addressing HIV and AIDS were deliberately selected and seen to be more likely to produce rich data (Denscombe, 2005). Both schools identified stigma as a barrier to efforts aimed at combating HIV while they were involved in the Learning Together Project (De Lange et al., 2003; Moletsane et al., 2007). In 2005, when the schools identified stigma as a barrier to HIV prevention programmes, grade 8 and 9 learners, through photovoice, staged photographs of challenges and solutions in addressing the stigma that existed in their community. Using purposive sampling was also convenient for this small-scale research, because I did not intend to generalise my findings beyond the sample (Cohen et al., 2007). The criteria for selecting participants were that they should be from the school in the rural community; that they should be members of the peer educator programme that the Department of Education organised to address HIV and AIDS; that they should be in grade 8 or 9; that they should be computer literate; and that they should be willing to participate. This group was selected by the school based on their willingness to participate in the peer educator's programme and given that they were active in other programmes at school. The second last criterion proved problematic since most participants did not have access to computer literacy classes. Using these criteria enabled 12 secondary school learners to participate (see Table 3.1).

Grade	**Number of participants**	**Sex**	**Number of participants**	**Age**	**Number of participants**
8	4	Male	4	15	4
9	8	Female	8	16	2
				17	3
				18	3
Total	**12**	**Total**	**12**	**Total**	**12**

Table 3.1: Biographic information of participants

3.4.5 Research methods

My decision to use CBPR motivated me to also employ data generation methods which enable participants to take the lead by making their voices heard and also by articulating possibilities for taking action. With this idea in mind, I chose to combine several data generation methods to strengthen my study (Nieuwenhuis, 2007), using digital storytelling as the main tool for data generation, complemented by focus group discussions and reflective writing. This approach allowed me to generate in-depth information on the issues and solutions to HIV- and AIDS-related stigma that concern secondary school learners from different angles and sources. The benefits derived from richness of data produced by combined techniques have been observed in the areas of HIV and AIDS research. Since data generated from different tools may differ, multiple ways of data generation may assist to confirm or filter the data.

I will now discuss and also qualify the choice of the data generation tools, and explain the theoretical underpinnings of each and say how these were used in the research.

3.4.5.1 Digital storytelling

Digital videos in research existed before 1990 (Gubrium, 2009; Hartley & McWilliam, 2009; Lambert, 2006) in various forms but were mostly the production of experts such as digital artists and film makers. Dana Atchley, an American scholar helped create the digital storytelling movement in the late 1990s, as cofounder of the Centre for Digital Storytelling (CDS), a non-profit, community arts organisation in Berkeley, California. Digital storytelling has proliferated because of the widespread availability to consumers of inexpensive communication and technology tools (Miller, 2008). Dating back from the early 1990s, the CDS has afforded an opportunity to a number of trainees who had an interest in digital storytelling to produce and share their stories (Robin, 2008). Atchley's innovation involved a workshop-based approach to educating ordinary citizens, young and old and even those without computer skills on how to produce their own personal digital stories (Hartley & McWilliams, 2009). Hartley and McWilliams (2009) suggest that everyone has a story to tell and that digital storytelling can be seen as enhanced traditional storytelling, a modern version of oral history, also suited to rural youth (Duveskog, Kemppainen, Bednarik & Sutinen, 2009; Duveskog, Tedre, Sedano & Sutinen, 2012).

As with traditional storytelling, mainly, digital stories focus on a unique topic and have a specific point of view. Digital stories are usually short and to the point, ranging from 2-3 minutes in length. They are narratives accompanied by images, videos and music. These two to five minute visual narratives therefore synthesise images, video, audio recordings of voice and music, and text to create convincing narratives of experience (Gubrium, 2009). Thanks to technology, storytelling moves "into the digital age, to give a voice to the myriad tales of everyday life as experienced by ordinary people, in their own terms" (Hartley & McWilliam, 2009, p. 3).

Digital storytelling is part and parcel of many visual research methods and is arguably an indicator of the potential direction which visual research representation may take in the future (Clark et al., 2010). As Banks (2007) points out, digital delivery systems have changed the way visual research is conducted and has opened up the creative potential of data generation, storage, dissemination, and access. Using point-and-shoot cameras, video equipment, and computers, researchers and practitioners work with community members, in this instance with secondary school learners, to capture different visual and oral data in constructing narratives about their communities (Mitchell, 2008). Digital storytelling involves script-writing and narrating, and is therefore powerful when we are dealing with sensitive topics such as HIV- and AIDS-related stigma (Bal, 1997; Pithouse, 2007). Roberto and Carlyle (2008) argue that the use of computers and the Internet has important strengths in HIV interventions. The argument is that such technologies are becoming more popular, they provide cost effective means of access to a large number of users; they allow individually tailored messages to be regularly updated; and they provide researchers and practitioners with high levels of control over implementation and monitoring.

Several authors (Barrett 2006; Howell & Howell, 2003; Hofer & Swan, 2006; Hull & Katz, 2006; Ohler, 2006) concur that digital storytelling has the potential to enable participants to produce self-tailored information that can serve as a tool for exercising agency (and possibly effecting social change). There is also the possibility of becoming “critical thinkers and critical viewers of media”. Others identify benefits ranging from “increasing participants’ reflection [and] prompting participants’ creativity” which also means an increase in participants’ technology skills and enhanced communication skills which can trickle down to the community (Robin as cited in Lowenthal, 2009, p. 300).

I conducted a review of digital storytelling programmes in the popular and academic literature. I found that the existing literature frequently alludes to the possibility or promotion of the promise of production of these stories to empower individuals and, in doing so, create conditions for organisational and community change (Kajder, 2006; Ohler, 2007). However, my review found much less discussion about how, where, and when the stories are used and what change is to be achieved. The digital storytelling literature, which is growing, places less emphasis on using it as an intervention and more on community participation in media production. This gap raised a number of questions for me: How and to what extent are digital stories making underserved voices heard? How does one know if the stories increase knowledge about issues which have an impact on affected people? How are digital stories creating spaces for critical engagement and action? While these questions did not guide the study, they engaged me as I was thinking about how I could get the young people involved in this study of HIV- and AIDS-related stigma.

Stories created using photos and drawings have served different purposes in community initiatives, including needs assessments, participatory evaluations, policy making and as components of health campaigns (Wang & Burris, 1994; Wang & Burris, 1997). Photovoice projects have also been used to bring attention to youth and adult perspectives on community health issues (Wang, Morrel-Samuels, Hutchinson, Bell and Pestronk, 2004), and with African American breast cancer survivors to promote understanding of the issues that survivors face. Similar methods, like documentary photography and video, have been used for decades to draw attention to stories of underserved and marginalised populations, using images to record social inequities and isolation in rural and urban communities (Lambert, 2006). Digital storytelling, I believed, could tap into the stories of stigma and provide insight into how stigma manifests itself in this rural community.

In this study the main focus was on working with digital stories of learners' experiences, real and/or imagined, of HIV-related stigma and ultimately on using the digital stories. This would enable documentation of these experiences and make them electronically available for researchers, policy makers, and HIV-infected people elsewhere (Mnisi, 2009). The completed stories could be used as powerful tools for social activism since the digitally preserved stories can be shared and can promote HIV intervention, in this case HIV- and AIDS-stigma prevention programmes. Using their own images and language, participants reflect on, discuss, and present their local knowledge through these user-generated digital stories to inform research, practice, and policymaking on issues that have an impact on them.

The rationale for choosing digital storytelling as a data generation tool was partly because I noticed that all the previous projects leveraged access to multiple technologies in communities where participants may otherwise not have had access to it (De Lange et al., 2003; Stuart, 2006; Mnisi et al., 2010) (See Chapter One 1.6). This exposure was important to my study because it would create opportunities for community members — here the secondary school learners — to learn how to use this technology, including computers and software, in participatory methods.

Digital storytelling has also gained popularity as an "innovative CBPR method that increases community members' participation in research on local health issues" (Gubrium, 2009, p. 186) and its use is growing in health and community education practice. Digital storytelling is still viewed as an emerging method for promoting community health (Gubrium, 2009; Educause Learning Initiative, 2007; Kajder, 2006; Ohler, 2007) and its use is particularly pertinent to this research which focuses on the well being of the learners. While digital storytelling came into use as a way of making the voices of often silenced people heard, it was made possible by the accessibility of technology and digital media (Hartley & McWilliam, 2009). To produce a digital story electricity is required, as well as a desktop computer or a laptop, Windows Movie Maker software, a camera or a scanner if photos or drawings or picutures are to be included in the digital story, a digital recorder and a cable to download the recording (or a laptop with recording function), and headphones to enable individual listening to the stories. Gubrium (2009) warns of the digital divide, that is, the difference between those who have access to computer technology and are computer literate, and those who do not. Although well-intended the existence of digital divides in most rural school contexts can derail the process of digital community storytelling. This is also observed by Burgess (2006, p. 8) who asserts “that the participants in research of this kind are often on the wrong side of the ‘digital divide’, and are not necessarily likely to be participants in the new media cultures that are frequently celebrated.” When participants are creating digital stories some form of motivation and support is needed, otherwise many of the participants will not want to try their hand at digital storytelling, nor use a computer. If they do try and are unsuccessful, it might cause them to feel badly about themselves. However, I was aware of these challenges of using digital stories within a rural community and took necessary precautions, which I explain later.

3.4.5.2 Focus group discussion

Focus group discussion (FGD) can be described as a form of group interview that enables communication between the researcher and research participants so that rich data can be generated (Bryman, 2004; Featherman, 2006). FGD is “a form of interview in which there are several participants, including the facilitator, with an emphasis on fairly defined topics, and the accent is upon interactions within the group and the joint construction of meaning” (Bryman, 2004, p. 346). While several authors are not specific about the number of participants to be included in a group, Marshall and Rossman (2010) recommend 7 to 10, while Kitzinger (1994) recommends between 8 and 12 participants as an ideal composition. Kelly (2006) recommends a smaller group and argues that participants are likely to have a lot to say, and might be emotionally involved with the topic. With FGDs, the difference is that the question is not directed to one person: the researcher asks a question and the group members can deliberate with each other before answering. It also allows other people to comment on the other members' ideas, points of view and experiences. FGDs works well in exploratory research about people's knowledge and experiences (Kreuger, 1994).

If FGDs are successfully conducted, the ideas that emerge from them are developed by the participants (Smithson, 2008). In this study my role was to encourage discussion and maintain focus, and produce data by taking notes, voice recordings, and video recordings. Greene and Hogan (2005) suggest the use of single sex FGDs for sensitive issues and Rodham and Gavin (2006) argue that boys tend to dominate in mixed sex groups and take longer in discussions. HIV- and AIDS-related stigma affects both sexes with females being more affected, so I thought it important to work with a mixed sex group so that they could grow together in the understanding of such issues. While this method helps to involve the participants in a participatory way, blending well with digital storytelling, I had to be aware of the possibility that participants might feel uncomfortable in sharing their work in such a group.

The FGD was not the main tool for data generation but, following Short (2006) and Campbell et al. (2010) I saw it as a complementary method for participatory research and for discussing AIDS-related stigma. The choice of the FGD allowed for discussion before, during and after the production of digital stories. Ulin, Robinson, Tolley and McNeill (2002) are of the opinion that using FGD produces data and insights that would not be easily accessible without any kind of interaction in a group. In keeping with the suggestions of Marshall and Rossman, (2010) this particular data generation provided me, as a researcher, with an opportunity to get additional information about the participants' understanding of their own experiences of HIV- and AIDS-related stigma as well as those of others which may have been missed in the digital storytelling.

In this study, the FGDs also provided a space where views that were troublesome or not socially shared by the youth, (see Flick, 2008), could be revised and validated by the participants in the group. This accords with a participatory research approach, in this case CBPR, since participants' views emerge naturally in the course of the discussion. Moreover, it has been argued that results from FGDs have high levels of trustworthiness because the method is readily understood; more people pool their views at the same time and so their findings appear to be believable (Flick, 2008). In this study, the use of FGDs also provided a further opportunity to explore unanticipated but related issues which arose in the discussions. For example, the issue of ethics involved in photography, the issue of virginity testing and the issue of sexual orientation were raised (see Chapter Five).

3.4.5.3 Reflective writing

This section provides a detailed description of reflective writing since this was one of the data generation tools.

Reflective writing has become widely used as a key component of reflective practice which is embedded in the idea of learning from experience (Jasper, 2005). It has been used in many fields such as education where written ‘reflection’ is defined as a way in which teachers construct, through writing, meanings and knowledge that guide their action in the classroom (Francis, 1995). It involves standing back, being as objective as possible, describing in detail all that you heard and saw in response to: How? When? Where? and Why? (Bolton, 2010). Reflective writing, as an exercise, allows the writer, in drawing from a personal response to the possible meaning of the incident, and also from his or her emotions or experiences to thoroughly describe all that she or he sees in, or thinks about, something (Bolton (2010). Such expressive or reflective writing could then be seen as a mechanism for coping with critical incidents (DasGupta & Charon, 2004).

Reflective writing “develops the writer’s critical thinking and analytical abilities, contributes to their cognitive development, enables creativity and unique connections to be made between disparate sets of information and contributes to new perspectives being taken on issue” (Jasper, 2005, p. 247). It also allows participants to reflect deeply on their personal experience (Bolton, 2010; Watt, 2007). Reflective writing as an exercise, allows for that confidential space where one can feel safe while narrating the account of what has been observed and expressing feelings about and responses to experiences (Bolton, 2010). In that way, more information is brought out into the open, through the writing, which might otherwise be impossible or challenging to communicate verbally (Ryan, 2011; Ryan, 2012).

Reflective writing is actually a method in its own right and it can be used in qualitative research as a data generation method. In this study, after every session with the participants, I required them to write a reflective piece. The reflection was not meant to be shared with other participants but to assist in deepening their own understanding of the knowledge and skills being developed in the research process, and, of course, to provide me with data about their understanding of the research process.

3.4.5.4 Data analysis: Participatory analysis

Keeping in mind the choice of a critical research paradigm and CBPR, it is necessary to choose an analysis approach which is in line with the underpinnings of the paradigm and methodology. I therefore explain my choice of participatory analysis.

Participatory analysis as method is gradually gaining consideration in research which involves children and young people (Nind, 2011). This method of analysis is seen to reflect a paradigm shift (from traditional research) to also addressing concerns such as the rights and voice of communities in development research in qualitative inquiry (Nind, 2011). The participatory nature of the study allows for participatory analysis. The process creates the link from participatory data generation and data analysis to participatory reflection and community action projects (Peace Corps, 2007). The participatory analysis allows for hearing from the participants; for clarification; and it enables participants to identify the emerging themes as well as being engaged in the provision of solutions. The purpose of participatory analysis is to focus on the participants' voices. For that reason, analysis is layered. The narratives of the participants, i.e. the digital storytelling, and how they themselves make sense of stigma serves as the first layer of analysis (Riessman, 2002). When the participants show and tell their digital story, the audience of other participants look and listen and possibly add another layer of meaning. A further layer of analysis takes place when we flesh out themes from the data using thematic analysis. Finally, the findings are contextualised using existing and relevant literature to dispute or agree with the findings (Marshall & Rossman, 2010).

The first layer of participant data analysis can serve as the starting point and can open doors for reflexivity and further data generation and analysis – on the part of the participants and the researcher - resulting in different forms of data representation and knowledge production (Cole & Knowles, 2008; Moletsane et al., 2007). I concur fully with the idea that researchers “claiming participatory approaches need to grasp the nettle of participatory data analysis” (Nind, 2011, p. 360). As other scholars note, despite developments in participatory approaches, participatory data analysis has not often been attempted in research with children and youth (Byrne, Canavan & Millar, 2009; Nind, 2011). Although participation in analysis is often neglected, scholars do highlight the potential benefits of participatory analysis for participants and for the research (Campbell & Murray, 2004). In this research participatory analysis was tried out with the participants in line with the research design and methodology.

3.5 PART TWO: PREPARING FOR THE FIELD WORK

3.5.1 Piloting data generation tools

Qualitative research is a systematic, controlled and self-correcting investigation (Creswell, 2009) and therefore a pilot exercise was done to refine the empirical aspect to ensure sound data generation. A pilot study is a small-scale study which is conducted before the main study to assess the practical aspects of a research project (Hulley, Cummings, Browner, Grady & Newman 2013; Yu, 2013). In this preliminary study, factors such as “feasibility, time, cost, adverse events” were assessed “to improve upon the study design prior to performance of the full-scale research project” (Hulley et al., 2013, p. 168-169). As Blessing and Chakrabarti (2009, p. 114) put it, the aim of a pilot study is “to try out the research approach to identity potential problems” that may affect the trustworthiness of the findings, and then to resolve the problems.

The piloting of the data generation tools was done with learners from an urban school which two of my children attend. They brought three of their friends from the same school so the group consisted of five boys. I informed them about the study and why I needed to pilot the methods with them. I acknowledge that the participants with whom the pilot study was done differ in terms of their location (urban), their access to and ability with computers, but I knew that it would give me a feel for what was going to happen in the field work of the study.

I started with a session aimed at understanding stigma, in which the participants were to individually write down stigmatising statements they hear in their own areas. This was followed by a discussion in which they shared their statements and then indicated which statements were more common than others. I then introduced the notion of digital storytelling and briefed them on how it works and the steps involved when one is creating digital stories. This was followed by the prompt which was to guide their stories: “Write a script (narrative) of an experience of HIV- and AIDS-related stigma”. I also asked them to be clear about where the story took place; when it happened; who the characters were; what the experience was; how it made the characters feel; what they thought; and whether they had told anyone. When they were done with individual writing of the script the boys, in one pair and one group of three, were to share their stories. After listening to each other and helping each other to clarify their stories, they used a voice recorder to record each other while they were retelling their revised stories. The next step was to generate visuals with which to illustrate their stories. They used a camera to capture pictures and two of them opted for using drawings. I provided pencils, coloured pencils and paper and let them draw what they wished to illustrate their stories. The next step was to use the computer software, Movie Maker, to upload and then to combine the sound and the visuals to create the final product of each digital story.

The piloting was actually intended for piloting the digital storytelling using the software programme to see how the process unfolded and what adjustments I needed to make in my engagement with the participants. Even though there were only five pilot participants and even though they were fairly computer literate, I realised that I would need some assistants who would be able to support me when I had 12 participants working individually on their digital stories on computers in the field.

I also noted the challenge of explaining the concept of ‘stigma’ to the learners. The issue of HIV- and AIDS-related stigma clearly was too abstract for some of these pilot participants which made me realise that when I got to the field (working with learners from rural schools) I should first do a workshop on stigma, spending time on the concept, but being careful not to contaminate their thinking. Therefore, I devised a brainstorming activity in a way that ensured that I would not influence their thinking, to ascertain their level of understanding before embarking on the generation of digital storytelling.

3.5.2 Data generation site

There was a need for computer and technical support for the digital story creation to be successful. I also needed to be sure that the necessary software was installed and accessible. The university computers had the software that I needed, and hence the idea of bringing the learners to the university where I work seemed sensible. A computer LAN, with Internet connectivity, was reserved for the study. Although one school has a fully-fledged computer laboratory where I could have installed the software, I was not sure about the availability of the technical support at the school. Furthermore, the idea of making the learners from the two schools meet in the computer laboratory of one school, where some would feel more at home than others, was another consideration.

There was also the need to spend a long period of time with the learners in continuous sessions until the stories were created, so I arranged for us to work together for three days, with the participants being accommodated on campus, giving us time to both work and rest. The idea of bringing the Vulindlela learners to the university had been tried and tested (see *Blogging as a liberatory praxis: How digital media can engage learners, educators and researchers* (Pascarella, 2010); *Every voice counts*: *Critical partnerships for teacher education and rural communities* (2009); and *HIV and AIDS possibility* (Mnisi, 2011), and I therefore felt comfortable to do so again. The existing partnership between the university and the two schools has had a history since 2004 (see De Lange et al., 2003; 2010) and I could draw on it again.

3.5.3 Ethical considerations

Ethical dilemmas are contained in all research, but require greater consideration in sensitive and health-related research such as HIV- and AIDS-related stigma. In the next section I describe what I mean by being sensitive in this study.

3.5.3.1 Sensitive research

Sensitive research is research that potentially poses a threat to those who are involved or have been involved in it (Cohen et al., 2007). Sensitivity infers the social context in which research takes place as well as the consequences of the research on all parties (Cohen, et al., 2007). Sensitivity can be derived from content, for example, taboo or emotionally charged areas of study like deviance, sex, race, bereavement, violence, politics, human rights, drugs, poverty, illness, religion, sacred lifestyles, family finance, and physical appearance (Arditti, 2002; Chambers, 2003). Lee and Renzetti (1993) further draw attention to sensitivity that may come from intrusion into private spheres and deep personal experiences. Sensitivity is not limited to the experiences of those being studied but also to those involved in the study who may suffer stigma contagion, which means sharing the same stigma as those being studied. The area of HIV and AIDS "is commonly seen as highly sensitive, as it is still determined by issues of personal shame and guilt as well as social stigma and discrimination" (Kühner & Langer, 2010, p. 73). Any HIV research that investigates personal experiences, especially with populations like sex workers, and gay people who were stigmatised from the beginning of knowledge of HIV, are further at risk of being re-stigmatised (Langer, 2010).

Deacon and Stephney (2007, p. 52) write that "research on stigma is stigmatised", meaning that being involved in research on HIV stigma may further exacerbate stigma in the participants; therefore, being involved in such research, I had to be extremely alert and considerate. The choice of CBPR as methodology seeks to avoid the ethical issues which often arise in traditional research, by involving the participants in the entire research process (Minkler, 2004). I am thus aware that doing research is not only a matter of designing a project and collecting, analysing and reporting the data but that it is also a matter of interpersonal relations, potentially continual negotiation, delicate forging and sustaining of relationships, setbacks, modification, and compromise (Cohen et al., 2007). This is where one sees the importance of a CBPR methodology and why the study was designed along these lines to deal responsibly with such challenges.

I took necessary ethical issues into consideration, and, since this research project complied with the Nelson Mandela Metropolitan University ethical clearance policy, ethical clearance was granted (see Appendix A). I also applied for permission to carry out the study in the two schools in KwaZulu-Natal through the KwaZulu-Natal Department of Education. I was called to demonstrate how I was going to maintain confidentially since I was researching such a sensitive issue. Permission was granted (see Appendix B) on the premise of doing 'least harm' and 'most good'. I also obtained parents' consent, both verbally and written; I did home visits, explaining the study and asking them to sign consent forms (see Appendix C). Since schools exist within the community, as Donald et al. (2006) assert, I obtained permission from the principals to work in the school and to work with the learners (see Appendix D). I also obtained written assent from the participants, although they were 18 and under (see Appendix E).

While protocol was observed as far as seeking permission was concerned I also drew from the UNESCO Declaration to ensure that the conditions of informed consent, that is, the right to privacy and protection from harm, confidentiality, human dignity, and human rights were adhered to (Cohen et al., 2007). Even though this work is CBPR, Article 9 of the Universal Declaration on Bioethics and Human Rights (on privacy and confidentiality) states that personal information must be respected and used only for the purposes consented to (UNESCO, 2005). Therefore, privacy and confidentiality was maintained throughout the research. All recorded sessions were permitted by the participants who were informed about the use of the audio-tapes and video camera. These recordings were to accurately document what the participants said. The digital stories were recorded by the participants themselves.

I am aware of the ethical issues involved when doing research with children, especially regarding such a sensitive topic, and also the ethical dilemmas of using visual data as raised by a number of seasoned visual researchers (Karlsson, 2007; Mitchell, 2008; Pink, 2007; Clark et al., 2010; Weber, 2008). Because of the relative newness of visually oriented educational research there is limited agreement among ethics committees and even researchers on visual ethical guidelines (Clark et al., 2010). I was sensitive to Deacon and Stepheney's (2007, p. 66) warning that my work with the children "should not further stigmatise children infected or affected by HIV and AIDS nor should [it] unduly privilege one group over another where problems are shared". I also adhered to Schenk and Williamson's (2005) *Guidelines and Resources for Ethical Approaches to Gathering Information from Children and Adolescents*. In addition to what has been outlined above, support was put in place for participants through debriefing and counselling (Rager, 2005). In a nutshell, I kept with faith with Papademas' (2004, p. 122) notion of respect for the person, respect for their autonomy and the assurance that all the participants would be protected from being identified:

"beneficence and complementary requirement to do no harm and to maximize possible benefits and minimize possible harms; justice and the fair distribution of the benefits and burdens of research".

Researchers such as Moletsane et al. (2008) trouble the notion of doing 'least harm' but doing 'most good', to which I referred earlier. They argue that given the significance of the emerging agenda of participatory research in addressing the issues that affect the communities, the ethics of conducting such research is critical. But if the intention of the research is to make marginalised voices heard, then why should it be done anonymously? When the participants say that they want their voices to be identified, why should they not? While this is a contentious issue, and seeing that I worked with learners, using digital storytelling that contains visuals, I did not show faces and used pseudonyms which the participants themselves chose. It is possible, however, to recognize the voices of the participants in the digital storytelling, if you know who they are.

A number of justifications for having maintained ethical considerations throughout the research could be put forward but most importantly it was in line with what the Belmont Report suggests: research has to produce substantial social benefit while also maintaining the basic ethical principles of respect for persons, beneficence and justice (National Institutes of Health, 1979).

3.5.3.2 Getting help from senior learners from Thandaza secondary school

As mentioned earlier, when I piloted the digital storytelling, I realised that I needed assistance. In a previous MACAIDS Fellowship programme at Thandaza I worked with grade 11 learners. They worked with a digital archive and acquired technical training on computer programmes, and had already been exposed to skills related to digital storytelling. I decided to draw on the same group of learners, who were then in grade 12, to assist me. I invited them to co-facilitate the digital storytelling sessions. Four were willing — two boys and two girls.

3.5.3.3 Finding participants

Finding participants and securing consent to work with minors is challenging so I asked the principals to assist me with getting permission from parents. The first phase was negotiating with the principals, as the gate keepers, to be permitted access to the learners. I initially intended to identify grade 8 and 9 boys and girls who had computer skills or who displayed willingness to learn computer skills. This was not possible since both schools are rural and even in the school with a computer laboratory, students at these grades had never been taught computer skills or been allowed access to the computer laboratory. The principal suggested that I approach a group of peer educators in the school. This was an existing club of learners who were trained as peer educators in HIV and AIDS by the Department of Education. For the study, I needed a group of five from each school and because of the ethical issues involved I introduced my project independent of their existing roles as peer educators in the schools. I requested only five to participate voluntarily in this exercise. I also made telephone calls and personal contact with the parents. There were many learners who indicated their interest in participation but I had to choose five from each school for the purpose of this study. While the learners were excited about the project, I was aware of the fact that I was dealing with minors who might be vulnerable. The principal from Khuleka notified and requested permission from the parents for their children's participation (see Appendix F). In the end I found myself obliged to work with six participants from each school as I could not refuse the willing participants.

Having worked with young learners before, and being aware of challenges which cannot be assessed at face value, I wanted to get to know my participants better. I embarked on a house-to-house visit to explain the project and negotiate the children's participation with the parents. While this exercise was daunting, I was happy to meet the parents face-to-face and to learn more about where my participants came from. It allowed me to get insight into whether I was dealing with children who had parents or not, and whether they were in good health or not.

3.5.3.4 Getting to know the participants

While the process of getting to know my participants was going to be ongoing throughout the research process, I also designed a short document to elicit biographic information, including a question about whether they had prior 'training' in HIV and AIDS issues, and also a question about their level of computer skills (see Appendix

G). Since I was going to work with them over a three-day period, away from home, it was also necessary to know whether they had allergies, special dietary requirements and if they were on medication. After completing the biographic information document I talked to them individually.

Upon inviting the learners to the University for the fieldwork/workshop on digital storytelling, a parent who had initially given permission for her child to participate called me to say she was no longer comfortable with the arrangement. I was quick to explain that she was free to withdraw her child at any time as I had indicated in the consent form. At the same time I was curious to know what could be the cause, but it was not easy for me to ask straight away. After I explained and clarified her rights, she felt free to tell me without my asking and referred me to a newspaper, *umAfrika*, dated 24 June 2011 (which I later checked). She explained that she had read a story about some research in Durban where tests were done on young girls from rural areas without their parents' consent. She mentioned that the tests included pap smears, and the complaint was that some young girls lost their virginity because of the instruments that were used. While this statement might not be medically accurate, it was important for me acknowledge and respect the concern. This point raised by the parent was very important because social science researchers are obliged to give participants full information about the research project, including research instruments to be used. I was aware that more attention needed to be paid to human rights, dignity and the deserved respect especially when doing research with children (Fargas-Malet et al., 2010). We had a long conversation during which I explained that I did not want to influence her decision but needed her to understand the difference between social and biomedical research, and that I was doing social science research. I acknowledge that this in itself could be problematic.

3.5.3.5 Psychological and social support for participants and researcher

Although I set out to do 'most good' and 'least harm' the possibility of trauma could not be excluded. The two Life Orientation teachers, one from each school, accompanied the learners to Durban, and were available at all times during the data generation process, and served as a support resource to both the learners and to me as the researcher. Although there was a teacher from each of the schools whom the students could relate to I saw the necessity of having debriefing sessions. So I engaged the participants in daily reflections in the form of writing and in the evenings we had face-to face discussions and reflected not only on the research process but also on anything else that might have arisen. During the debriefing sessions learners wrote reflective pieces on what they had done during the session, how they felt about the session, and what could have been done differently. Rager (2005) argues that it is very important to set aside debriefing time immediately after the data generation for the researchers to go through the notes or recording themselves, and to try to recreate the session while it is still fresh in their minds.

We also had an in-house counsellor from the university for all the sessions that took place at the university. For the sessions which took place in the schools, a representative from the Department of Social Welfare and Development was available to provide support. The fact that we were together as a group and spent quality time in the evenings like a family was therapeutic as well.

I have a background in Psychology of Education which equipped me with basic guidance and counselling skills, but there were some days when I, as a researcher, also needed debriefing. I applied Rager’s (2005) self-care suggestions, wrote in my journal and noted how I felt. Rager’s advice for researchers dealing with sensitive topics include keeping a journal, debriefing, counselling, and also taking necessary breaks from the research field. As a researcher, who is also the research tool, I am aware of my own position with regard to HIV and AIDS which contributes to my sensitivity towards the participants and the disease. Considering that I also went through these experiences I found it important to constantly do the debriefing exercise which helped me to refocus and to alleviate anxiety and other emotions which may have been triggered during the data generation process.

3.6 PART THREE: IN THE FIELD

In this section I give a detailed description of what happened in the field. I describe each step and how the use of computers in the digital storytelling by participants who had never used them before worked out. Even though I had fears about using such technology with rural learners, I persevered and drew on Muchie and Baskaran (2006) who assert that it is imperative that innovative technology is taken advantage of as a tool to be used for the benefit of all.

The critical issue in this study was exploring stigma experiences with the learners. This includes awareness and “understanding of the role played by both macro-social and local” (community environments), “and of the way in which AIDS” and AIDS-related “stigma undermines effective HIV-prevention and AIDS-care, significantly weakening the social support needed for an effective response to the epidemic” (Campbell et al., 2007, p. 414). Also, the other issue was enabling learners’ voices to be heard in their taking action in addressing stigma. Therefore, the digital stories had the potential to generate discussions which could help to clarify the complexities of stigma experienced in the community. The community as context cannot be separated from the context of addressing the issue of stigma as a key aspect of working towards preventing HIV transmission. It was vital to not ignore the fact that working with community members helps in identifying key individual and group strengths available as community resources to tackle HIV- and AIDS-related stigma more effectively.

3.6.1 Introducing ourselves

I began each session with an ice-breaker and in between the sessions I used an energiser exercise to keep the participants interested since we worked together for long hours. The first ice-breaker consisted of an introductory exercise in which they introduced themselves briefly. The participants had to pick a blank card and then think of any animal they liked, along with reasons for their choice. This was followed by the prompt: “Draw an animal that you would like to be and explain why you like it.” The participants showed their drawings and explained their choices one by one. The participants opted to use the animal ‘names’ as their pseudonyms throughout the research process. They chose insects, rodents, reptiles, butterflies, birds, domestic animals and vertebrates as ‘animals’.

Use of symbols - in this case animal - is a central tenet of symbolic interaction which supposes that symbols represent shared meanings in a community. In many African cultures, the use of animals in telling traditional stories and folk tales has been a way of passing on values and is part of a natural storytelling process. Van Laren (2007) and Loubser and Müller (2011) write about the use of metaphor and symbolism in creating an openness in discussion around HIV and AIDS issues. Once each participant had introduced him or herself and had introduced his or her chosen animal — we recorded this session — we were ready to begin the exploration of stigma.

3.6.2 Towards understanding stigma

This study explored learners' HIV- and AIDS-related stigma experiences — their own or those of others they had heard of or witnessed — a phenomenon that is very complex. I found it important to have a session for the participants to understand this before they needed to gather their memories of their own HIV- and AIDS-related experiences of stigma or understandings of the experiences, real or imagined, of others. Producing a story script is not possible without a proper understanding of the phenomenon which forms the main theme of the story. A relaxed atmosphere which allowed for thinking and discussion was needed, so producing digital stories was not simply about recording the stories and working with computers to edit and publish the final product: it was a process that involved a number of sessions.

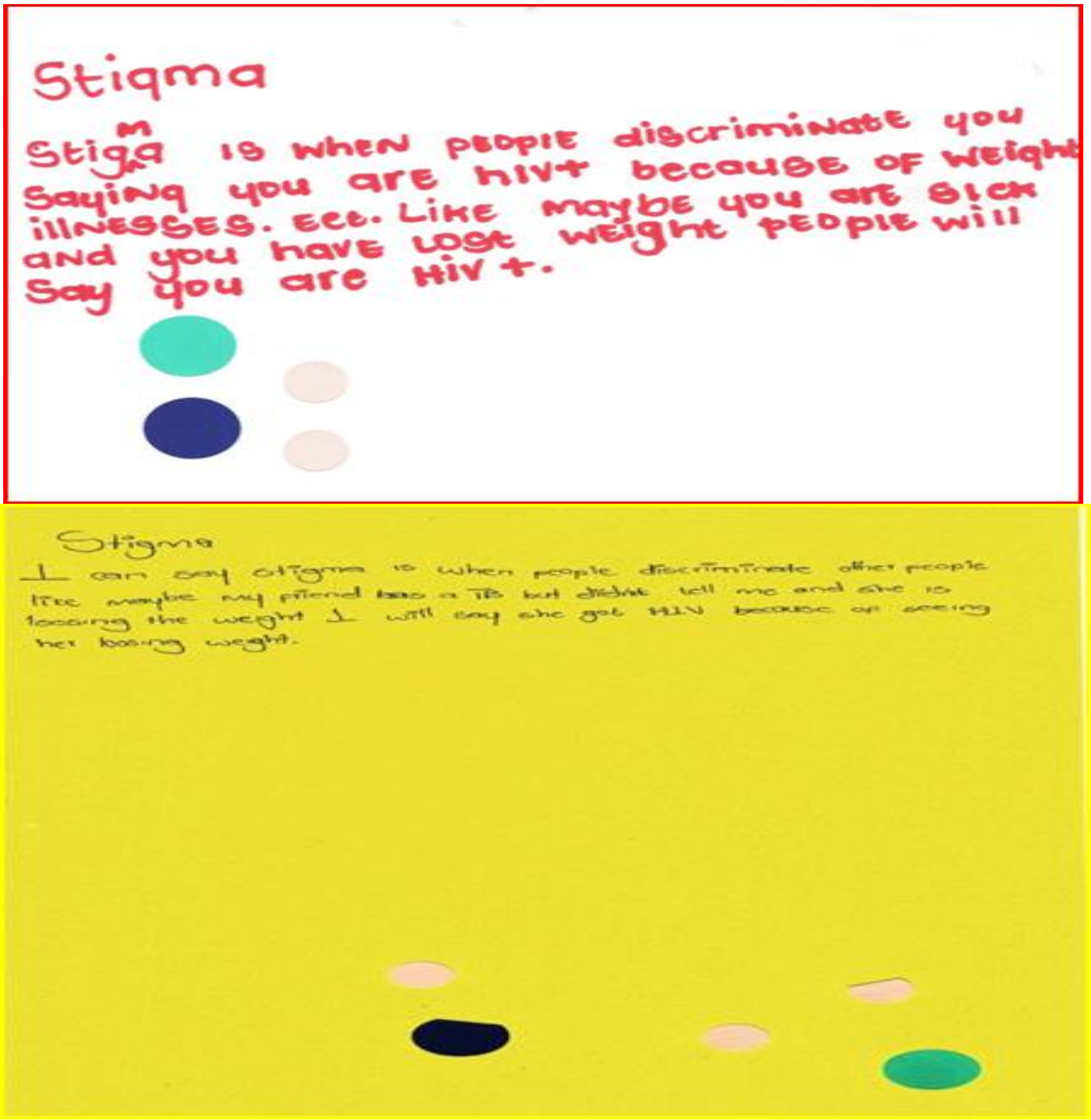
3.6.2.1 Brainstorming

The initial prompt for brainstorming focused on the participants' understanding of stigma. I simply asked, "What does the term 'stigma' mean to you?" I facilitated the brainstorming and the discussion. The twelve learners, as a group, brainstormed words that reflected their understanding of stigma. They thought, discussed and tried to collaboratively suggest a definition of stigma. This was done through giving examples of definitions which they looked up in the dictionary. The participants also tried to understand stigma by looking for a word in isiZulu and also by trying to find out what people do or say that is stigmatising.

Participants were then asked to write the most common stigmatising statements they had experienced or had heard of on a piece of paper. To ensure that the exercise was fully participatory and everyone's ideas were acknowledged and objectively viewed, the written stigmatising statements were put into a paper bag.

3.6.2.2 Voting

I requested the assisting learners to draw the statements from the bag and display all twelve individually written stigmatising statements (constructed statements) on the wall so that they could be read by all the participants and then voted for. The twelve statements were different although some had similar ideas of stigmatising (see Figure 3). Each participant was given four adhesive dots. The prompt was: “Vote for the most common stigmatising statements by placing an adhesive dot next to the statement.” The purpose of the voting (by then counting the adhesive dots next to the statements) was to ascertain the most common stigmatising statements experienced or understood by the learners. The two statements which drew the most votes were:



Stiqma

Stigma is when people discriminate you saying you are hiv+ becouse of weight illnesses. ect. Like maybe you are sick and you have lost weight people will say you are Hiv+.

Stigma

I can say stigma is when people discriminate other people like maybe my friend has a TB but didn't tell me and she is loosing the weight I will say she got HIV because of seeing her loosing weight.

Figure 3.1: Stigmatising statements and votes obtained

3.6.2.3 Discussion

Participants reached consensus on the most common stigmatising statement. This was followed by a discussion which was video recorded and transcribed. The discussion was lead by a prompt: “Why do you think some statements got the highest votes and others got the lowest votes?” This was done to enable the learners to talk through their statement in depth, making examples of issues which exist in the community.

3.6.2.4 Presentation

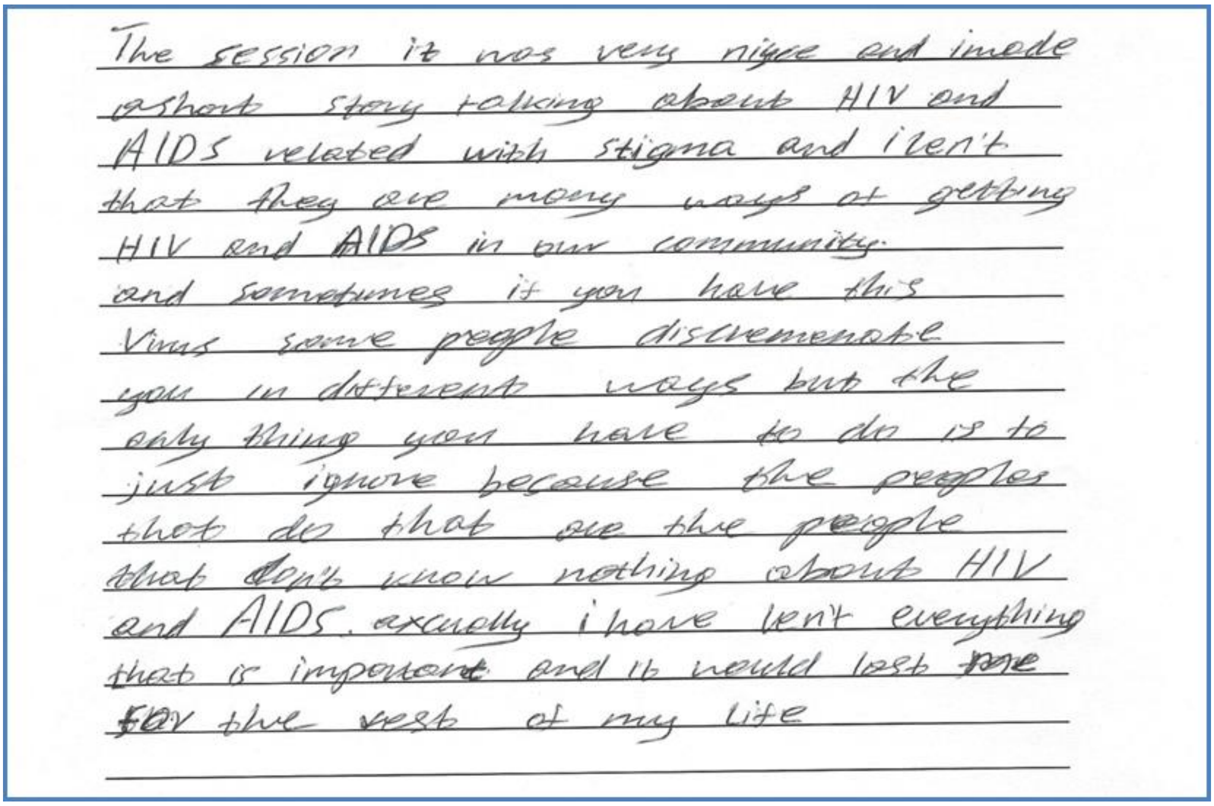
I then followed this activity with a presentation drawn from the literature on HIV- and AIDS-related stigma. This presentation was interactive in that the participants gave concrete examples drawing from their own context. I was careful not to impose my thoughts on the participants: I wanted them to draw from their experiences and understandings of stigma which they had written about in the statements.

3.6.2.5 Focus group discussion

In the FGD participants were asked to consider their knowledge and the presentation, so as to determine whether they and I had the same understanding of stigma and experiences of stigma. I posed probing and clarifying questions. This took about 20 minutes. The focus group discussion was recorded using a voice recorder and video recorder.

3.6.2.6 Written reflection

Participatory work has the potential of tapping into the participants’ views (Israel et al., 2005), and since not all people can freely share their views publicly, each participant was asked to write a reflective piece after the session. The prompt was: “Write a reflection piece about the session.” This open-ended prompt gave them an opportunity to write what they perhaps had not spoken about for me to read so that I could check that they were still comfortable with the activities. I offer an example of a written reflection that took about 15 minutes on a brainstorming session on stigma.



The session it was very nigce and imede
ashort story talking about HIV and
AIDS related with stigma and ilen't
that they are many ways of getting
HIV and AIDS in our community.
and sometimes if you have this
Virus some people discremenate
you in different ways but the
only thing you have to do is to
just ignore because the peoples
that do that are the people
that don't know nothing about HIV
and AIDS. excually i have len't everything
that is impotant and it would last me
for the rest of my life

Figure 3. 2: Written reflection on brainstorming on stigma

I also allowed for time to meet participants on a one-to-one basis every evening since the data generation took place over three days and the learners were under my care for all that time since they were staying at the university. Therefore such a debriefing exercise was seen to be important (see Chapter Four: 4.10). Also, although there was a lot to be done during the data generation, we made a point of taking necessary breaks (see Appendix H).

3.6.3 Digital storytelling production

The digital story production was spread over two days. We worked for seven hours each day, with a one and a half hour break. The participants had already been introduced to the whole process but I made a point of explaining the steps clearly for each and every session. Having given the background of what was needed and how to go about I highlighted the two important ‘must haves’ — the story they wanted to tell and ideas about the visuals they would need to illustrate their story. I will now discuss the briefing, the drafting of stories, the story circle, and recording the first-person voice-over narration.

3.6.3.1 Briefing

This session began with an overview on the production method: writing; telling; choosing who to share with; refining; voice recording; making the visuals; and assembling the digital story. I was aware of the fact that one way of introducing the processes could be to show the participants an example of a digital story (see Meadows, 2003; MacEntee & Mitchell, 2011). I had a copy of a digital story produced by Gender Justice, but because it showed people's faces, I decided not to show it despite the fact that this had been the project with its powerful messages that had inspired and prompted me to use digital storytelling. I settled for presenting the concept of digital storytelling by explaining the whole process followed by a demonstration by the Life Orientation teacher and me on 'modelling' practical aspects of creating digital stories and questioning each other on issues of clarity. The process was done step by step to allow the participants to grasp the important parts. The participants were also advised to use their mother tongue so that they could express their experiences comfortably. When we were modelling the process we chose a story on virginity testing since we were determined to be careful not to influence the learners, and we did it in IsiZulu.

3.6.3.2 Drafting of digital stories

After the discussion on the method of digital storytelling, the participants drafted their stories individually. A pen and a piece of paper were given to each participant to craft her or his story. They were given an hour to put together their stories. The activity was guided by the following prompt:

> "Write a script (narrative) of an experience of HIV- related-stigma. Give clarity on where the story takes place. When does / did it take place? Who are the characters? What is the 'experience'? How does it make you feel? What do you think? Did you tell anyone? Do you think HIV-related stigma can make HIV worse?"

I was very careful not to stifle their creativity. When the participants first planned their stories they used a story circle. This enabled twelve stories to be created.

3.6.3.3 Story circle

Once the story is crafted, the story is shared in a story circle, an activity that took 30 minutes. The focus of the story circle is on the development of a clear storyline before the actual recording is done. The story circle provides space and time for the participants to work in pairs sharing their stories and working on clarity issues. The idea is not to make them practice the story until they are perfect through rehearsing and mastering the story, but to get to a clear storyline. Therefore, participants were neither encouraged to repeat writing and make lots of corrections nor to edit the story many times so as to avoid contamination. Only the areas that needed clarity in the story were revised. In essence, this session was designed to allow for reflective thinking about the ways participants represent their experiences and make visible the social construction of knowledge (MacEntee & Mitchell, 2011).

3.6.3.4 Record the first-person voice-over narration

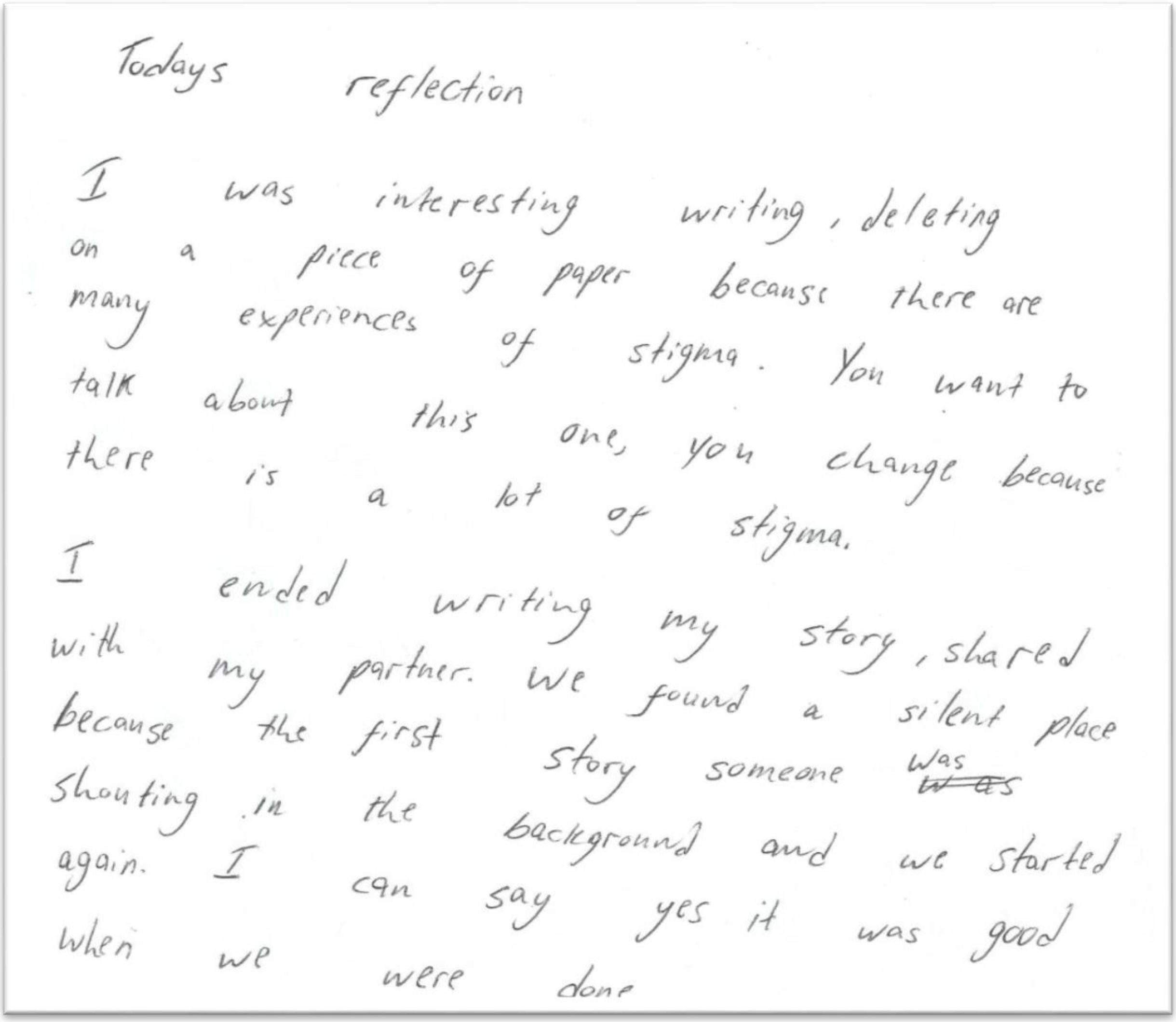
The story circle session was followed by a voice-over narration recording. I indicated that they had to record their story in a quiet place. One recorded while the other told/read the story and then they changed roles. I showed them how they could pause the recording and continue in the same file. This is similar to the No-Editing-Required method, coined by Mitchell and Mak to refer to the use of ‘on camera’ editing and developed in participatory video (De Lange, Olivier & Wood, 2008; Mitchell & De Lange, 2011). They had to have a file with a full story. Participants worked in pairs and used an audio/voice recorder to capture their stories. The recorded stories were then downloaded to the computer, using Windows Movie Maker software which allowed for editing. They were required to put all of the recorded audio files in a folder and name the folder using their animal names.

While the idea was to allow for the learners’ voices to be heard and to enable them to produce their own knowledge, drawing on their experiences, it was also important to use modern tools. In the last decade digital cameras, editing software, and other electronic media have encouraged the use of many more approaches and tools to help learners construct their own knowledge and ideas (Hartley & McWilliam, 2009).

While other types of digital storytelling are accompanied by visuals and / or music which go with the story (see MacEntee & Mitchell, 2011), in this case the idea of the visuals was to hide the identity of the participants by avoiding making their faces visible and taping only their voices. It is noted, however, that in this study some participants used photographs in such a way that they illustrated the story. For instance, when a participant was referring to family in the voice recording, a picture depicting a family could be seen. The participants made the decision to write the narratives as first-person accounts but in the voice of the animal they chose during the introduction exercise.

3.6.3.5 Written reflection

There was also a reflective exercise after the session on briefing on the method including voice recording of the stories about HIV- and AIDS- related stigma, and the following is one example from a participant.



Todays reflection

I was interesting writing, deleting
on a piece of paper because there are
many experiences of stigma. You want to
talk about this one, you change because
there is a lot of stigma.
I ended writing my story, shared
with my partner. We found a silent place
because the first story someone was ~~w as~~
shouting in the background and we started
again. I can say yes it was good
when we were done

Figure 3.3: Written reflection on producing a digital story

The next step was to generate the visuals.

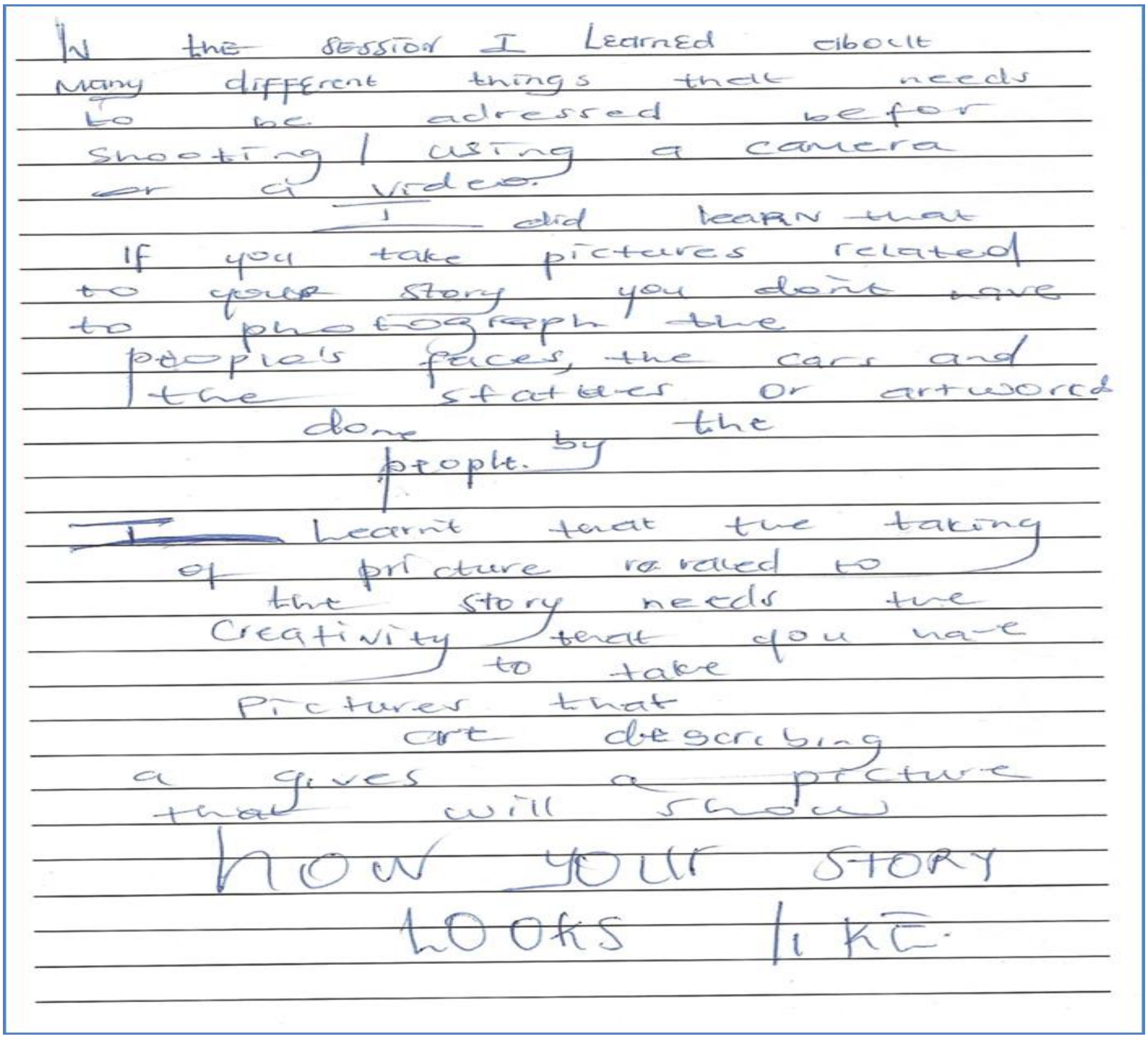
3.6.3.6 Photos and drawings to illustrate the story

Before the participants generated the visuals I gave them a briefing on visual ethics, making them aware of what not to photograph (Clark et al., 2010; Pink, 2007; Mitchell, 2008) since it could cause other people harm. The prompt that guided this activity was: “Create or find images to support your story. The images can be taken with your digital camera or cellphone, or you can make drawings which will be scanned with a scanner, or you can use pictures from a book or images found on the Internet.” Each pair shared a camera. Those with cameras were aware of how to take photographs as well as the ethics involved as suggested by Larkin et al., (2007). Some used secondary sources like photographs from books, and some used cartoons. The pictures were edited using a cropping tool in a programme called Picture Manager to remove unwanted bits. I did not refer to copyright issues in our workshops but focused only on the ethics involved in taking and using photographs. For example, following Mitchell (2011) I told the learners that they should not photograph people without their consent. Most participants used pictures from books they found in the library and pictures from the Internet that do not show the faces of people. I was uncertain if I should reference the sources. While I remained very concerned about not crossing the copyright line, I left the pictures un-labelled. I noticed that it is common for participants to create digital stories using images from archives. Shelly (2010) alludes to the fact that her participants used Google images to tell their own family stories. She argues that supporting learners’ understanding of visual media might be helpful as they use this content to author their stories. It was also interesting that Shelly’s learners used existing videos to present their stories on personal identity as opposed to personal images.

Some participants opted for making drawings, and were given paper, pencils, and colouring materials. It was interesting to note that they used their creativity and added captions to their drawings emphasising HIV- and AIDS-related stigma although they were not instructed to do so. The drawings they made illustrated their stories. This took about 2 hours. The making and viewing of the photographs and drawings created a lot of excitement.

The following is one example of the reflective pieces after the session for the generation of visuals to illustrate the stories.

3.6.3.7 Written reflection



IN the session I Learned about
Many different things that needs
to be adressed befor
shooting / using a camera
or a video.
I did learn that
If you take pictures related
to your story you don't have
to photograph the
people's faces, the cars and
the statues or artworcd
done by the
people.
I Learnt that the taking
of picture related to
the story needs the
Creativity that you have
to take
Pictures that
are describing
a gives a picture
that will show
how your story
looks like.

Figure 3.4: Written reflection on generation of photos and drawings

3.6.3.8 Assembling digital stories

For this part of the study we used the storyboard of Movie Maker, a programme which is used to make movies, but in this case it was used for the digital story. Using the storyboard enabled the participants to make their digital story by matching their voice-over recordings to the images they had created, and adding titles. Storyboards are used to plot out the unfolding of a story in movies, commercials, TV shows and cartoons. Storyboarding involves planning out in terms of time: this is what happens, and in this order. In terms of interaction, this is how the voice-over and music work with the images. In other words, this involves plotting out the sequence of events that unfold in the story (Oliver, 2009).

The next step was combining the voices and the images to create the final digital stories. Combining the sound and the images together in a Movie Maker programme has its specific steps. There are a number of programmes that can be used, namely iMovie, Windows Movie Maker, Windows DVD Maker (see Meadows, 2003; MacEntee & Mitchell, 2011). However, for this project we used Windows Movie Maker because I found it to be user-friendly.

I want, now, to explain and also to show some of the important steps of the digital storytelling process as it was done by rural learners who were not all computer literate at the beginning of the work.

For the following sequence of activities I acknowledge Barrett (2007), *How to create simple digital stories* suggestions (see also Figures 3.5, 3.6 and 3.7):

- Open Windows Movie Maker and create a New Project in a new folder [File Menu then New Folder].

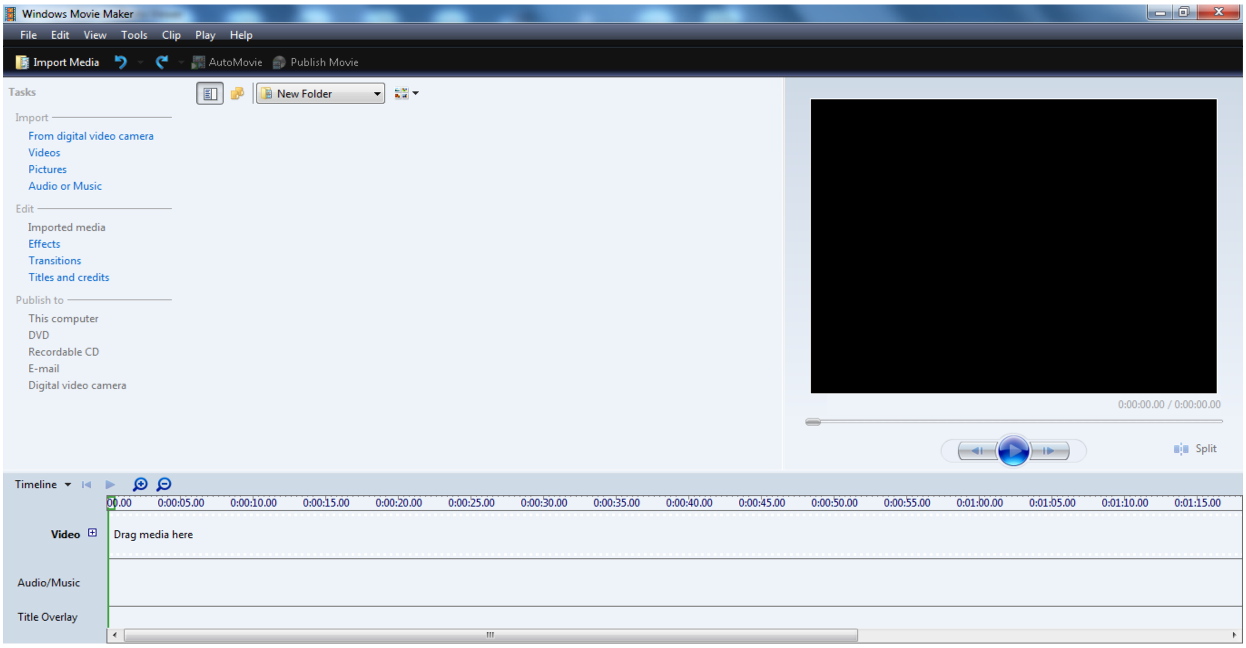
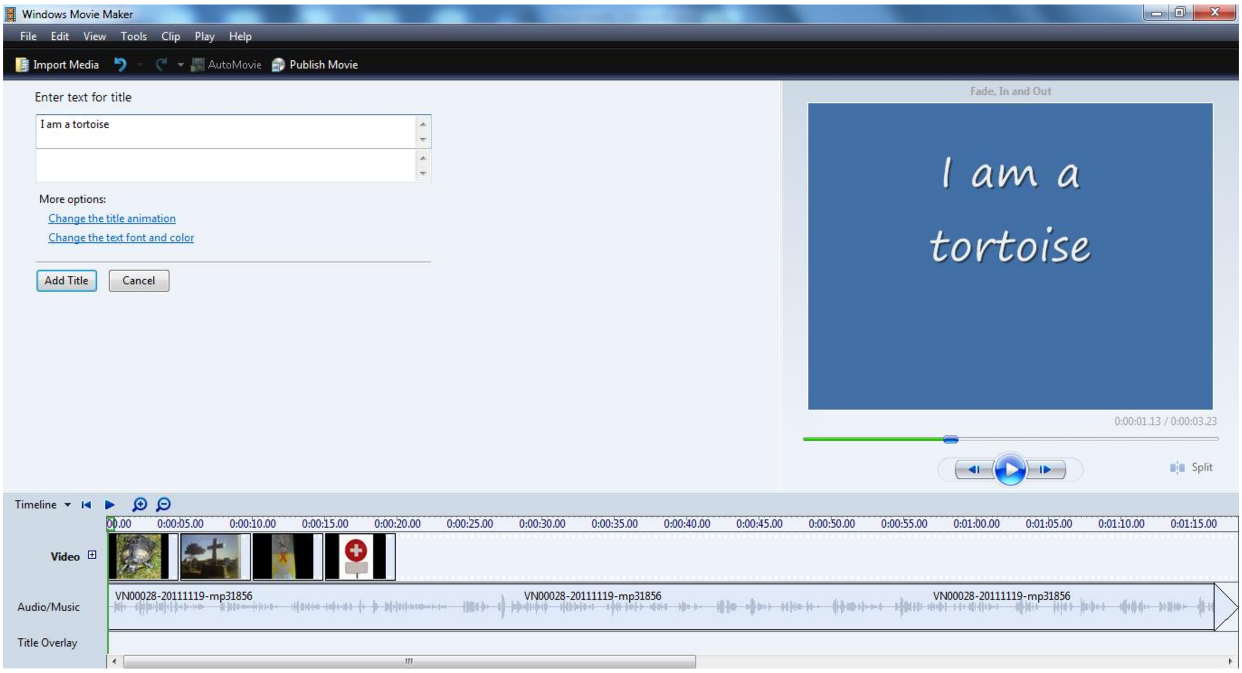


Figure 3.5: Windows Movie Maker programme on the computer

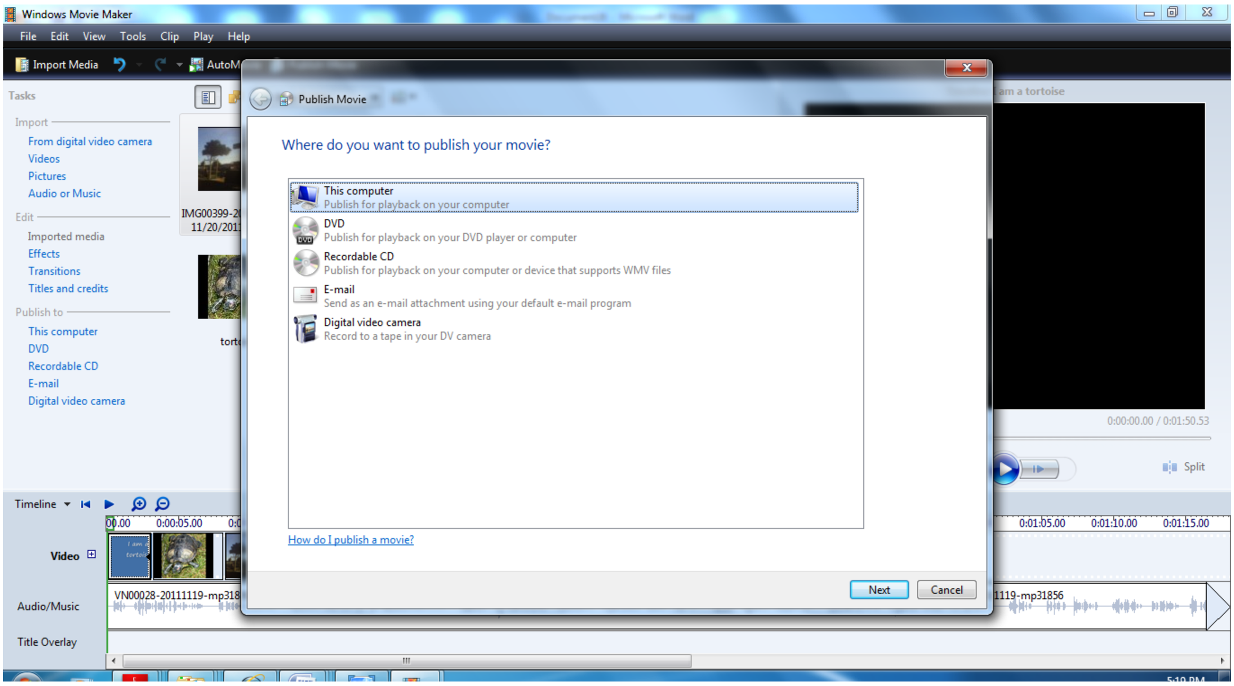
- Give the project folder a name (participants renamed their new folders using their animal names again) and save it on the Desktop.
- Select File Menu then Import into Collections (CTRL + I), that is, put all your clips into the File.
- Drag your audio clips onto the timeline so that you know where to place the images.
- Drag the images onto the video track in the appropriate order, adjusting the length of each image in Movie Maker.
- Create a Rough Edit. Place your narration, sound track, and images on the timeline in approximate locations using the same Movie Maker programme.
- Polish or Final Edit. Add titles and subtitles and test — ask for final feedback from your partner.


Enter text for title

I am a tortoise

Figure 3.6: Adding titles and subtitles and testing

- Export your movie to a playable format and publish to desk top.



Where do you want to publish your movie?

This computer
Publish for playback on your computer

DVD
Publish for playback on your DVD player or computer

Recordable CD
Publish for playback on your computer or device that supports WMV files

E-mail
Send as an e-mail attachment using your default e-mail program

Digital video camera
Record to a tape in your DV camera

How do I publish a movie?

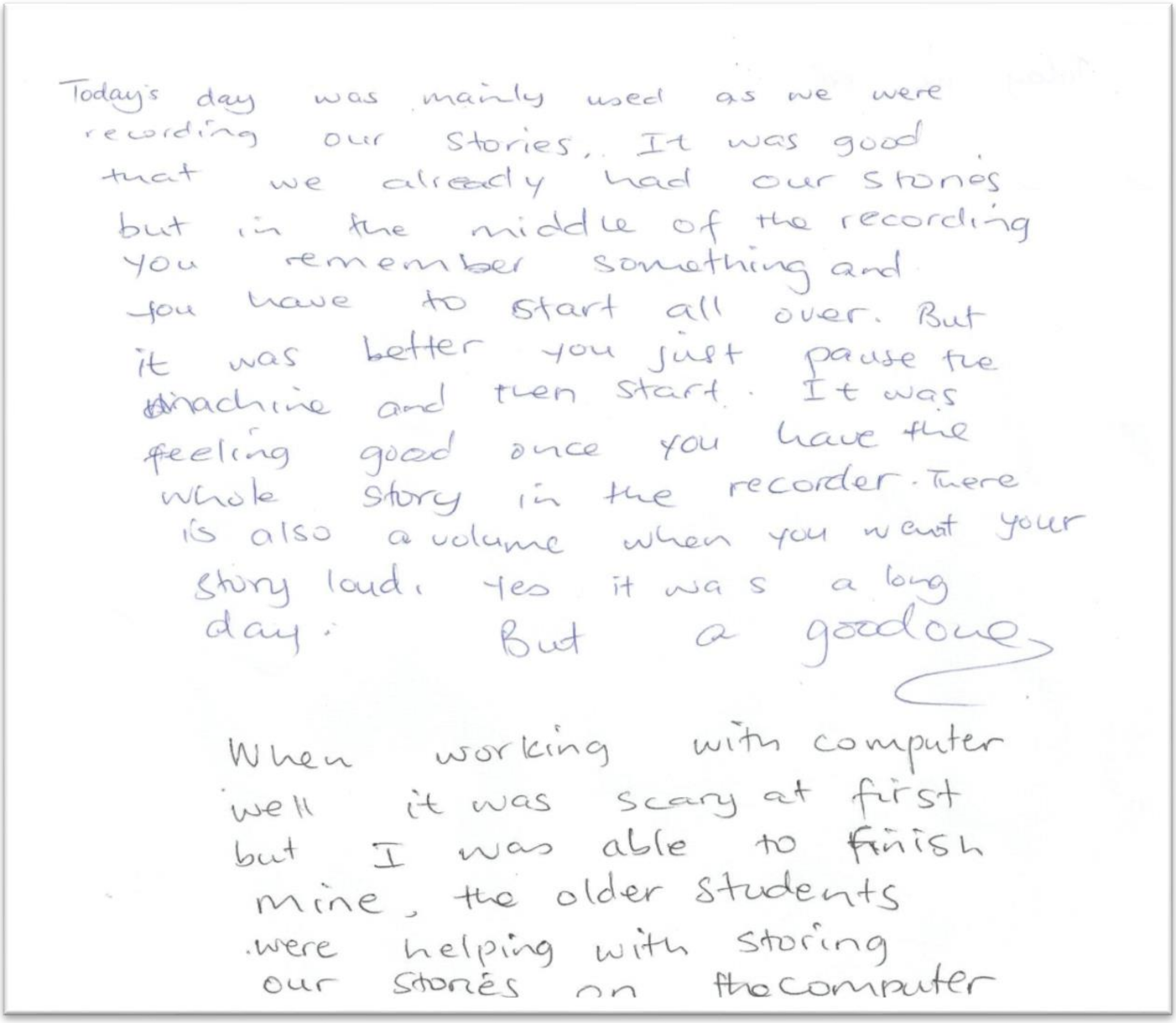
Figure 3.7: Saving the digital story by publishing to desktop

Each participant then added subtitles to his or her story and once they were satisfied with the production, the stories were published to the desktop.

This took 4 hours, and with the assistance of the grade 12 learners this part of the work was accomplished successfully.

3.6.3.9 Written reflection

The session ended with a 15 minute individually written reflective piece about the session on assembling digital stories. The prompt was: “Write a reflective piece about the session.”



Today's day was mainly used as we were
recording our stories. It was good
that we already had our stories
but in the middle of the recording
you remember something and
you have to start all over. But
it was better you just pause the
machine and then start. It was
feeling good once you have the
whole story in the recorder. There
is also a volume when you want your
story loud. Yes it was a long
day. But a goodone

When working with computer
well it was scary at first
but I was able to finish
mine, the older students
were helping with storing
our stories on thecomputer

Figure 3.8: Written reflection on assembling of digital stories

- Producing a DVD containing the stories

I saved the participants' stories on the desktop of each computer and I saved the stories on one flash drive. Later I combined all 12 stories of 2 to 3 minutes in length on one DVD (see inside envelope at the back of the thesis). I was careful to delete and empty the recycle bin in line with the ethical consent requirements.

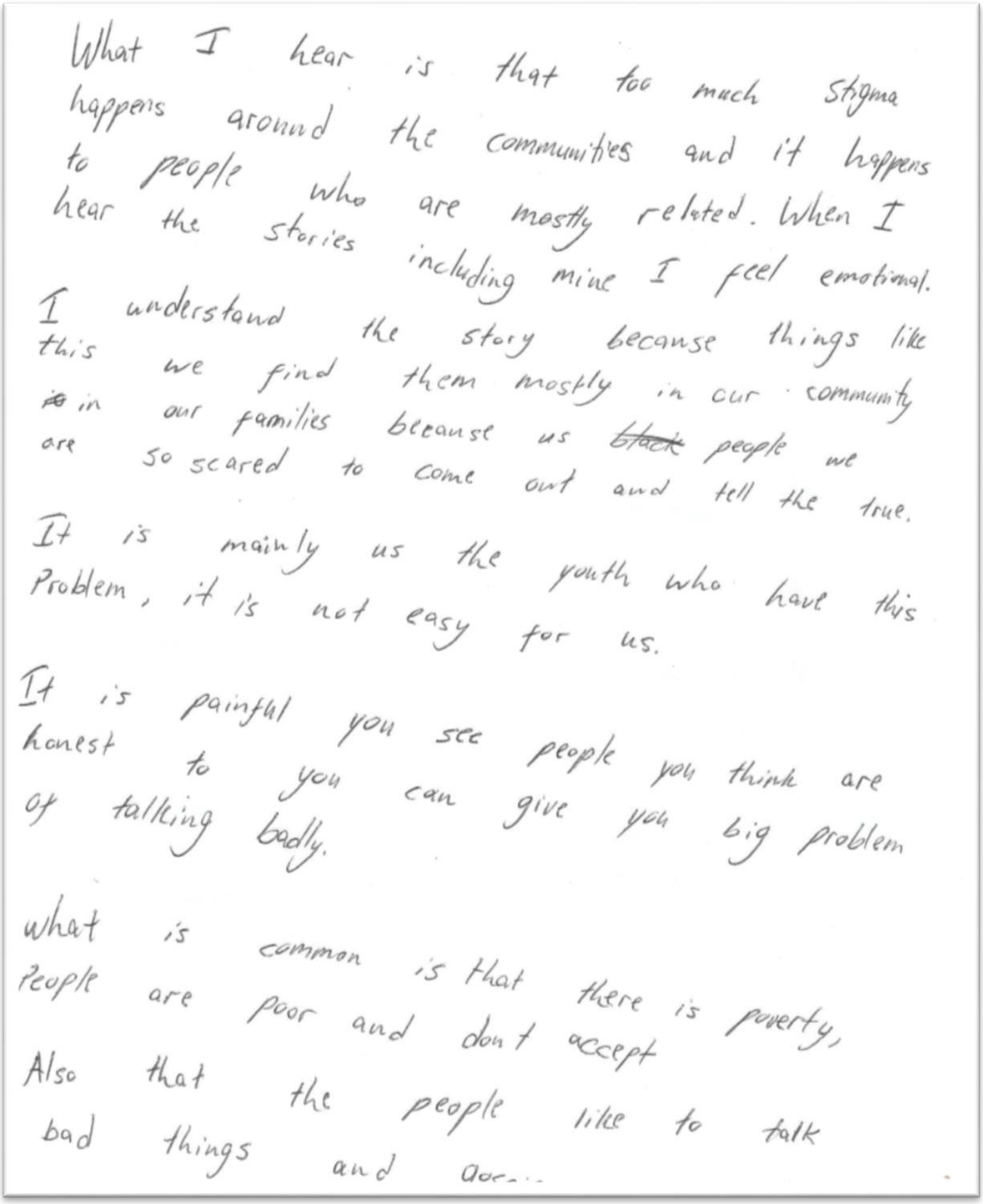
3.6.4 Viewing the digital stories and reflecting

3.6.4.1 Viewing the digital stories

The completed digital stories were viewed by the participants. This happened in Thandaza secondary school in their computer laboratory. Learners settled down while the four assistants helped with logging in to enable the watching of the digital stories. Each of the twelve participants was to watch all twelve digital stories on her or his own, using head phones to avoid disturbing each other. They were therefore able to rewind at will and re-view the stories. I observed that some of them viewed some stories more than once. This allowed for participation as audience, but also enabled them to reflect on their own story, each other's stories and the twelve stories as a collection. This session took about 45 minutes. In the case of digital storytelling, the audiences are not viewed as listeners only but also as learners who participate in shaping the story (Sadik, 2008; Psomos & Kordaki, 2012). In this way they make meaning of what they see in the digital stories. The participants individually wrote reflective pieces about the session but in this instance they were guided by some questions (see Mitchell, 2011). The following questions were used as prompts:

- What lingers in your mind about the digital stories?
- What do these stories mean to you, and what are the common themes?
- How can the stories be used to respond to HIV-related stigma?

The participants responded by either writing their responses on paper or typing them on the computer. The following is an example of a hand written response from one participant.



What I hear is that too much Stigma
happens around the communities and it happens
to people who are mostly related. When I
hear the stories including mine I feel emotional.
I understand the story becanse things like
this we find them mostly in our community
~~is~~ in our families becanse us ~~black~~ people we
are so scared to come out and tell the true.
It is mainly us the youth who have this
Problem, it is not easy for us.
It is painful you see people you think are
honest to you can give you big problem
of talking badly.

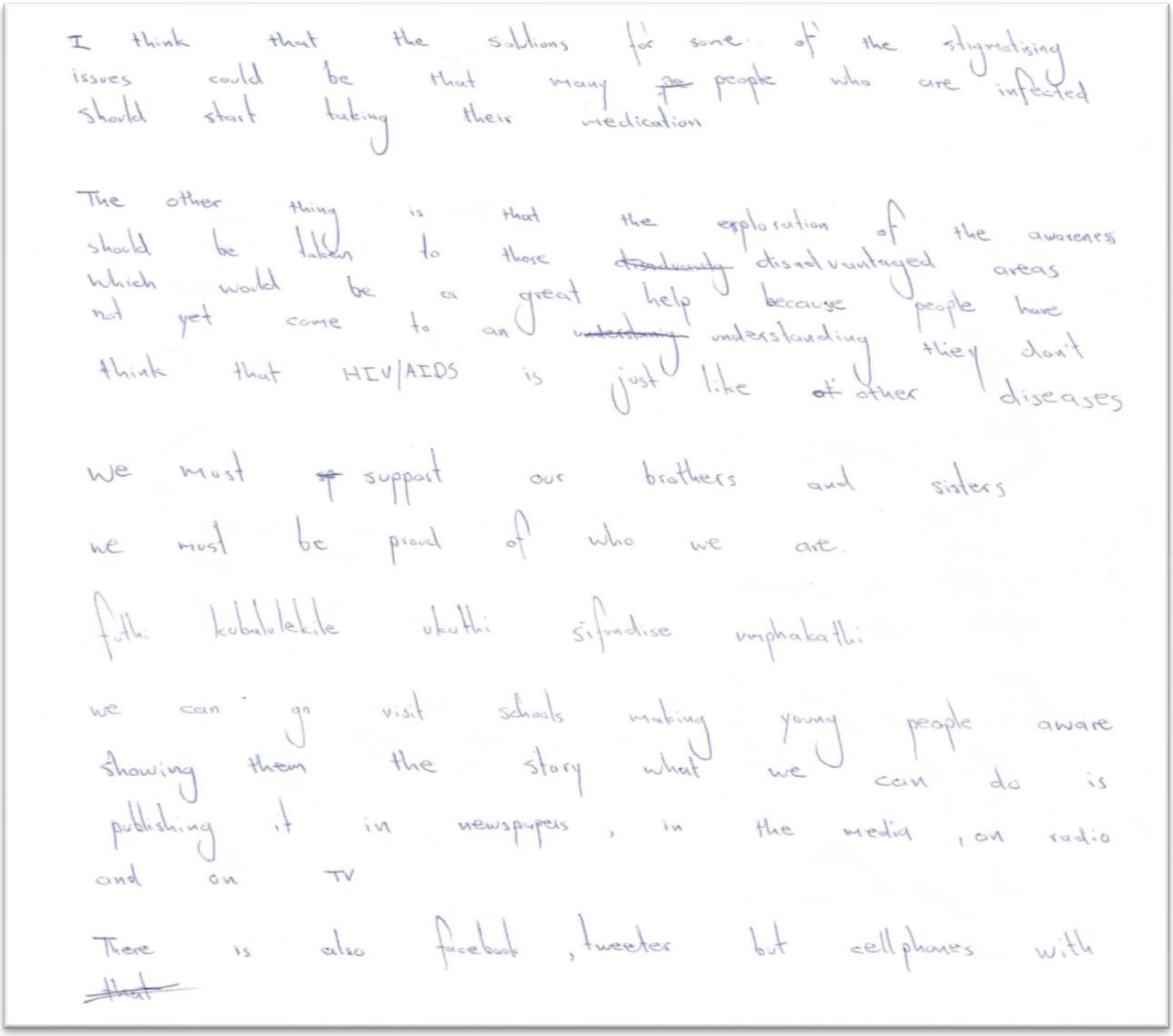
what is common is that there is poverty,
People are poor and don't accept
Also that the people like to talk
bad things and [illegible]

Figure 3.9: Written reflection after viewing the stories

Noticing that they did not really manage to address the third question, (How can the stories be used to respond to HIV-related stigma?) I did a further session focusing on how the digital stories could be used in the community to address HIV- and AIDS-related stigma.

3.6.4.2 *Using digital stories with the community*

The participants were asked to consider the digital stories and the issues identified and then to think of solutions for the issues highlighted. The learners used pen and paper to write their responses individually. After the individually written responses were done, a FGD followed and participants were given the same instruction: Consider the digital stories and the issues identified and then think of solutions for the highlighted issues in the digital stories. I aimed at getting a rich discussion which could then trigger other ideas. We recorded the FGD using a digital voice recorder and then transcribed it. The following is an example of the responses the learners offered.



I think that the sollions for some of the stigmatising
issues could be that many ~~pe~~ people who are infected
should start taking their medication

The other thing is that the exploration of the awareness
should be taken to those ~~dsadvanty~~ disadvantaged areas
which would be a great help because people have
not yet come to an ~~understaning~~ understanding they don't
think that HIV/AIDS is just like ~~of~~ other diseases

we must ~~t~~ support our brothers and sisters

we must be proud of who we are.

futhi kubalulekile ukuthi sifundise umphakathi

we can go visit schools making young people aware
showing them the story what we can do is
publishing it in newspapers, in the media, on radio
and on TV

There is also facebook, tweeter but cellphones with
~~that~~

Figure 3.10: Written reflection on use with community

The discussion on providing solutions was followed by a further FGD and the question that underpinned the discussion was: How can these digital stories be used in the community? The discussions were recorded using a digital voice recorder and then transcribed.

Several visual researchers (Mitchell, 2011; Clark et al., 2010; Flicker et al., 2007; Moletsane et al., 2007; Stuart, 2006) write on the importance of the process in visual and participatory research, and I am of the same view. Although the focus of the last day was on how the product could be used, the process was equally important for the participants. While the primary focus was on HIV- and AIDS- related stigma, the richness of the data produced in the suggested solutions for addressing HIV- and AIDS-related stigma by the learners is vital since it deals with issues that directly affect their community.

3.7 DATA ANALYSIS

As in most qualitative studies, the data generation tools are also the analytical tools because the data generation and data analysis, as stated by Nieuwenhuis (2007), are not treated as two separate processes but rather as cyclical and iterative non-linear processes. The participatory nature of the study allowed for participatory analysis. The process created a link from the participatory data generation and the participatory data analysis to participatory reflection and community action (Peace Corps, 2007). This study was analysed at different levels and stages and the analysis was layered. Some of the stories were done in IsiZulu and were translated together with the participants. The data from the three data generation tools — digital storytelling, focus group discussion and writing reflections — were analysed in a participatory way with the participants and the themes came from agreement on what counted as common themes in the data that was generated throughout the process.

Some digital stories, some feedback from participants (written reflections), and parts of the FGDs, had to be translated from isiZulu to English. I am an indigenous siSwati speaker and isiZulu has the same roots since both languages are Nguni although some concepts differ. Since English is also not my mother tongue, I made a point of not losing the meaning of the data by attempting to do the translation on my own. I did the first translation with the participants: I asked them to give the meaning in English which assisted me to get the idea and also to confirm that I got their ideas. I wanted to avoid losing data in the process of translation. I found it necessary to translate the stories which were written in IsiZulu into English. Those that were done in English were minimally edited to be readable, that is, make the digital stories easy to understand and intelligible since the learners are not English first language speakers, and neither am I.

The process of data generation also served as analysis in a way. The narratives of the digital stories and how the learners themselves made sense of stigma, served as the first level of analysis (Riessman, 2002). The participants then went further in analysing their stories and the stories of others by identifying themes, first individually on paper, and then also collectively during an FGD. This analysis was voice recorded and transcribed.

I later realized that some participants had mentioned why they had chosen the animal name while some did not. I then asked the participants to say why they chose the animals they did and what the animals symbolised. In this way I heard another layer of meaning which pointed out to me some of what might be missing.

Having had the participants' insight on HIV- and AIDS-related stigma through their data generation and their own analysis, I, as the researcher, did an overarching analysis, going through all the transcripts and finding themes in response to the research questions. Aronson (1994, p. 2) argues that themes can be identified through "bringing together components or fragments of ideas or experiences, which often are meaningless when viewed alone." Therefore, participatory analysis was used with the aim of limiting fragmented ideas, and making meaning of the participants' understanding of stigma. This is related to the notion of intertextuality which suggests that meaning in a text can be understood in relation to other texts; no work stands alone but is interlinked with the context in which it is produced (Allen, 2011; Fiske, 1986). Intertextuality involves a system of reading by moving between the texts in an attempt to extract meaning from text, reading and interpretation (Fiske, 1986). This involves the system of coding and interpreting text to discover its new meaning as an independent reader in order to trace the relations between the texts (Allen, 2011; Pugh, 2013; Warren, 2013). The act of reading the texts, even as a researcher reading data produced by participants, leads the reader into a network of textual relations. So, in this study, the data from the digital stories, focus group discussions, and written reflections were analysed with intertextuality in mind. This technique is of course not very different from Tesch's descriptive analysis technique which is used to identify units of meaning and to look for emerging themes as described by Creswell (1994), in answering the research questions.

Tesch's descriptive technique suggests that the researcher must carefully read through all the responses to form a sense of the whole and then write down ideas that come to mind about the transcribed data. I wrote down my thoughts in the margins and then identified units of meaning and categorised them in order to come up with the themes that emerged. Coding is a flexible process that allows for modification of the coding until a more appropriate code is exposed. Neuman (2006) defines coding as mechanical data reduction and analytical categorisation. Codes (Neuman, 2006, p. 460) are "tags or labels assigned to units of meaning in a study." Simply put, data pertaining to a similar theme is grouped together under a code. This was where I was able to identify emerging patterns and code the data, trying to understand what the data meant. Finally, I used existing and relevant literature to contextualise my findings (Marshall & Rossman, 2010).

In addition, an independent coding by a coder who was given the research protocol, research questions and clean transcripts, was done. The independent coder did her own analysis and we compared and discussed the themes which emerged and reached consensus. It is often argued that "qualitative research is more defensible when multiple coders are used and when high inter- and intra-coder reliability is obtained" (Nieuwenhuis, 2007, p. 114). As Nieuwenhuis (2007) puts it, inter-coder and intra-coder reliability refers to the consistency among different coders and within a single coder. Asking a coder to code some of your data is done to ensure trustworthiness in coding. By saying this I do not claim that the themes are not open to criticism. The study, in being qualitative by nature, allows for further analysis, and including the participants in this part of the research excludes opportunities of bias in the analysis by the researcher.

3.8 TRUSTWORTHINESS

Justifying the issue of trustworthiness depends on the paradigm used by the researcher. Qualitative researchers working in the critical paradigm, where the idea is to understand a phenomenon and to do research which could bring about change, do not necessarily generate data to prove facts. This is because the objective is for the participants to learn about themselves and issues in their context, and for emancipation and empowerment of participants to occur. I adhered to Guba’s model of quality assurance techniques in order to ensure trustworthiness (Lincoln & Guba, 1985). The principles of credibility, transferability, dependability and confirmability are maintained in this study (Lincoln & Guba, 1985).

Credibility is concerned with how a researcher can convince the audience that the findings represent descriptions or interpretations of the views of the participants such that people who share the same experience can recognise the descriptions. Using different methods of data generation facilitates crystallisation, ensuring that multiple facets and aspects of a complex phenomenon like HIV- and AIDS-related stigma is revealed, thereby increasing trustworthiness of the study (Maree & Van der Westhuizen, 2007). All the proceedings were digitally recorded and transcribed verbatim, notes were taken during focus group discussions with all this aiming at capturing accurately what transpired.

Transferability is the degree to which findings can be applied to other contexts and settings (Poggenpoel, 1998). The findings in qualitative research are specific to a small number of participants and to a specific context. Therefore, demonstrating wide applicability is difficult. For example, it can be assumed that the findings from this study could be transferable to another rural school setting, although generalisation is often not possible. Shenton (2004) argues that the researcher knows only the phenomenon studied and in the context in which the study is located. The researcher has no obligation to prove generalisability. Poggenpoel (1998, p. 349), however, refers to applicability, that is, “the degree to which findings can be applied to other contexts and settings within groups.” A thick description, which I provided, enables other researchers to replicate the research, and to take responsibility for transferability in their own contexts.

Confirmability or neutrality ensures freedom from bias from the procedures and results (Poggenpoel, 1998, p. 350). It occurs when people other than the researcher endorse and corroborate the findings as the product of the inquiry and not of the biases of the researcher. Vockell and Asher (1995) suggest that in qualitative research the value of the findings increases when the distance between the researcher and the participants decreases. In this research, a community-based participatory research approach was adopted and the researcher and participants worked collaboratively on the issues of HIV- and AIDS-related stigma using digital storytelling. This method is commended for minimising the distance between the researcher and participants. However, issues of bias cannot be avoided since this is research about people's experiences and it is also conducted by a person. I honestly wrote about how I positioned myself as researcher, acknowledging my own biases.

Dependability refers to whether the findings of the research would be consistent if the study was repeated with similar participants in a similar context (Bisschoff & Koebe, 2005). This construct is closely related to credibility. It requires the researcher to have a thick description of the research process. For this study, examples of stigma might be the same. However, the way participants present them might be different. The issue of dependability, which is consistency, was addressed by ensuring that the participants agreed with the themes generated. Member checking is key in participatory research, and the nature of the data generation enabled a constant checking of whether or not I understood correctly and represented the ideas correctly. The idea was to "learn from participants [rather] than to control them" (Bisschoff & Koebe, 2005, p. 5).

Besides Guba and Lincoln's constructs around trustworthiness in qualitative research, Merriam as cited in Maree and van der Westhuizen (2007, p. 38) puts forward the notion of internal validity. She classifies six strategies to ensure internal validity which are crystallization; member checks; long observation; peer examination; collaboration research; and clearing researcher bias. Some of these constructs are similar to those of but one that is of key importance is that of crystallization which ensures that a multifaceted and rich understanding of the phenomenon is arrived at. The participants were, for example, invited to engage in the data analysis, offering their own perspectives. The researcher and researched worked together to analyse their efforts to make meaning of the experiences of HIV- and AIDS-related stigma and to add to the body of existing knowledge. Their voices in the digital stories and discussions add to the authenticity of the data.

3.9 SYNTHESIS

In this chapter I drew on the theoretical underpinnings that informed the decisions for the design and methodological choices I made. I indicated how I did this, and then ensured that the methodology and methods were appropriate to the chosen critical paradigm. I indicated the possibility of digital storytelling bridging the gap found in most traditional HIV- and AIDS-stigma research caused by the absence of voices of young people. The next chapter presents the findings thematically.

CHAPTER FOUR

FINDINGS AND DISCUSSION

RURAL SECONDARY SCHOOL LEARNERS' EXPERIENCES OF HIV- AND AIDS-RELATED STIGMA

The stories are the real things that are happening in the community… (Giraffe)

4.1 INTRODUCTION

In this chapter I present findings for the first of my research questions: "What can digital storytelling reveal about secondary school learners' experiences of HIV-and AIDS-related stigma in schools in a rural community?" The chapter is divided into two sections: section one contains the textual transcriptions of the digital stories, including the pictures the participants used in their digital stories (see the CD of digital stories in the envelope at the back of my thesis). Section two offers the themes from the data sets, i.e. the digital stories, (and the process of creating them), the focus group discussions, and the reflections of the participants.

Digital storytelling, as used in this study, provides a way of exploring and understanding HIV- and AIDS-related stigma in that it enables the participants' understanding through what Barrett (2006) sees to be reflection and discussion, and participatory processes which are developmental. Furthermore, digital storytelling enhances learners' motivation to participate because they are engaged from the beginning of the study, and throughout the process, and are proud of their participation and of the digital story as product. The digital storytelling process increases learners' awareness of, and engagement with, the issues of HIV-related stigma. The process of digital storytelling has added advantages to that of traditional storytelling. The use of digital storytelling, especially with learners from rural contexts where there are challenges relating to both HIV and AIDS as well as to access to technology, can be seen as killing two birds with one stone. First, digital storytelling builds technological skills (Lambert, 2006) and therefore benefits the participants in both helping them to understand HIV- and AIDS- related stigma, and acquiring technological skills. Freidus and Hlubinka (2002.) point out that it promotes reflective practice, and connections with communities of learners (Duveskog et al., 2009). Put simply, participants learn to tell a story (possibly but not necessarily projecting their own story) and become more effective actors in collaborative work environments such as the school and community. Freidus and Hlubinka (2002) highlight the importance of written reflections in digital storytelling and point to the use of voice, the emotions involved, the content, the tension, and the story circle which allows storytellers to see fresh perspectives on the work being done.

Storytelling in the waiting room is a project which started in 2004, in South Africa, in the Limpopo Province. It uses traditional storytelling to educate the public who visit the local clinic about HIV and AIDS, showing how stories can be beneficial (Bernard, Vintges & Wijbenga, 2006). Traditional storytelling is not the same as digital storytelling (see Chapter One, 1.7.1) but has similar characteristics (Lambert, 2006). Using digital storytelling allows for real contextual issues to be raised. Zeelen, Wijbenga, Vintges, de Jong (2010) argue that while programmes about HIV and AIDS education and prevention draw mostly on western ideas, a few do fit the sub-Saharan African context. Digital storytelling could be seen as a beneficial approach: it is rooted in local customs which gives freedom of choice to a community in shaping their own interventions (Zeelen et al., 2010).

The following digital stories were constructed in English or in isiZulu and translated into English. The stories, created by the participants, are powerful in that the “listener constructs the story based on a verbal text, overlaid with personal images and memories” (Zeelen et al., 2010, p. 384). This, too, speaks to the intertextual nature of visual participatory research and the power it has to effect change in the listener, and, in this thesis, the reader. These digital stories are reflections of the participants’ real or imagined experiences, or those witnessed or heard about in their communities.

4.2 RURAL SECONDARY SCHOOL LEARNERS' DIGITAL STORIES ABOUT EXPERIENCES OF HIV AND AIDS-RELATED STIGMA

Figure 4.1: Tortoise's Story

I am a tortoise. I chose this animal because I wish I could just hide in the presence of people I know. I was born with HIV and I have recently started ARVs. It is hard for me to go to the clinic and get my ARVs because I always hear people - adults, even those with HIV - gossiping about me when I am in the clinic to get my treatment. They do not know that I was born with it [HIV]. They say "*izingane zishesha ziqale ucasi*" ["nowadays children have an early sex debut"] because they think I contracted it through sex. My friend's mother works in the same clinic and helps me with my needs such as the ARVs and the food that we get from the clinic. I always throw it [food] away in fear of bringing it to the school since I start at the clinic then to [go] school. The other students call me names and judge me because of my status. I fear carrying the food parcel because it is known that it is donated to the HIV-positive people. I need the food, this affects me at school. Even my school work has declined. My mother passed away two years ago and it has been hard for me as a teenager, growing with no one to talk to or no one who cares about me. I wish people can come to a better understanding about HIV and stop stigmatising so that I can feel accepted, especially [because I am orphaned] orphans. I chose a tortoise because I am trying to live with a purpose, but when someone offends me I crawl back into my dark, cold and lonely shell. After that I have to come out again and rebuild my character by trying to be optimistic …

Figure 4.2: Bird's story

I'm a bird. I live with my mother, my sisters and one brother and with my stepfather. My elder sister has been sick for quite some time now, and I ask myself, is it flu? Is it TB? Oh, I did not know at that time. Only to found out that she was HIV positive and she found out that when she went to take an HIV test at the clinic. She does not go out anymore and hardly even goes to school. One day when I walked in my parents' bedroom, oh, there she was in bed with my stepfather. I was surprised. She finally told me that he infected her. Now she cannot even go to the shop because everyone knows her status and they will start to call her names. Some say "She is Hlengiwe Ivy Vilakazi that's HIV". Some say that "She is Omo, the 'three words [letters], you know what it means". Some say that she is thin like she eats vinegar, and some do not want to sit next to her in the taxi. My mother was told [that my sister was sexually abused by my stepfather], but she did not want my father to be arrested because she will be poor, starved and people will laugh at her. I also don't feel comfortable at school because many learners think that I am sick just like my sister. But why? They even say that we even eat HIV from the pot at home. And we all, like all have it. I'm confused. I don't know what to do.

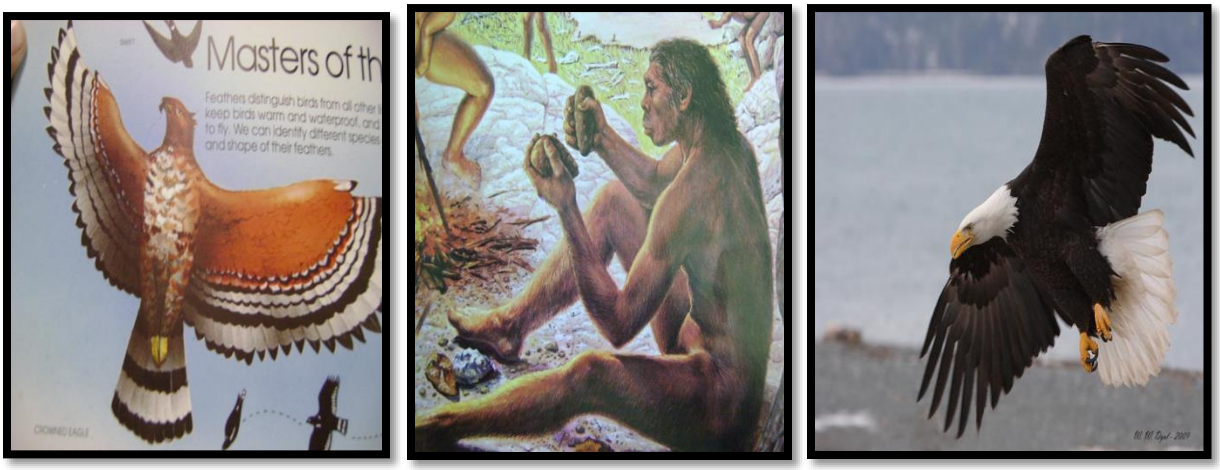


Figure 4.3: Snail's story

Mina ngingumnenke. Ekhaya ngihlala nomama wami. Nginabangani ababili abajwayele ukungivakashela njalo ekhaya. Akuvamisile ukuthi kuphele usuku singabonananga uma kwenzeke njalo bajwayele ukungifonela babuze ukuthi ngisaphila yini. Nasesikoleni sihamba sonke, uma kukhona onenkinga siyakwazi ukuthi sisizane. Ngelinye ilanga umama wami wangithuma edolobheni ukuba ngiyothenga impahla yasendlini. Endleleni yami ebuyayo ngazithola ngisengozini yetekisi ngenxa yokuthi umshayeli wayedle amanzi amponjwana sathathwa sayiswa esibhedlela ngenxa yokuthi sasilimele kakhulu. Emva kwezinyanga ezimbili ngahamba ngayohlolela igciwane lengculazi. Ngathola ukuthi ngiHIV positive. Emva kwalokho ngagula kakhulu ngaze ngehla ngisho nasemzimbeni. Abangani bami bangibuza ukuthi kwenzenjani njengabantu ebekade sitshelana nabo izimfihlo, ngabatshela ukuthi nginegcewane legculazi. Kusukela ngalelo langa angizange ngibabone bengivakashela nasesikoleni abasafuni ukuhamba nami. Uma ngithi ngibavakashela emakubo bayaphuma bangishiye endlini ngicacelwe kamhlophe wukuthi abasafuni ukuhlala nami. Nomama uke angibuze ukuthi abasangivakasheli ngani abangani bami kuvele kwehle izinyembezi ngikhale. Okusobala ukuthi abangani bami abafundisekile ngaleligciwane lengculazi. Empilweni yami akekho umuntu engimthanda nengimkhonze njengomama ngoba nguye kuphela onginika uthando. Igciwane lengculazi alitholakali ocansini kuphela kepha litholakala ngezindlela eziningi. Kumele abantu bazinakekele bangafuni ukuba njengomnenke kodwa noma usulitholile zinakekele ngoba side isikhathi osazosiphila futhi kumele wazi ukuthi when days are dark friends are few.

[I am a snail. I live with my mother at home. I have two very good friends that always pay me a visit at home. A day never passes without us meeting. If a day did pass, my friends would make sure that they call me to find out how I have been. Even at school we used to hang out together. If there is anyone of us who is battling with anything, we will assist them. One day my mother sent me to town to buy some groceries. On my way back home I got involved in a car accident. It was caused by a taxi driver who was very drunk. Some of the passengers and me were taken to the hospital because we were badly injured. After two months I went to do an HIV test, and I found out that I was HIV positive. After I knew about my status I got sick and I lost weight. My friends were worried about me and they asked me what was going on with me since we never keep any secrets among ourselves. I told my friends about my HIV status. After that they never paid me a visit at home and they stopped hanging out with me at school. I did try to visit them in their homes, and when I'm around they will leave me alone in their house. This indicated that they wanted nothing to do with me since I'm now HIV positive. One day my mother asked why my friends were not visiting me anymore and I had no answer, I just cried. It is clear that my friends are not aware of how HIV is spread. There is no one that I admire and love in my life besides my mother. She is the only person who cares about me. HIV and AIDS is not spread by having unprotected sex only, but one can get it in so many different ways. It is therefore our duty as human beings to take good care of ourselves and not act like a snail, because once you are infected you can still live for many years. One should be aware that when days are dark, friends are few.]

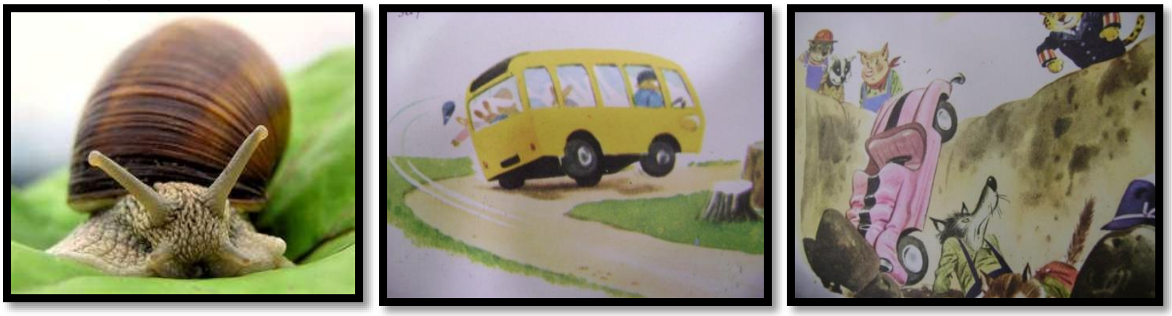


Figure 4. 4: Giraffe's story

Ngiyindlulamithi. Ekhaya lami sibahlanu abazali bona abasekho emhlabeli. Futhi abazali bethu basishiya sisebencane. Kanti lokhu kwangibangela ukuthi mina ngishiye isikole ngisemncane. Njengoba ekhaya kwakuyimi omdala ezinganeni zasekhaya. Kwabanga ukuthi mina ngiphume ngiyosebenzela izingane zasekhaya. Kwathi uma sengithole umsebenzi impilo yashintsha impela. Kodwa emphakathini wakhona lapho sihlala khona kwakukhona ukungaphathani kahle phakathi kwethu nomphakathi. Into ababehlala beyisho ukuthi phela ekhaya thina siyahlupheka futhi sizitshela ukuthi thina sihlakaniphile. Babefuna ukuthi sikwenze, ukuthi sihambe siyocela kwabanye abantu emzini yabantu. Okwangiphatha kabi ukuthi ngesikhathi sisahlupheka abazange bafune ukufaka uxhaso emndenini wami. Kodwa kwathi uma sengithole umsebenzi ongcono kwakuyimanxa sebeqala ukukhuluma. Into engayiqhaphela ukuthi uma umuntu esenezinkinga abantu baphatheka kahle, kodwa kuyothi uma usuthola usizo noma indlela engcono yokuziphilisa bayaqala bakhulume amagama angamahle futhi amagama angahlali kahle enhliziweni. Lokhu kwangiphatha kabi impela, ungathi umphakathi ubonile ukuthi ukhule kanzima kanjani kodwa futhi kube iwona amalunga angakini omphakathi akuphatha kabi ekubeni ukhule uhlupheka impilo inzima. Kodwa ngiyabonga umdali ungiphile amandla negqondo yokuthi ngiphilise izingane zasekhaya, futhi ngibonge umdali ukukhulisa izingane zakithi nazo seziyakwazi ukuziphilisa. Bafowethu asifundeni isikhathi sisekhona nani bodadewethu asifundeni isikhathi sisekhona impilo inzima.

[I am a giraffe. In my family, we are five in total, my parents passed away [through HIV]. Our parents died when we were still young. This made me drop out of school when I was still young. I was the eldest at home, and I was forced to go and look for a job to help my siblings. By the time I got a job our lifestyle became better that before. However, in my community some of the members were not pleased with the changes in my family. Their argument was that we think that we are much better than other people and we are a poor family but we present ourselves as an intelligent family. I guess they wanted us to be beggars. What pains me is that when we were suffering, nobody offered support to me and my siblings. They started gossiping about us when I started doing a better job. I have noticed that if one has problems, people tend to be happy with that, but if a person begins to improve his or her situation, people start talking about that person in a bad way, they say hurtful things. This kind of an attitude really upset me. I ask myself how the members of my community can say all the bad things about us when they know our situation. I thank God for giving me the wisdom and power to look after my siblings, and I thank God for letting my sibling grow up and now they can take good care of themselves. My fellow brother, let us empower ourselves with education while there is still time, and my fellow sisters, let us empower ourselves with education while we still have time. Life is hard.]

Figure 4.5: Mosquito’s story

Ngingumaskito, ngikhule ngihlala kwa Anti. Ekuhlaleni kwamii kwa-Anti ngangazi ukuthi kusekhaya lami uqobo. Kanti akusikhona ekhaya kukwa-Anti. U-Anti wabe engithanda kanye nobaba wekhaya kanjalo wabe engithanda. Mangabe bengikhula ngikhule nomfana wakhe uqobo olingana nami. Ngelinye ilanga ngazinika isibindi ngahlala phansi no-Anti ngambuza ukuthi kungani ngilingana nalomfana. Wabe esengitshela ukuthi akasiye umama wami uqobo yena wangithatha wangikhulisa ngenxa yokuthi abazali bami babekade beshone ngenxa yesandulela ngculaza wabe esengikhulisa. Kuso lesosikhathi ngaqhubeka ngahlala kwa-Anti. Kuthe sekunonyaka ngazi konke ngabazali bami ngahlukumezeka ngihlukumezwa izingane zakhona kwa-Anti zingigcona zithi ngiziqedela uthando kumama wazo. Zazingibiza ngomaskito zithi ngincela igazi likamama wazo zithi futhi mina ngizenza gcono ngoba ngangikade ngikwenza konke okwakushiwo lapha ekhaya, ngiyigcina yonke imithetho ebengikade ngifundiswe yona lapha ekhaya. Okwaba buhlungu kakhulu ngathi ngicela izicathulu ku-Anti kwaphendula usisi wakhona okwakunguyenayena omdala wathi angihambe ngiyovusa umama wami onegculaza ethuneni angithengele lezo zicathula ebengikade ngizidinga. Okwakungihlukumeza kakhulu ukuthi kwakungusisi wami engangimhlonipha kakhulu nengangimthanda njengokungithanda kwamama wakhe kanti uyena owayezongihlukumeza uqobo.

[I am mosquito. I grew up in living in my aunt’s house. I have always thought that my aunt’s household was my real home. However, it was a different story. My aunt loved me and so did my aunt’s husband. I grew up with her son who was the same age as me. One day I gave myself courage and I set my aunt down and asked her how come I am the same age as her son? She finally told me that she is not my biological mother. She took me in and raised me because my parents died of HIV/AIDS. I continued to live there with her after I heard the truth. One year after I learned about my past, I was abused by my aunt’s children. They were teasing me by saying that I am taking their place from their mother. They called me mosquito because they believed that I was sucking their mother’s blood. They even said that I make myself better, because I pretend to follow all the orders and the rules of the house. It was true that I obeyed the rules of our home. One day I asked for a pair of shoes from my aunt, and what upset me was the negative response I got from my aunt’s elder daughter. She told me to go and wake my mother who died of AIDS in the grave so that she could buy me shoes. What upsets me the most was that this was a person I respected a lot and loved. I cared for her since her mother was looking after me, but she was the one that hurt me.]

Figure 4.6: Black cat's story

Mina ngiyikati, ikati elimnyama. Emphakathini wangakithi bayangibandlulula ngoba ngiyikati elimyama. Mina ngashonelwa abazali bami bobabili ngasala nogogo. Ugogo ngahlala naye wangondla emva kwezinsukwana ezimbalwa ugogo wami washona ngenxa yeBP wanyukelwa wushukela washaywa yistrokhi ngenxa yobuhlungu nokukhathazeka kwezingane ezishonile ezimbili. Ngahlupheka sengisele ngedwa ngahamba ngaya esikoleni. Mangifika eskoleni ngaphatheka kabuhlungu ngenxa yokuthi isischool fees ngangingasakwazi ukusikhokha ngoba ngingakwazi ukuzinakekela kwadinga ukuthi ngisishiye isikole ngihambe ngiyofuna umsebemzi ukuze ngikwazi ukuziphilisa. Ngahamba ngayofuna umsebenzi ngawuthola. Ngasebenza kahle ezinyangeni ezimbili ezendlule imanenja yami yangibiza yathi ukuze umsebenzi wami ukwazi ukuthi ulunge, ngiqhubeke ngikwazi nokuswebenza kumele ngilale nayo. Bonke labo abasebenzayo lapha bayakwenza lokho, ngakwenza. Emva kwalokho ngaqala ngagula ngagula ngazitshela ukuthi hhayi kusewumkhuhlane emva kwalokho ngaqhubeka ngahamba ngaya eclinic, kwathiwa nginengculazi. Kwaba buhlungu lokho emva kwalokho ngaqala ngagula ngangakwazi ukuzinakekela kungekho onginakekelayo ongikhathalelayo, ongekho ozibuzayo ukuthi ngilala ngidlile noma ngingadlile. Baqala bangicwasa umphakathi wangakithi wangisho ngamagama ngazisola ukuthi yinindaba kwenzeka kimina lokhu. Ngaze ngathi ukuba nami ngahamba kanye nabazali bami. Ingenxa yokuhlupheka yingakho sengigcine senginegciwane legculazi, yingakho sengigcine senginje, ngiyakwesaba kuhlupheka!

[I am a cat, a black cat. I am discriminated against in my community because I am a black cat. I lost both my parents and was raised by my grandmother. My grandmother took care of me for a couple of days, and she also passed away as a result of high blood pressure, diabetes and a stroke. This happened to her because of the pain her children went through before they died. I was left alone and I suffered. I went to school the other day and when I arrived there I was so hurt because I could not settle my school fees and could not afford them, let alone look after myself. Because of this I was forced to leave school and go out and look for a job so that I could survive. I left home to look for a job and I got one. I worked, and after two months my manager called me and he told me that I have to have sex with him so that I could continue with my job. He said all other employees have done it, and that was the reason they never had any problems and kept their jobs. I accepted. After a while I stated getting sick but I thought it was flu. My sickness persisted, then I went to the clinic. From there I was told that I was HIV positive. I was devastated, as my sickness continued in such a way that I was helpless; I had no one to look after me, no one to ensure that I was fed. The members of my community began to discriminate against me and they called me hurtful names. I felt bad about this and asked myself why this was happening to me. I even thought that it would have been better if I had died together with my parents. This was happening to me because of poverty, and that's the reason why I got infected. That is why I ended up like this. I'm afraid of you, poverty!]

Figure 4.7: Ant’s story

Ngiyintuthwane, ngakithi kwakukhona intombazanyana esencane eyayingasenabo abazali. Lentombazane yayingumfundi, umfundi ozimisele ngemfundo yakhe. Yase ithola abangani, labangani babephuma emindenini enemali. Labangani babenakho konke abakufunayo. Ngokuhamba kwesikhathi, yagcina isibona ukuthi abangani bayo babenakho konke abakudingayo kodwa yona cha ayinalutho. Yabuza oyedwa kubangani bayo ukuthi kufanele yenzenjani ukuze ithole imali njenganabo. Wathi kuye, ‘nawe kufane uzitholele umuntu omdala futhi onemali’. Wenzenjalo, kodwa inkinga yaba wukuthi lomuntu wayengafuni ukusebenzisa ikhondomu uma belala. Lenkinga wayixoxela abangani bakhe, akashongo ukuthi useHIV positive kodwa wathi ‘akazi ngoba lomuntu wakhe akayisebenzisi ikhondomu njalo’. Abangani bakhe bazitshela ukuthi unamanga kusho ukuthi usenalo igciwane. Babemuhleka mihla namalanga, bethi usehlile nasemzimbeni kodwa yena wayeyazi ukuthi akanalutho. Isifundo engasifunda kulokhu ukuthi kufanele wamukele lokho ophiwa kona noma wamukele leso simo sempilo ophila ngaphansi kwaso. Ungabinandaba ukuthi labo abaseduze kwakho bathini kodwa ubheke empumelelweni.

[I am an ant. In my community there was a young girl who was an orphan. This young girl was a student who was dedicated to her studies. This young girl got herself friends who were from wealthy families. These friends of hers had everything they wanted; they were never short of money. As time passed by this girl realized that all her friends were rich, yet on the other hand she was poor. She then asked one of her friends what she could do in order to get money just like them. The friend of hers said to her ‘you have to get yourself a sugar daddy’. The young girl did exactly as she was told; the only problem was that the sugar daddy refused to use condoms when they were having sex. She then discussed this matter with her friends. However, she never mentioned that she was HIV positive, what she said to her friends was that this old boyfriend was refusing to condomise during all their sexual activities. Her friends ignored her, thinking that she was already infected with HIV. They were mocking her every time they saw her, saying that she has lost weight, but this young girl knew that she was not infected with the virus. The lesson that I have learned in this story is that one needs to accept what you have received in life and live according to your means or accept the situation that you are living in. Never mind people’s response - concentrate on facing the bright future ahead of you.]

Figure 4.8: Cat's story

Ngiyikati eliyintombazane. Leligama ngilikhethe ukuveza ukuthi lisebenziswa yilabo abadayisa ngemizimba ngasemphakathini wangakithi. Manje njengoba igama lami ngingukati bayangicwasa. Ekhaya asibona abantu abayizigwili sibuye silale singadlile. Manje ngivele ngizacile, manje babona ukuthi ngempela nginegculaza ngoba phela amantombazane lawa adayisa ngemizimba ngoba alahlwa emakubo ngoba kwatholakala ukuthi banegculazi futhi bastigmatised kanti benzela ukuthi bathole mali yokuziphilisa. Kanti ekhaya sebeyangicwasa sebengihlukanisela zonke izinto ezisetshenziswayo njengezitsha zokudlela nekamelo. Kanti ingiphatha kabi lento ngoba bayangidiscriminator. Kanti ingculazi iyaspredeka njengoba bedayisa ngemizimba bebenengculazi.

[I am a female cat. I chose this name in order to expose it, because that is the name given to prostitutes in my community. I am discriminated against in my community because of being a cat. We are not a rich family, so sometimes we sleep on an empty stomach. Now that I am a skinny person, this gives people evidence that I am infected by the HI virus. So many girls who sell their bodies are deserted by their families because they prove to be HIV positive and are stigmatized. On the other hand, those girls do what they do because they want to survive. I am also discriminated against in my home; my family separates kitchen utensils such as spoons from their own, including bedroom linen. This saddens me because I feel discriminated against. The fact is that the HIV virus can be spread easily by the prostitutes who are infected.]

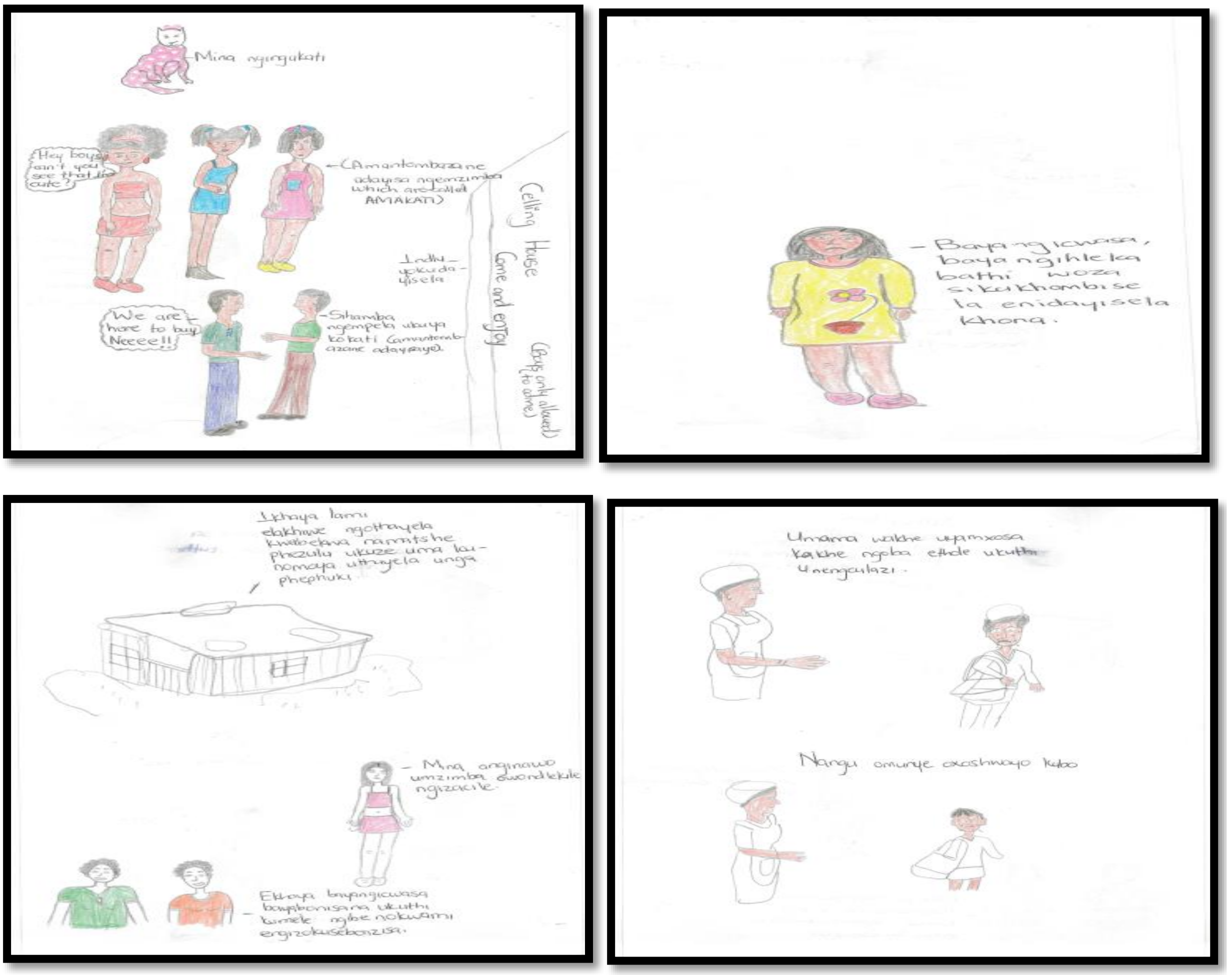


Figure 4.9: Lion’s story

Emphakathini engiphila kuwo mina ngiyibhubesi. Abantu bakhona abangifuni, ngoba angisenabo abazali bobabili. Bathi, kwakungashona abazali bobabili ngonyaka owodwa? Yini lengaka eyayibaphethe? Kusobala ukuthi babephethwe isandulela ngculaza enegcewane lalo uqobo. Bathi ‘pho mina ngingasinda kanjani ekuthol… ekutheni ngingabi nalo’? Ngoba kuvele kucacile ukuthi babevele benegciwane. Lapha ngize ngazwelwa abanye abazali bakomunye umuzi kodwa izingane zakhona ziyangethuka. Zithi mina nginegcewane, noma kuhlekwa nami ngithi ngiyahleka kuthiwa kahle thula wena lento enengculaza. Kungiphatha kabi lokho, abazali babo bayangithanda banginika lonke uthando bangenzela konke bangithatha njengomntwana wabo. Noma ekubeni babekwazi ukuthi abazali bami banengculazi. Okubuhlungu ukuthi ke zihamba zikhuluma ngami ngaze ngathatha isinqumo sokuthi ngiyophuza utshwala. Ngathi sengiphuze utshwala ngathola omunye usisi ngamthatha ngahamba ngaya kolala naye. Sengidakwe utshwala safike salala senza ucansi sangayisebenzisa iprotection. Ngayithola lapho nami ingculaza kodwa lona engithandana naye yena uma ngabe senza ucansi naye weza isiqinisekiso sokuthi uyayisebenzisa iprotection ukuze singeke sibhebhethekise igciwane. Zihambe zikhuluma ngami maje emphakathini. Angisenabo abangani ngoba bayangibalekela ngoba sebezwa ukuthi nginengculaza. Kungiphatha kabi ke lokho. Bonke bayangibalekela, bonke abasangifuni, bonke abasangithandi bathi ngeke bahlale nami.

[In my community I am a lion. Members of my community do not like me because I have lost both my parents. ‘How can both parents die in the same year?’ they ask themselves. ‘What was the cause of their death?’ they ask. ‘It is clear that they were both infected by HIV’, they say. How can I be not infected with the virus, as my parents were infected? They conclude by saying that it’s clear that my parents died as a result of HIV/AIDS. I have received some help from other parents from my neighbourhood, but their children keep on insulting me. These kids keep on saying that I’m infected with HIV. Even if we share a joke and I laugh out loud, these kids will rebuke me and command me to be quiet since I am HIV positive. This hurts me a lot; I know that their parents love me, they give all the kind of love a child deserves, and they provide for all my needs just like I’m their own child. My guardian knew about my parents’ status. What pains me is that my guardian’s children gossip about me. I went out drinking due to these frustrations. I happened to hook up with a girl one day while I was drunk and I took her to have sex with. We had sex without protection and this is where I got infected with HIV. However, we use protection when we are having sex so that we don’t spread the virus. I am the talk of my community because of my HIV status. I don’t have friends anymore; they ignore me because they know now that I am infected with HIV. This upsets me. None of them pay me any attention, they run away from me, they do not like me anymore, and they say they will not stay with me.

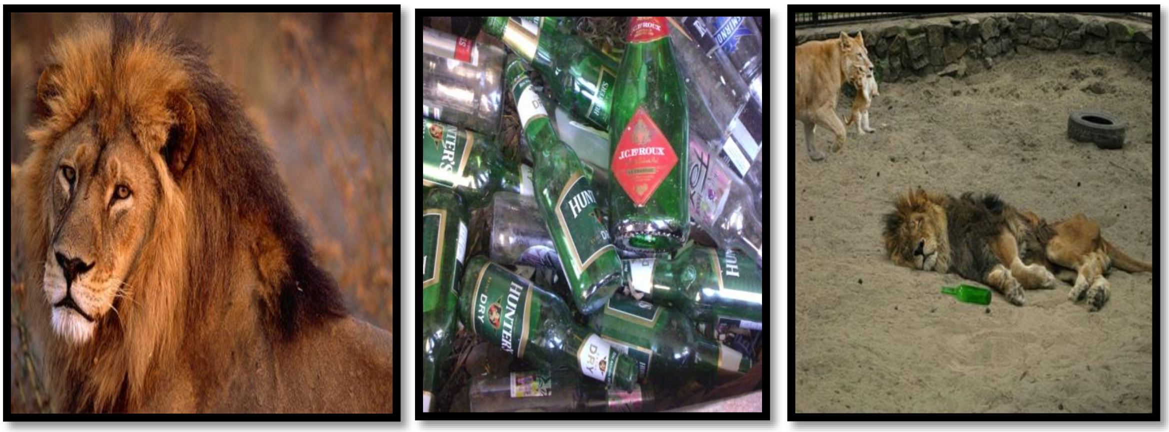


Figure 4.10: Rat's story

I am a rat. My parents died two years ago. I'm at university, I passed matric with exemption. Ngathola ibursary. Imali into engekho ngoba babebamba amatohwana abazali phela. I lived inside the university and ku worse. Some of students they used to laugh at me because anginazo phela izingubo ezibizayo. Nalezo enginazo ziwusizi nje. Nokudla sometimes ngibuye ngilale ngingakuthanga mbibi. Sometimes ngibuye ngilale ngingakuthanda mbibi I work hard to get good results ukuze one day ngiphume kusizi enginalo. One of the girls visit me on my room wangitshela ukuthi owakuphi wake waba kwisituation engikuyo njengamanje wathola iboyfriend enemali. Wathi uzongikhipha tonight ukuze sihambe siyodla. Than akuphelanga maseko nami ngmthola umuntu weslisa ngangingenzenjani? Ayishiwo kodwa le, kwasekuguge kwaze kwaguga zona nezingubo zangaphansi. Wangthanda ngamthanda. Engikwaziyo ukuthi I was not the only girl kuye and wayenano nkosikazi. I had sex with him because ngangiyidinga lemali and ngangingasanake namastudies wami because ubumnandi owayengikhipha engifaka kubo. Amaresults engwathola ngaleso sikhathi kwakuwukuthoa ingane and I get that I was HIV positive. What else can I say to the young girls out there angisona isifo I'm proud of uNkulunkulu akunike kona.

[I am a rat. My parents died two years ago. I'm at university, I passed matric with exemption. I got a bursary. We have no money at home since my parents worked contract jobs. I lived inside the university and it is worse. Some of students used to laugh at me because I don't own any expensive clothes. The clothes that I do own are very old. I sometimes sleep without eating food. I work hard to get good results so that one day I will free myself from this poverty. One of the girls visits me in my room; she explained where she came from and that she has experienced the same things as me, but she got herself a wealthy boyfriend. She promised to take me out for dinner. Then I did not waste time to get a rich boyfriend - what else was I supposed to do? Things were bad, so bad that even my underwear was old and torn. The boyfriend loved me and I loved him back. I knew that I was his mistress and he had other girlfriends besides me. I had sex with him because I needed money and I was not focusing on my studies since he was taking me out to cool places. The reward that I earned from this was to give birth to a child and to become HIV positive. What else can I say to the young girls out there but: 'I'm proud of what God has given me.']

Figure 4.11: Parrot’s story

Ngiwupoli. Ngiwupholi othanda ukusiza abantu. Imvamisa ngisiza abantu abanesifo segculaza. Emphakathini bayangicwasa bathi sengizobashiya emhlabeni, ngoba ngisiza labantu laba. Futhi bacabanga ukuthi nami senginalo. (sigh) Lento ayingiphathi kahle ngoba kwesinye isikhathi uma ngibasiza angisakwazi ukuthi ngigxile kubona ngicabanga lezizinto abazisho ngabo futhi ayingenzi ukuthi ngikhululeke ngoba bangabantu abaphilayo njenganathi, banemizwa. Engikufunayo nje kuphela ukuthi…ukusiza abantu bezwe lakithi benze… ukusiza abantu bezwe lakithi. Baze basho ukuthi ngeke umsize umuntu, umuntu ngento ongenayo. Isifundo osifundile ukuthi, isifundo engisifundil ukuthi unganaki ukuthi umuntu uthini yenza lokho okulungile.

[I’m a parrot, a parrot that likes to help out people. I lend a hand to those who are infected with the HIV virus. I am discriminated against in my community; the members of my community believe that I will soon die because I assist the HIV-infected people. They believe that I am infected as well [sigh]. This is wounding me because when I help those infected people I lose concentration and I keep on thinking about the hurtful words that people are saying about infected people. These people are still alive just like us, and they have feelings just like us. All I need and all I plead for from the society of our country is to help each other. People are not ashamed to say that they cannot help others if they do not have the same problem as those people. The lesson that I have learned is that do not mind people but do right.]

Figure 4.12: Butterfly’s story

I am a butterfly, I had a friend who was part of the campaign of HIV and AIDS and was a poet. The people didn’t listen to what she said because she was HIV positive, and they thought that she could have done more to prevent that before she got infected. She wrote a poem and the poem read like this:

> “I happen to live in a crowded community, with teenagers giving birth at a young age. One of my friends found out that she is HIV positive and just gave birth to a young bouncing baby boy who was infected too. Who are we to judge? The people are stigmatising her, saying that the feeding porridge she gets at the clinic is only for the HIV/AIDS-infected people. Judge not and you shall not be judged. Condemn not and you shall not be condemmed. Help those with AIDS, help your eternity. The clinic was not wrong for giving out the porridge. The people were saying that ‘Paragon for the *dieres*’[diaree]. Paragon was the porridge.”

So I am emphasisng that we have to help those who are infected with HIV/AIDS because they are also the people and they are living with us. They have got the blood, we have got the blood. Who are we to judge? They did not want to have HIV/AIDS, but then we have to accept that they have the disease.

4.3 SECONDARY SCHOOL LEARNERS’ EXPERIENCES OF HIV- AND AIDS RELATED-STIGMA IN SCHOOLS IN A RURAL COMMUNITY

I now present the themes that emerged from the three data sets —the digital stories, the focus group discussions and the written reflections. When the participants were listening to each other’s stories of stigma they observed that the stories were similar. Even though the expressions varied from learner to learner, themes and issues seemed to point in the same direction. Hence, the learners in this study had a shared understanding of the notion of HIV-and AIDS-related stigma. This is in line with the assumption of symbolic interactionism that meaning is socially constructed through interaction.

The themes are presented, using direct quotations from participants in both isiZulu and English, and, following Marshall and Rossman (2010) and Poggenpoel (1998), discussed and re-contextualized within the relevant literature. The re-contextualisation revealed an intertextuality of the data - how learners’ texts played upon other texts (Fox, 1995), in this case the literature on stigma. Where direct quotations are in the learners’ mother tongue, the participants translated these into English after which I had them minimally edited for the sake of intelligibility: they are presented here almost verbatim.

Themes 1 to 3 (see Table 4.1) respond to the first research question on what digital storytelling can reveal about rural secondary school learners’ experiences, real or otherwise, of HIV- and AIDS-related stigma in schools in a rural community. Three themes emerged here: first, the learners see experiences of HIV- and AIDS-related stigma as a hardship; second, victims find themselves in a vicious cycle of silent suffering; and third, some cultural aspects fuel stigma.

THEMES	***CATEGORIES***

THEME 1: HIV- AND AIDS-RELATED STIGMA IS A HARDSHIP	• ***Hardship***
	  • *In the community*
	  • *At school*
	  • *With friends*
	  • *In the family*
	• ***For the individual***
	  • *Intrapersonally*
	  • *Interpersonally*

THEME 2: CAUGHT IN A VICIOUS CYCLE OF SILENT SUFFERING	• ***Personal vulnerability***
	  • *Orphanhood*
	  • *Material poverty*
	  • *Transactional sex*
	• ***Treacherous environment***
	• ***Community gossip***

THEME 3: 'CULTURE' FUELING STIGMA	• ***A culture of not talking about sex*** • ***Stigma on the basis of religion*** • ***Stigmatising language*** • ***Early sexual debut***

Table 4.1: Learners' responses to experiences of HIV- and AIDS-related stigma

4.3.1 Theme one: HIV- AND AIDS-related stigma is a 'hardship'

The essence of this theme revolves around the notion of HIV- and AIDS-related stigma being experienced as a hardship at multiple levels which, in turn, have an impact on the individual.

4.3.1.1 Hardship

Although the focus was on stigma as experienced at school in a rural community, the participants shared the ways in which stigma also manifested itself in other ecologies such as the community, in school, among and between friends, and in the family. It is clearly difficult to separate how and where the stigma occurs. The experiences recounted in the stories were lived personal ones as well as imagined, heard or witnessed ones.

In the community

A community could refer to the local one, to a wider one, or to the whole community (Donald et al., 2006). Local communities are made up of the people in the immediate sphere of social contact, for example in the rural neighbourhood. The wider community is broadly defined in socio-cultural terms as the district legislative structures within a community, while the whole community is defined as being within a country. A local community with a strong sense of community can afford excellent support to its people in many ways. When a community grapples with HIV- and AIDS-related stigma, for example, without knowing how to deal with HIV, much damage could be done to individuals, families, friends and to the school (see Chapter Two 2.6). In this study the participants indicated that there is a high level of HIV- and AIDS-related stigma at the level of the local community. The following statements highlight their examples of stigmatisation.

> *…there is more stigma in our community … many communities treat infected person badly instead of supporting them…*
>
> *Another thing that I have learnt from the stories is that most of the stigmatisation that happens within the community is done by people we trust…*
>
> *…abasizi babukelwa phansi ngoba basiza laba bantu abaphila ngegciwane. Bachubeka basize noma umphakathi ubabukela phansi ngoba sebazinikela ukusiza…*
>
> *[Community Health Workers are rated too low because of assisting the HIV positive people … they continue assisting in the community although they are*

> *discriminated against for helping the sick.]*
>
> *…I live in a community whereby the members of the community kill people who are infected with HIV virus.*
>
> *…you always know that if you are HIV positive you are regarded as stupid or you got what you wanted]*
>
> *…look at Giraffe, he has a problem with the community following that his parents died of HIV. When he was not able to continue with school the community was happy because they thought it was over with him. They were disappointed when he made a plan about life and was able to survive and assist his siblings.*

Such utterances confirm that a community can also stigmatise an illness and those affected by it. In the South African context HIV is referred to by different names (see Chapter Two 2.7.5), thus contributing to the silencing of the truths around HIV and AIDS but also exacerbating the stigma. The title of Steinberg’s work, *The three letter plague* (2008) is an ironic example of how people refuse to name the epidemic specifically. His work speaks about a rural village in which the HIV prevalence rate is high and HIV stigma is very common. Steinberg writes about how those who seek help in the form of testing and accessing ARVs are stigmatised. Even those working to assist and support, such as Community Health Workers (CHWs), are stigmatised in fulfilling their duties. Stigmatising communities deter people from testing (Populations Council and Health Systems Trust, 2006) and using HCT services where local community members are employed because they fear these workers compromising their confidentiality. As mentioned earlier in this thesis, an example of the effects of the stigmatisation is that of a 37 year-old woman in the Eastern Cape who committed suicide and also killed four of her children after being continually harassed by the community for her assumed HIV status (Booi et al., 2008, see Chapter Two 2.6.5). Even though some communities might not condone actually killing HIV positive people the stigmatising can kill people living with HIV in the sense of driving them, in one way or another, to death. If HIV positive people experience treatment failure, it is presumed to be because of “sexual activity while on ARVs, and thus a ‘deserved’ outcome of unacceptable behaviour” (Roura, Urassa, Busza, Mbata, Wringe & Zaba, 2009, p. 310). The young people, too, are faced with being blamed for contracting HIV because of having unprotected sex. In a rural community within an African society the concept of *Ubuntu* is expected to be upheld. Ubuntu refers to the belief that a person is “a person-in-relation, a ‘being-with-and-for-others’ and not an isolated, atomistic individual” (Mkhize, 2004, p. 24). This seems to fade away in the context of HIV and AIDS.

These quotations above suggest that even trusted people or people the participants are supposed to trust also stigmatise. There also seems to be little sense of empathy in the community in this era of HIV and AIDS. Statements such as “you got what you wanted” also show a lack of empathy in the community. If such stigmatising happens at the level of the wider community it filters down to other levels of the community.

At school

School plays an important role within a community in being responsible for teaching its children and young people. When being at school is compromised by HIV- and AIDS-related stigma, the learner loses out. In order for optimal learning to take place, it is important to address the health and wellness issues of the learners (Olivier, Wood & De Lange, 2007). The participants were quite vociferous in providing evidence of stigma experiences at school, from both their peers and teachers.

> *… one of your [the] learners says they do not want you, he/she does not want you to use his /her things because you are sick and you will leave your sickness on his/her things…*

> *…they do not want to share anything with you and also refuse to play with you…*

> *…in a school context a lot of unintentional stigma ... like when teachers want to identify orphaned and vulnerable children, they stigmatise unintentional when they say: ‘Those whose both parents died, or those who do not have food at home’, or sometimes they say ‘those who do not have uniform must come and see me in the office’“*

> *…sometimes they [teachers] would say double orphans, sometimes they would say HIV and AIDS orphans and it is painful to us as learners…*

It is interesting to consider whether these quotations refer to their own experiences or whether they are projections or witnessed, heard or imagined experiences. Whatever the case, the prevalence of HIV- and AIDS-related stigma is evident in these schools, as in other South African schools. Both learners and educators contribute to stigmatisation. It is worth repeating that Francis and Francis (2006) write, for example, about an educator who asked an HIV infected learner to share with the class how she got infected and then warned the class not to get close to her. As in this study, I cannot help but wonder at the lack of sensitivity of a qualified teacher in a country where the Department of Basic Education has a policy for dealing with HIV and AIDS. While the willingness to support the learners might be there, at least officially, the lack of tact is seriously harmful. Research confirms that while children stigmatise each other, educators stigmatise learners, adolescents in particular (Deacon & Stephney, 2007).

The school itself and the building such as the toilets have become sites to perpetuate stigma as one quotation pointed out:

> *…you go to the toilet at school and find that learners wrote [on the toilet wall] that they do not want HIV positive people in their school...*

Schools are expected to be safe environments; however, they have turned into scary spaces in which the writing of stigmatising statements on the wall for everyone who uses the toilet to see can happen. We see that it is not only gender-based violence that can occur in the toilets but also acts of stigma. Mitchell (2009) speaks of geographies of danger; school toilets are one of the common sites of gender-based violence. Mitchell and Larkin (2004), in a study conducted in Swaziland where learners were taking pictures of unsafe places, and giving reasons why they feel the spaces are not safe, they indicated that they, the learners, are vulnerable to gender-based violence including rape in the toilets. Not only that, but also an act such as the use of Jeyes Fluid, referred to in Chapter Two, in a study by Francis and Francis (2006) illustrates that toilets are also school context spaces of stigma.

The stigmatisation of HIV-infected people by children is not unique to South Africa as several studies refer to children in other African countries stigmatising HIV-infected people. For example in the rural contexts of Mali and Botswana children’s attitude towards HIV-positive people in general are negative and some of these children stigmatise each other (Castle, 2004; Letamo, 2004). Such stigmatisation of each other was seen to be harmful and affected their access to education. This concurs with the findings of the South African study by Moletsane et al. (2007).

With friends

Adolescence is a critical period for identity formation: adolescents have a great need to be part of a peer group and to fit in and to conform to the norms of their peers (MacLeod & Austin, 2003) in order to be accepted by them. Therefore, they are likely to experience more conflict around feelings of being different, of being an outsider, than younger children (see Chapter Two 2.7.4). Friends, too — platonic and intimate — are shown to take part in stigmatisation, as is revealed in the quotations below.

> *…The snail was stigmatised by his own friends, they did not want to be part of his life because of his status…*
>
> *…The rat was also stigmatised by her own friends after divulging that she do not use a condom with her partner….*
>
> *…the storyteller got stigmatised by his girlfriend…*

Stigmatisation linked to losing friendships is so real that, as mentioned above, HIV-positive people might choose to skip taking their medication when they fear that their friends might discover their status (Borgart & Uyeda, 2009). At an intimate friendship level, females would probably be the first ones to know their HIV-positive status and when they disclose this to their boyfriends, they could experience physically enacted stigma. In this study narrative the boy, however, was stigmatised by his girlfriend. In an earlier study in the same community, a sample of learners from the same grade revealed that boyfriends often beat their girlfriends when they tell them about their positive status (Moletsane et al., 2007). This stigmatisation, coupled with violence, clearly reduces the chances of disclosing lest the friendship or intimate relationship be broken.

In the family

A stable family is key to the fulfilled lives of children. A family is expected to provide a caring and consistent environment, encourage competence with coping skills, and provide a strong coherent and consistent set of values, as Deacon and Stephney (2007) put it. However this is not always the case. In the following set of quotations participants position HIV- and AIDS-related stigma as part of family life in their rural community.

> *…abantu bahlukunyezwa ngezindlela eziningi nezahlukene ngisho nasemndenini yabo…*
>
> *[…people are discriminated and victimized in various ways, even at the level of the family…*]
>
> *…what I hear is that too much stigma happens around the people's communities and it easily happens to people who are mostly related*
>
> *Cat was stigmatised by her family, they did not even know [not sure of] her status, but they did not want her to share anything with them…*
>
> *…when you are staying with relatives it is even worse although they are supposed to be family, you see mosquito…*
>
> *…maybe what I can say is that in the stories, from observing, young people still show that ... they are being discriminated and ill-treated by their families.*
>
> *…in families, they discriminate their own family members, and they also discriminate their friends. Maybe something still needs to be fixed in that area…*

The findings show that stigma in relation to family plays itself out in two ways: stigmatisation within the family; and stigmatisation from outside the family. Learners reported that the affected families are at risk of being socially isolated and ill-treated in the community. As Campbell et al. (2007) point out, families stigmatise their members in many ways: they sometimes hide away their sick relatives; limit their access to health care or support; and, as mentioned earlier, sometimes even disown their dead relatives, to the extent of not collecting their bodies for decent burial.

Family structures may vary. For example, in most Western societies a nuclear family consists of a father, a mother and children in common but in most African societies, an extended family of grandparents, parents and other relatives is more common (Deacon, 2006). The above quotations show that the inclusive care which used to be provided by African families is challenged by the HIV and AIDS pandemic.

Learners also felt stigmatised when people stigmatised their relatives; stigma directed towards a sibling or a parent affected them. Wight, Aneshensel, Murphy, Miller-Martinez and Beals (2006) suggest that this symbolic contagion experienced by families of people infected by HIV may have a negative impact on care-giving relationships, depending on the specific circumstances around HIV contraction and family members' HIV status. Borgat et al. (2008) observe that families may be vulnerable to a unique form of stigma because of the misconception that HIV positive family members are exposing the rest of the family to infection. This was revealed by Bird's story that other learners were stigmatising her, saying her sister had HIV. *"[T]hey say we even eat HIV in the pot."* Airhihenbuwa et al. (2009) concur that HIV puts pressure on millions of families and there is evidence that stigmatisation by family members is the most hurtful experience (Campbell et al., 2005a). However, some more recent (and encouraging) studies do show that many families do not stigmatise the infected person and they share kitchen utensils with HIV-positive members and give them full support (Airhihenbuwa et al., 2009).

4.3.1.2 For the individual

The effect of stigmatisation from the community and its different structures on the individual is profound. HIV- and AIDS–related stigma has a direct impact on the individual, and this affects her or him at an intrapersonal and interpersonal level. In the case of young people already confronted with many developmental changes, trying to come to terms with who they are and where they are going, experiencing stigma becomes yet another challenge: they need to negotiate who they are (as individuals) and how others see them in the community while being framed by stigma (Donald et al., 2006). Such extra burdens at adolescence could trouble their intra- and interpersonal development.

Intrapersonally

According to Blumer (1969) humans are constantly engaged in an internalised conversation with the self through the thought process (see also Rober et al., 2008). This intrapersonal relationship with the self is about a person's the inner world, about knowing oneself and what motivates one (Weiner, 2013). The intrapersonal includes self directed thoughts and self directed emotions related to self esteem, guilt, and shame (Weiner, 2013). Self esteem refers to how people feel about themselves; it has to do with the "positive or negative evaluations of the self" (Smith & Mackie, 2007, p. 107). Self concept is more about how we see ourselves (Donald et al., 2006). This includes how much we respect ourselves, and how well we know our desires and our motivations (Alderman, 2013). People need to be in charge of their intimate personal world and be able to construct it in a way that is in harmony with their needs. This will then be reflected in their interpersonal relationships. These are important because a lack of self-respect and impaired self acceptance, related to the internalisation of stigma leading to guilt and blame affects the individual's ability to live a harmonious life. Two issues emerged from the findings: the loss of self-respect; and the failure to accept the self.

If the intrapersonal image is disrupted, it is likely that one's self concept and self esteem become troubled, and this affects how we engage with the inner world within the outer world. What the participants show is that in the first instance poverty or the lack of material goods causes a young person to stick out and this affects how they see themselves (self concept) and how they feel (self esteem) about themselves. This leads to risky behaviour, to possible infection and then, in turn, to further stigmatisation. This is revealed in following quotations.

> *The girl got pressure from friend, the girl wanted to be part of the crowd, she got stigmatised by the friends who told her to get a boyfriend who has money. Many people are not grateful for what they have, so they end up having sugar daddies to support them financially and in most cases you will not be the only one having sex with and that is how HIV is spread...*

> *… young people have lost I respect for themselves, of which sometimes we go around complaining that we are not loved, but the only thing that we should do is treat ourselves with respect*

Symbolic interactionism sees the self as a product of what has been termed the 'looking glass self' - a person's self image is influenced by the way significant others perceive him or her (Lee, 1990). In this way, the person strives to be that which others think he or she is, and adjusts his or her behavior accordingly. Peer influence amongst young people has been well-known as an arbitrating predictor of social behaviour including high-risk behaviour such as unsafe sexual (Bhana & Petersen, 2009). If this is behaviour that is frowned upon, such as risky sexual behaviour, it can be used against the individual and can contribute to her or his loss of self-respect. Loss of self respect may lead to behaviour that is stigmatised, such as engaging in transactional sex. What is noteworthy in this study is that the participants reflect back on the need for inner strength to stay true to behaving in a way that will not diminish their self-respect. It is hugely challenging to ensure that learners, in spite of social factors that so disadvantage them, continue to see themselves as worthy and as having the strength to resist pressures.

By asserting stigma as a contributor to the loss of respect among the youth, these young people show how many challenges they experience because of stigma. Material needs have been identified as increasing the loss of self respect in girls who then think that engaging in risky behaviours — having multiple sexual partners and/or having transactional sex in order to secure the financial and materials they need — will remedy this (Hunter, as cited in Shisana, Zungu & Pezi, 2009). Although the participants raised this issue, it does not imply that all poor girls lack self esteem or necessarily engage in risky behaviour.

Of course, poor self-acceptance and impaired self-confidence would exacerbate how HIV- and AIDS-related stigma is experienced. Some participants alluded to this.

> *…what I can say is that these stories show lack of confidence in people, to not want to come out in the open about who we are and where we come from, what we have, and what we want from life…*

> *…I understand that the sister of the storyteller was stigmatising herself because she does not want to go on shop because people know her status, the story teller got stigmatised by the school learners…*

Utterances like these show that these young people are aware of the interface between HIV and AIDS, HIV-related stigma and self acceptance.

Interpersonally

The concept of interpersonal relationships refers to being able to relate to the other, to function well in social situations, and to be able to understand the needs of others (Weiner, 2013). If people believe that they are hopeless and not capable of doing any good things, they will not be able to engage in interpersonal relationships. But if they have some sense of empathy, there is the possibility of pro-social behaviour. Sympathy, empathy and motivation elicit pro-social behaviour (Weiner, 2013; Alderman, 2013).

The assertions by the learners show that stigma makes them feel socially isolated, without anyone to turn to. Such isolation leaves them lacking a sense of belonging, with only a few persons or even no one to have quality relationships with (Nicholson, 2012). References to this kind of isolation were made by the participants.

> *…being left alone, having nobody that could guide you through bad and big problems end up having no future…*

> *…it's just that what I have learnt is that once you have HIV people tend to avoid you. They don't want to be around you and they don't want to help you…*

> *…Being discriminated by family because you are HIV positive is bad, you end not knowing whom to trust…*

> *….What I have learnt is that when you are HIV positive, you end up being blackmailed even by the person whom you trusted. You trust a person to be your friend, even your family turns away from you…*

> *…it is by people that we as young people trusted. It is those that we really trusted*

> *that discriminate us, people who should be giving us support…*
>
> *…this leads to those infected hide their status and they don't trust anyone…*

In being without parents, guardians or anyone to trust, the vulnerability of an adolescent usually increases. The participants realize the importance of support and of having someone to trust. The stigma reduces the access to social support networks (Campbell et al., 2007): once symbolic othering has been established it is often translated into social isolation (Goodall et al., 2011). Social isolation can compromise people's ability to live positively and this can then exaggerate their suffering and this may make their life miserable and shortened (Campbell et al., 2007). The above quotations confirm that for the learners stigma deprives people of social interaction; they have no one to trust, and they live in isolation.

This is in line with Strode and Barrett (as cited in Campbell et al., 2010, p. 976) who document that the stigma directed to children affected by AIDS "by their extended families, communities, school peers and health and social services [leads to]… consequences [that include] reduced access to care and support, increased vulnerability to poverty and exploitation, fear of disclosing HIV status, emotional pain and powerlessness". The social isolation clearly affects young people both interpersonally and intrapersonally.

4.3.2 Theme two: Caught in a vicious cycle of silent suffering

The learners talked about challenges, associated with orphanhood and material poverty that become further sources of stigma. The lack of support experienced in settings like the home, the school, and in health care centres, as well as the gossiping about them in the community, increases their vulnerability, and reduces their chances of a normal childhood. This leads to silent suffering among these young people who are often not able to share the problems they have with supportive and trustworthy people. This results in their resorting to risk taking behaviour and possibly contracting HIV, which, as we know, is highly stigmatised. This leads to a cycle of illness which will lead to their being further stigmatised.

4.3.2.1 Personal vulnerability

In this age of HIV, vulnerability is deepened when parents are ill and cannot work, or if they die leaving the children, who are not yet old enough to secure employment, behind with no bread winners (Deacon et al., 2009) and no adult to head up the household. This becomes a challenge that young people often face.

> *…the people that are mostly facing challenges are indeed the young people; older people hardly find themselves in the same position…*

The participants refer to how their socio-economic position directly affects their schooling. In most of the participants' narration of experiences — lived or imagined, heard or witnessed — it was apparent that socio-economic challenges compel many young people to make choices which are not in their best interests, for example, dropping out of school. A male participant, who narrated a witnessed experience that included dropping out of school because of socio- economic factors, says the following:

> *...futhi abazali bethu basishiya sisebencane. Kanti lokhu kwangibangela ukuthi mina ngishiye isikole ngisemncane. Njengoba ekhaya kwakuyimi omdala ezinganeni zasekhaya. Kwabanga ukuthi mina ngiphume ngiyosebenzela izingane zasekhaya. Kwathi uma sengithole umsebenzi impilo yashintsha impela.*
>
> *...and our parents died when we were still young. This made me to drop out of school when I was still young. I was the eldest at home, I was forced to go and look for a job for help my siblings. By the time I got the job our lifestyle became better than before*.]

The lack of resources leads to a high rate of school dropout; children in need may be forced to leave school. The possibility of education therefore being utilised as a means to address poverty would be weakened for such individuals; having limited education would further disempower them, and worsen their situation. The unaddressed poverty, according to (Shisana et al., 2009), in turn leads to another vicious cycle of HIV infection, vulnerability and likelihood for the next generation to live in poverty.

Orphanhood

The interrelationship of HIV, orphanhood and HIV- and AIDS-related stigma can cause a vicious cycle of suffering. Although orphanhood has, of course, always existed, its nature has been changed by HIV. In the past, orphanhood was not stigmatised in African society because other members of the family would happily take care of the child who had lost her or his parents (Deacon & Stephney, 2007). In many communities now, this is no longer the case. Orphanhood now often comes with challenges related to care and guidance: orphans become vulnerable; they may have to find substitute care and are then often abused, and they face stigmatisation for having been orphaned.

> *Kujwayelekile ukuhlukumezeka uma sewashiywa abazali emhabeni. Akukho amagama amahle abhekiswa kuwe.*

> *[…It is very common to see orphans being mistreated. Once you lose your parents, people will always say bad things to you.]*

> *…Bheka inkinga ka mosquito ukuthi uyahlukunyezwa emndenini wakhe nakhu kwaziwa ukuthi abazali bakhe nbangempela bashona ngalesifo, the other thing is that they stigmatise him because doesn't have parents…*

> *[…Just to relate to mosquito's story, he is discriminated and ill-treated by the other family members because his biological parents are deceased…]*

> *…I have also realized that you end up staying with other families when all your parents die of HIV and the very same people end up stigmatising you.*

> *...I think that there is no greater pain than having to live in people's homes because everything that you do seems to be wrong, but the things that the members of that family do are always right.*

> *…HIV and discrimination is such a problem. When I remember the story about Mosquito, they discriminated him, dangerously side-lining him also saying that his mother died of HIV/AIDS. That could make him want to try things in life in the wrong way which could lead him to getting this disease...*

> *….the most painful part is that everything that happens, happens in such a way that you clearly see that you are not a member of this family. They won't cook*

> *because you have to do it while they are watching television. They don't buy you any clothes and they don't even appreciate your work...*

Research on young people in South Africa confirms that more than half of the population of those between 10 and 14 years of age, a critical stage of development, lose one parent or both because of AIDS-related illnesses, (Richter, Stein, Cluver & de Kadt, 2009). The challenges represented by the quotations above show that orphanhood continues to create opportunities for the further spread of HIV and then, in turn, for HIV- and AIDS-related stigma to arise and thrive. Children who have lost a parent to AIDS experience emotional distress at the death of their parents as well as the upheaval of moving to a family where they may not feel welcome, and, of course, the HIV stigma as well (Cluver & Gardner, 2007; Cluver & Operario, 2008; Richter et al., 2009). There is not sufficient intervention to support young people and children who are orphaned yet there are numerous challenges facing them which make the young people vulnerable (Engle, 2008). UNICEF (as cited in Richter et al., 2009, p. 77) reveals that "more than 95% of children who lose one or more parents to AIDS or other causes live with members of their extended family, including grandparents".

The safety net which African extended families provided previously is gradually diminishing, if it even exists at all, because all families are affected by the premature deaths which in turn cause economic hardships. In instances where the orphaned children are taken in and looked after by relatives, economic challenges cause hardships in these families (DeWaal & Whiteside, 2003). Such cases are particularly common in various African societies that observe the tradition of relatives taking over the raising of the "children of deceased relatives, regardless of whether the prospective family is financially capable of doing so" or not. "The accommodation of new household members" in financially instable "households, [is] likely to sink" the family "even deeper into poverty" (DeWaal & Whiteside, 2003; Shisana et al., 2009, p. 96). This is turn, causes the family members to resent the newcomer, and then to engage in stigmatising behaviour.

Material poverty

Challenges such as being stigmatised within the community because of poverty and having parents who are infected put further stress on young people who are ostracized by the community (Deacon & Stephen, 2007; Shisana et al., 2009). Here what stands out is that material poverty perpetuates vulnerability and stigma.

> *…people discriminate other people because they are poor…*
>
> *…money and poverty are the biggest issues…*
>
> *…because of his poverty, he found himself stigmatised…*
>
> *…the family got stigmatised by the community because of their poorness…*
>
> *…some of the people they get this virus because they are poor, they fall in love with adults so that they can get money to feed themselves…*
>
> *…poverty is another cause of HIV because you will need things that you cannot afford. Then you will sell with your body to get money…*

In the context of HIV, poverty is seen to be a cause of stigma. Poverty is seen to have a catalytic role in increasing vulnerability to HIV infection (Kalichman et al., 2006; Shisana et al., 2009). The issue of the connection between HIV and poverty was foregrounded, in South Africa, at the beginning of 2000, when the former president of South Africa, Mr Thabo Mbeki's denialism caused an international outcry. He had expressed his doubt that HIV was the exclusive cause of AIDS and argued for a consideration of socioeconomic causes (Fassin & Schneider, 2003). Many studies report that when there is a shortage of resources, especially money, jobs and services, HIV- and AIDS-related stigma becomes rife (Campbell et al., 2007). This is also revealed by Patient and Orr (2003) who assert that people with surplus or sufficient resources are likely to offer compassion to those affected than people who have scarce resources. Studies such as Deacon and Stephney's (2007) about children and HIV- and AIDS-related stigma, in showing a strong link between poverty and stigma, demonstrate this.

Poverty can also cause people who are affected to be less concerned about long-term risks and to focus only on what can help them in the short term. This is in line with Shisana et al.'s (2009, p. 89) study which revealed that the affected "believe that their lives will be short because of poverty, [so] they have nothing to lose by risking infection in the quest for survival”. For most poor people the concern is about today, and about how they get their basic needs for the day such as food and shelter (Loewenson, 2007). This illustrates how the stigma attached to poverty and the need for material goods exposes individuals to situations that make them more vulnerable to HIV infection which, in turn, is also more stigmatised (Shisana et al., 2009).

Transactional sex

Transactional sex —engaging in a sexual relationship in exchange for money and or other resources — was seen to be an option for some of the young people, especially the girls. This, however, increases their vulnerability rather than remedying the situation which gave rise to the need for transactional sex in the first place.

> *…sithole ukuthi abantu abathinteke kakhulu ezimweni ezifana nalezi abantu abasha abagcina sebezifake ezinkingeni…*
>
> *[…what transpires here is that the youth is the most affected group and they end up engaging in risky endeavours…]*
>
> *…and what is really bad is that those you sell to them do not want to condomise…*
>
> *…people do not use protection when they do sex and they are afraid to tell their partners…*
>
> *Selling your body is not the best way to solve your problems at home because it comes with diseases…*
>
> *…like some boys opt for sugar mamas who give them money…*
>
> *…she got herself into bad issues because she wanted to keep her job, she got stigmatised by the community but they did not even know what was going on with her, they did not know her status, she got HIV because of poverty…*
>
> *…having many partners [multiple concurrent partners]) increases the chances of contracting sexually transmitted diseases, early fatherhood…*

The abundant quotations above, point to the learners' recognition that young people engage in transactional sex because of poverty. They find themselves having no choice but to be involved in sugar daddy and sugar mommy relationships, which also put their lives in danger and present a threat to their health in that the risk of infection is increased since these older partners have a tendency to be in multiple sexual relationships (Shisana et al., 2009). In this situation young people are dependent and powerless to negotiate safe sex and this often leads to HIV infection, especially among young girls (Campbell et al., 2005b). Affected people respond to these challenges in different ways such as adolescents and others engaging in high risk sexual endeavours.

> *Intuthwane inkinga yayo yathi uma ihlekwa ngokungabi nabazali, then she decided to find a solution to satisfy her needs by finding herself a sugar daddy, and u sugar daddy wakhe wayethi uma beya ocansini bengayisebenzisi icondom…*
>
> *[The ant's problem is that when her friends mocked and stigmatised her for being an orphan, she then decided to find herself a sugar daddy for satisfying her needs, and the sugar daddy did not want to use a condom]*
>
> *…and poverty is the big problem in South Africa, poor people do bad things ngoba befuna imali (in trying to get money, but at the end bathole izifo [contract diseases] HIV, STIs. Abanye (Others they fall in love with sugar daddies or sugar mom just to get money abanye besuke bengabathandi [others get involved with sugar daddies and sugar moms not because they are in love]…*
>
> *She found herself being used as a sex slave because she did not have parents. She was forced to do something she did not like and at the end they did not sympathize with her instead they were telling people that she is HIV positive…*

Young people from rural settings are targets for sugar daddies because of social ills such as material poverty (Bhana & Pattman, 2011). Although not part of my study, I note that this is true, too, of urban settings (see Van den Bergh, 2008). "In the context of an emerging materialist youth culture and a dominant patriarchal system, young females are increasingly” rendered vulnerable to being coerced into having unprotected sexual intercourse (Bhana & Petersen, 2009, p. 61).

4.3.2.2 Treacherous environment

In the context of HIV and AIDS a supportive environment is crucial to the survival and thriving of people. When the support is lost from those expected to offer it, suffering is worsened. The quotations from the participants show that such support is gradually lost from families and the environment becomes unsupportive rather than supportive.

> *My friend’s mother works in the clinic, she helps me with the food parcels…but everybody knows now that I am HIV positive…*
>
> *While I was listening to the stories I learnt that we find that stigma happens in different ways, we find that people get stigmatised by people they trust.*
>
> *I was abused by my aunt’s children…they called me mosquito because they believed I was living on their mother’s blood…*
>
> *What upsets me is that this was a person I respected and loved…*

HIV- and AIDS-related stigma has been accompanied by discrimination, affecting access to care and support (Airhihenwenbuwa et al., 2009; Campbell et al., 2005b; Roura et al., 2009). The excerpts above show how stigma prevents HIV-infected and HIV-affected people from getting much needed support.

A useful primary healthcare resource is found in the local clinics in rural communities, with doctors, nurses and health care workers being available. Community health care workers, referred to as the “community/lay workers in the health sector” were introduced at a time when addressing the HIV and AIDS epidemic was being prioritised (Schneider et al. as cited in De Lange & Mitchell, 2012, p. 7). The community health workers were given “limited training in basic health services”, and then were meant to provide basic health services to the members of their surrounding community (De Lange & Mitchell, 2012, p. 7). The health care providers are key in supporting the community and are supposed to be empathetic and supposed to maintain confidentiality. However, the following quotations show that the health care environment is not necessarily supportive and that stigma is experienced in the health care centre, and that it also emanates from the health care centre.

> *In the community that I live in, here in eMayemaye* (Pseudonym)*, there was an issue of a nurse that was responsible for giving out treatment at the clinic, going around and talking about the people and laughing at them...*
>
> *By my house people are not at ease with the idea of community health workers coming to help them. They think that they will go around gossiping about them to the community saying that so and so has HIV. It is so unlike them. That is why they are not comfortable with the idea…*

The quotations above show that stigma exists in health care centres and this confirms studies by Mill et al. (2010). In sub-Saharan Africa, a study done in five countries, Swaziland, Lesotho, Malawi, Tanzania and South Africa, also showed stigmatising behaviour in health centres (Holzemer et al., 2007). Such unprofessional attitudes from the personnel may deter people from accessing medical support (Nyblade et al., 2009; Singhal & Rogers, 2003). Nyblade et al. (2009) claim that the HIV- related stigma may be caused by a lack of awareness of the damaging effects stigma has. The situation is further exacerbated, as I have noted above, by the space allocated to HCT, and HIV and AIDS treatment rooms which does not enable confidentiality (Population Council and Health Systems Trust, 2006; Steinberg, 2008). While individuals may exhibit stigmatising behaviour, the family and the health care centres are two key institutions that people living with HIV have to rely on (Airhihenbuwa et al., 2009). A person gets to know about his or her HIV diagnosis from a health care centre and the family has to provide health and social support. If stigma exists in both these structures it prevents people not only from accessing such services but also from disclosing their status to the family. If health care workers are thought to be disclosing the status of their patients to the community, this may also deter people from seeking health care, which includes testing and accessing the life saving HIV treatment.

4.3.2.3 Community gossip

Gossip — talking about other people's business — is not a new practice. It can be seen as a way of “maintaining community control through the elucidation of a public morality" (Abrahams, 1970, p. 290). Early writing by Herskovits (1937), an anthropologist, posits that gossiping provides an informal and indirect sanction where one cannot risk an open and formal harassment, or where there are simply no other sanctions available. Paine (1967, p. 278) too, draws attention to the connection between gossip and communication and terms it "information management." The author argues that gossip is, first, a genre of informal communication and, second, a device intended to forward and protect individual interests. Gossip is seen as a purposive behaviour. Halligan (2002), interestingly, rejects the widespread criticism of gossip and defends the activity by stating that it is an interesting and effective method of exchanging news.

Every community has gossip which can divide or bind people together. In a rural community the people are close and they get to know of everything that happens to their neighbours. The gossip that goes around in the rural community emanates from families, friends, health care workers, and teachers and learners at school. What came up in my study is that the gossiping comes from the people on whom the stigmatised rely for support.

> *People will always talk and gossip about people with HIV, even their own relatives, they don't care about stigmatising …*
>
> *The community likes to talk and the advice here is that you must not listen to what people say…*
>
> *Mina ngibona kubalulekile ukuthi uma wenza into yakho uyenze ngokuzimesela ngoba abantu bayohlala bakhuluma ngoba wena usuthole isifo sikagawulayo…*
>
> *[It is important that you concentrate on your health once you are diagnosed with HIV because people will always gossip once they hear you are HIV positive...]*
>
> *I have learnt that in life you don't have to listen what people are saying to [about] you.*
>
> *I have learnt that there are some people who use you in order to get money for food and after that they start spreading gossips that you are HIV positive…*

What is highlighted here is that HIV- and AIDS-related stigma is intertwined with gossiping and victimisation experienced by young people in different ecologies such as the family, friends, school, and community. These findings concur with those of a study done by Campbell et al. (2005a) who, in her article, "*I have an evil child in my house"* describes how a parent would go around telling the neighbours and the community that her child was HIV-positive and evil. She also writes that other families, who would try to keep the knowledge of the infection of a family member quiet, will eventually know through the gossiping which might come from other ecologies such as the health care workers. When a person dies of AIDS-related illnesses, the family often does not disclose the illness for fear of stigma (Campbell et al., 2009). However, there would still be gossip and rumours spreading like wild fire, since the people in rural communities are closely connected. This, in turn, leads to silent suffering sparked by the gossiping and stigmatisation. It seems clear that the silent suffering of extreme vulnerability, in a treacherous environment, fuelled by community gossip, "is relational and is embodied physically, socially and emotionally" (Lee, 2013). It would appear that gossiping is the norm among Africans, irrespective of the context, as can be seen in a New Zealand study done with HIV positive African immigrants. They revealed that African people "are talking, talking, talking" … they can "gossip about you behind your back and come before you and laugh with you" (Poindexter, Henrickson, Fouché, Brown & Scott, 2013, p. 110).

4.3.3 Theme three: 'Culture' fuelling stigma

Culture generally refers to the beliefs, values, and artefacts that hold and bind people together, shaping, modelling and moulding every human being. Individuals and groups are represented within cultures and each culture structures behaviour and shapes the attitudes of its members (Baxen & Breidlid, 2009; Pekarsky, 2009a;). Speaking, eating, religion, beliefs, and norms are instilled by culture (Deacon & Stephney, 2007; Pekarsky, 2009b). Culture, as pertaining to one's roots, cannot be overlooked; it permeates almost everything a person does.

4.3.3.1 A culture of not talking about sex

HIV- and AIDS-related stigma seems to be fuelled by troublesome traditional beliefs regarding not talking openly about HIV, about how HIV is acquired and transmitted, and about the treatment in place for HIV. Not talking about sex is another of these taboos.

The ever-changing face of HIV and AIDS means that we must have accurate information about HIV and must also address the myths that change as the pandemic matures. In a context such as this rural setting, where culture seemingly makes it difficult for some people to freely discuss sex-related issues, myths are likely to exist. The young people pointed to people not being clear about how HIV is contracted thus increasing risk and also stigmatisation.

> *I think that people still lack the knowledge as to how HIV can be acquired…*
>
> *...like that story where they were separating dishes for the person Yes, the person can see that other people don't really know how they can get infected…*
>
> *Many people do not know about HIV and AIDS that is why they stigmatise other people.*
>
> *Some people do not know about HIV and AIDS, they still do not know that you do not only get HIV through sex.*
>
> *The stories are the real things that are happening in the community and it is interesting story and learnt that you can get HIV not only by having unprotected sex but also through a car accident…*
>
> *…and the thing that the topic on sexual intercourse is avoided, and also, indirect words are used …*

The most potent determinant of HIV- and AIDS-related stigma seems to be the supposedly sexual nature of the illness. People ignore the existence of sexuality in young people. Campbell et al. (2005a) confirms that in conservative communities, parents simply do not talk to children about sexuality or about sexual health. “Parents even switch off the TV when something about sexual issues comes up” (p. 410). HIV and AIDS and sex is never freely discussed with youth, and almost certainly not with parents. This clearly ignores the realities of people in communities having sex.

The participants, however, do seem to have knowledge of HIV and how it is contracted. From the stories it becomes clear that sex is viewed as the main transmission route of HIV, but the learners think that their community views sex as the sole method for the transmission of the virus.

> *Many people ... still know that the HIV virus is contractible through sexual intercourse only. Now, in their minds, they don't have that that how a grown person who is found with HIV could have been born with it…*
>
> *If you are involved in a car accident you must be careful because you would not know about the [HIV] status of everyone involved in the accident. Also if you want to assist people who are bleeding in the accident you must wear gloves. From the stories I get that there are many ways in which people get infected.*
>
> *Being HIV positive does not mean that you have HIV because you had unprotected sex even in car accident you get it. People take HIV like it is a bad as if it is always it is about sex.*

There is evidence that lack of knowledge surrounding HIV and AIDS, as well as the harmfulness of stigma related to HIV and AIDS, are cited as one of the major contributors to stigma construction and its drivers (UNAIDS, 2008). In this study, most learners demonstrated an accurate knowledge and a good understanding of the disease although in their communities there still seems to be a lack of clarity, and subsequently an irrational fear about the transmission of HIV. This is similar to findings in Goodall et al. (2011); almost all the learners in the sample expressed significant fear relating to HIV and AIDS. Learners expressed these fears in different ways, some focusing on fear of the physical manifestations of the disease, while other learners (particularly older ones) were more concerned about the social consequences of the disease. Goodall et al. (2011) also found that older learners (grade 9) tended to comment on the impact an HIV-positive status has on relationships with friends and family. It is this kind of limited understanding that causes young minds to stigmatise, and perpetuate such thinking until they are older (Goodall et al., 2011). This points to the need to understand the cause of stigma so as to inform stigma reduction intervention.

One of the implications of not taking about sex and its relationship to HIV is that HIV remains stigmatised, and that people still view HIV as a killer disease and do not seek support in terms of medication such as ARVs.

> *A lot of people still believe that HIV is a killer disease, and they don't know that if it so happens that you already know that you are HIV positive, you can still get help by taking ARV's and by visiting organisations like groups that assist those with HIV. So what I see is that a lot of people are lacking the information that an HIV positive person is like everybody else, and that he or she should live within a community…*
>
> *…the youth end up killing themselves because of not understanding HIV...*
>
> *HIV does not mean it is the end of the road. There is treatment available in clinics.*
>
> *…people have not yet come to an understanding of what HIV/AIDS is because they don't think that it is like any other disease…*
>
> *…you may still be able to live a long and healthy life without even your body showing signs of you being HIV positive. ARV's are there not to cure the disease but to suppress it so that you may still live a longer life…*
>
> *…and another thing is that many people still think that if you are HIV positive, you can die any moment…*

One of the biggest factors that undermine HIV prevention and care is stigma (Ogden & Nyblade, 2005). The complex interplay between the availability of ARVs, HIV- and AIDS-related stigma, and HCT is a challenge. The availability of effective treatment was expected to turn HIV into a manageable condition, by the scaling up of HCT and by reducing self stigma (Roura et al., 2009). However, this is offset by the persistence of stigmatising attitudes and the emergence of new sources of stigma as the availability of ARVs increases. Where "anticipated stigma prevails, provision of antiretroviral drugs alone is unlikely to have sufficient impact on" HCT uptake (Roura et al., 2009, p. 308). While ARVs may be available, many people do not to come forward to ask for them (Campbell et al., 2007).

4.3.3.2 Stigma on the basis of religion

Culture and religion are closely linked, with religion making it clear that certain values are to be upheld: these include the belief that sex outside of marital relations is prohibited, and that sexuality other than heterosexuality is unacceptable and therefore frowned upon. Thus, through religion, the social role of an ‘ideal’ moral person is constructed. By logical extension - through the same process of classification - the social role of an immoral person is constructed. People then reflexively apply such constructions to themselves or others (Lee, 1990). Religious leaders have also contributed to stigmatising by judging those who are HIV-positive by assuming that they have had sex outside of marriage. The participants indicated that religious judgementalism exists in their community context. They, as the youth, are encouraged to adhere to values such as virginity and purity, and if found in the wrong, are warned that some form of punishment will be meted out. This punishment could include not being allowed to perform any church duties carried out by young people or not being allowed to sit with other young people, so that everyone can see that these offenders have indulged in adult behaviour. Given the symbolic interactionist premise that actions are based on the meanings situations have for people, there is a possibility that learners who have been openly shamed might live up to the expectations of an ‘immoral’ person and further engage in sexual behaviour. The following citations show some of the stigmatising statements based on religion:

> *Umzimba uyithempeli lika Nkulunkulu awungancoliswa…*
>
> *[This body is the temple of the lord it must be kept pure…]*
>
> *Besho njalo okusho ukuthi singalokothi senze izinto zabantu abadala singashadile…*
>
> *[They say so, meaning that we should not dare do the ‘adult’s thing’ before marriage…]*
>
> *Phela uma uke wayenza leyo kusho ukuthi usunesono, awuseyona intombi noma insizwa…*
>
> *[if you do that thing its means that you have sinned, you no longer fall under the*

> *youngsters…*
>
> *…you are not allowed to perform church duties assigned to youth…*
>
> *…sometimes you will not be allowed to sit with the youth and also not allowed to sit with the married people…so that everyone can see that you are not doing the adults' thing….*

According to the existing literature, most religions are consistently judgmental when it comes to HIV contraction and how people living with HIV are treated (DeWaal et al., 2006; Paruk et al., 2006). This is more so, as I have already pointed out, because religions such as Christianity, Hinduism, Islam, Judaism, Buddhism and the Bahai faith, to mention a few, advocate abstinence before marriage (Petros et al., 2006; Shefer & Foster, 2009). HIV- and AIDS-related stigma is therefore informed by religious norms about sexuality. HIV is frequently associated with norm-violating sexual behaviour, such as prostitution and adultery, as is AIDS. People tend to hold those infected by HIV as being personally responsible for becoming infected because of their own immoral sexual behaviour such as engaging in prostitution and adultery (Nyblade et al., 2003) and this leads to even stronger stigmatisation. Many regard HIV as a punishment from God for sexual sins (Nyblade et al., 2003).

This construction, from a religious viewpoint, of sex as an activity for adults, along with the stigma attached to learners who are sexually active, is problematic in ensuring safe sex for the already vulnerable young people. This judgementalism then encourages silence and discourages the accession of commodities such as condoms for safe sex, as well as health care services.

4.3.3.3 Stigmatising language

Language is part of culture and how language is used can be part of and central to stigmatisation. Perkarsky (2009), indicates that speaking, behaviour and other norms are instilled by culture. The choice of words when we are talking about HIV and sex clearly has power and impact in the sense that it ascribes certain identities to behaviour, identities that have an 'othering' connotation (Lee, 1990). When words are used in a derogatory way, the context in which these are used adds to the meaning they carry. The participants' responses to the disease were reflected in their identification and re-naming of it, as illustrated by the following examples.

> *Words like Lamagama u HLengie Ivy Vilakazi and OMO …The words are very painful because they can be used in front of the person with HIV and the very same person who is trying to get her life together… …Ivy , omo, isifo sikagawulawulayo….*
>
> *Amagama amathathu...*
>
> *[Three names…]*
>
> *…useshintshe isibongo, sewakwaKhumalo.*
>
> *[**…**meaning the person is now 'swallowing [powder]'…]*
>
> *Usedla umgcakazo.*
>
> *[He is now eating grain.]*

The above identification and re-naming of HIV and AIDS concur with Goodall et al.'s (2011) findings in the study in which learners mentioned that there are numerous euphemisms for HIV and AIDS, three of which are commonly used, namely: '*Iqoks*', '*amagama amathathu*' and '*Z3*'. Directly translated, '*iqoks*' is a thin high heel shoe (stiletto like) which learners relate to the weight loss experienced by people with AIDS, but which also makes reference to sex work (Goodall et al., 2011, p. 191). *Amagama amathathu* means 'three names' in *isiZulu* and references the acronym HIV which has been used since the early conception of the virus (see also Francis, 2004).

There are several reasons for using these euphemisms and one is to maintain secrecy (Goodall et al., 2011). As mentioned by one of the participants in that study, the names enable a "… third party to speak about the virus without alerting or offending people with HIV and AIDS" (Goodall et al., 2011, p. 191). Renaming the disease might also be a form of othering since many of these euphemisms are derogatory. For instance, '*iqoks*' and '*Z3*' carry negative connotations which evoke images of sex work (Goodall et al., 2011, p. 191). These euphemisms also make it possible to talk about sex a bit more publicly and, since it is common in African culture to avoid talking about sex related issues, especially using the correct words (Lubinga & Jansen, 2011), it can be useful. Motalingoane-Khau's (2010) study with female teachers reported that they prefer to use English words rather than talk directly about sex and issues of sexuality in their indigenous language. In this study we found that some names are derogatory and the participants use names like *Usengu Khumalo* (He has changed his surname to Khumalo) where 'khuma' is loosely translated as '*swallowing a mouthful powder'*, so, to ensure that they are able to use the term in a derogatory way and also ensure that the person does not notice that they are referring to him, they use the surname Khumalo. Other terms such as *usedla umgcakazo* (he is eating granules) to say that a person is taking ARVs are also used. Although unintentional, these euphemistic ways of talking about HIV and AIDS are seen as 'othering' the condition, a condition that cannot be spoken about openly. Clearly, this kind of talk creates an 'us' and 'them' divide, suggesting that the community has not yet learnt to deal with the issue of HIV and AIDS, leading to further HIV- and AIDS-related stigma.

The role of terms used in a language, particularly in communities, is very important. Language is determined by context and linked to culture (Airhihenbuwa et al., 2009). For example, the meaning of terms may be understood only by the people in that community since the meaning may change. For example, *ukuzeka*, in isiZulu is getting married, in Nguni languages, such as SiSwati, *ukuzeka* means 'having sex'. As Airhihenbuwa et al., 2009, p. 427) put it, in a community dialogue, attention must be paid to the "language used, expressions (verbal and nonverbal) used for communication, and meaning ascribed to what is being discussed". The point that I am raising here is that words may remain the same but their meanings change as they cross cultural boundaries. "The importance is not always *etic* (scientific) accuracy of usage but rather *emic* (cultural and community understanding) of what is being discussed" (Airhihenbuwa et al., 2009, p. 427). For example, derogatory terms such as 'winning the Lotto' (Uys et al., 2005, p. 11), when referring to an HIV-positive person who is on ARVs, can be understood contextually and culturally. Some of the derogatory terms used in certain geographical areas do not carry the same connotation as they do in other areas. Mills (2006, p. 499) also studied how "stigma inhabits the symbolic realm of words and gestures," for instance, two people can use three fingers (standing for HIV) to "secretly communicate that the third person in the group is HIV-positive.” Not only that, the terms such as the *'riding Z3, umahosha'* (a sex worker, are sometimes widely used and understood, as well (Goodall et al., 2009, p. 191).

4.3.3.4 Early sexual debut

In Zulu culture, the culture of the participants, some practices such as virginity testing for girls are still in use to encourage the delay of sexual debut until marriage (Buthelezi, 2006). In the Nguni culture, of which the Zulus are part, it is instilled in young girls' minds that they are the pride of the family and the Zulu nation, and that their purity and virginity are very important since they are considered to be the wealth of the family. Even if a girl is born from a poor family, the family, especially the father as head of the family, will hope for riches coming in the form of bride wealth (*ilobolo*), paid by the groom in appreciation of the virgin bride (Hunter, 2011). *Ilobolo* value depends on the virginity of the girl. If the girl is found not to be a virgin, but so-called damaged goods, the value depreciates. Her parents have to charge fewer cows, depending on how ‘damaged’ the girl is. Therefore, girls are encouraged to remain virgins, so that the *ilobolo* is charged in full. It also brings disgrace to the family if the girl engages in sex before marriage and, even worse, gives birth before marriage. Here too, sex before marriage is stigmatised.

> *…so when you are young you suffer more, you are accused of doing adults ‘things’*
>
> *…the fact that they want to go do virginity checks on girls is also a stigma…*
>
> *yebo siyatshenwa ikuthi masigcine isibaya sikababa sivalekile*
>
> *[...yes, we are always reminded to keep our father’s kraals closed...]*
>
> *Kwesinye isikathi bathi, izozwa indoda uma inkomo ingaphele...*
>
> *[Sometimes they tell the men will know if the ‘cow’ does not have an eye [if we are no longer virgins]*
>
> *People still think HIV can only be contracted through unprotected sex…*

It is worth noting that one of the root causes of stigma, according to the participants, is the link between sex, HIV and perceived sexual immorality (Campbell et al., 2007). This suggests a link between HIV and a conservative sexual morality, linked to culture and then closely linked to the control of young people (see Campbell et al., 2005b). The stigmatisation of sex is particularly marked in relation to young people. There are some programmes such as the virginity testing that are in place and which aim to ensure that girls delay their sexual debut.

This study has also revealed that in KwaZulu-Natal, *ukuhlola* (virginity testing) encourages stigma in relation to young girls who have lost their virginity. A young girl will be seen to be bringing stigma to her family if her hymen is not intact. This is illustrated here:

> *Izingane sisheshe zicale ucansi…*
>
> *[The youth engage in sex very early in their lives]*
>
> *Nalena isiyenza? imihlola le!...*
>
> *Even this one is sexually active, this is really taboo!...*

Therefore to avoid the loss of physical virginity, they engage in anal sex which will protect their hymens but they ignore the fact that this exposes them to HIV. Clearly, being stigmatised for having lost one’s virginity, opens up the possibility of engaging in other risky behaviour. The following quotation shows how the young people are obliged to keep up with cultural practices.

> *Some girls practice anal sex, to protect their virginity and that is how they contract HIV.*

Culture is described as dynamic in nature and transmitted from one generation to another. It is not fixed and can change and develop (Turuk, 2008; Vygotsky, 1978). Culture is also multi-layered and multi-faceted and in a culture in transition new things are added and others are adapted, and some are changed. Behaviour or characteristics that evoke stigma are defined by the cultures or subcultures in which they occur, and are, in this sense, socially constructed (Neuberg, Smith & Asher, 2000). Stigma, therefore, is a complex social process dependent on specific cultural contexts (Maughan-Brown, 2006; Parker & Aggleton, 2003). Culture influences psycho-social issues such as the HIV- and AIDS-related stigma

4.4 SYNTHESIS

The chapter presented three major themes which emerged in answer to the first critical question: “What can digital storytelling reveal about secondary school learners’ experiences of stigma in schools in a rural community?” The themes were presented with their support in categories. I discussed each category; direct quotes were taken from raw data to support the findings, while the literature was used to recontextualise them. The next chapter presents the findings in answer to the second critical question: “How can digital storytelling enable secondary school learners in a school in a rural community to take action to address stigma?”

CHAPTER FIVE

FINDINGS AND DISCUSSION

DIGITAL STORYTELLING ENABLING SECONDARY SCHOOL LEARNERS IN A SCHOOL IN A RURAL COMMUNITY TO TAKE ACTION TO ADDRESS STIGMA

5.1 INTRODUCTION

Having presented the findings of what digital storytelling can reveal about stigma, in this chapter, focusing on digital storytelling and taking action, I present the findings for the second research question. Here, too, all data sets were used and two major themes, with supportive categories, emerged. The findings are discussed and contextualised within the literature. In the next section I introduce the summary of the findings using themes and categories.

5.2 DIGITAL STORYTELLING AND ENABLING SECONDARY SCHOOL LEARNERS IN A SCHOOL IN A RURAL COMMUNITY TO TAKE ACTION TO ADDRESS STIGMA

Themes four and five (see Figure 5.1) emerged in the answers to the second question, “How can digital storytelling enable secondary school learners in a school in a rural community to take action to address stigma?” Two themes emerged: digital storytelling enabling learners to take charge of stigma; and digital storytelling enabling a critical space for participation.

THEMES	CATEGORIES
THEME 4: ENABLING TAKING CHARGE OF STIGMA	• **Strengthening resilience** • **Promoting education** • **Easing talking about disclosure** • **Halting Stigma** • **Dissemination to the community**

THEME 5: ENABLING A CRITICAL SPACE FOR PARTICIPATION	• **Democratic space for engagement**
	• **Sharing experiences**
	• **Trying out digital media**
	  ◦ *Making voices heard*
	  ◦ *Using media to educate*
	  ◦ *Going online*
	• **Bridging digital divide**
	• **Remembering new stories**

Table 5.1: Digital storytelling enabling taking action

Digital storytelling allowed the participants to creatively express meanings and emotions, and to realize the complexity of their experiences. In both the process and product, it came out clearly in this study that in exploring experiences, addressing, and taking action towards HIV- and AIDS-related stigma, digital storytelling can enable the taking charge of stigma as well as create a critical space for participation (see Hull & Katz 2006; Lowenthal,2009). The stories the participants told about their experiences were influenced by the digital storytelling process which enabled them to tell what they know and also to offer possible solutions. This is illustrated by the following themes.

5.2.1 Theme four: Enabling taking charge of stigma

The learners showed that they are able to do something about the situation of stigma they experience and see in their school and community. The use of digital storytelling allowed for strengthened resilience, agency in ensuring that the individual self and the community become educated, halting stigma, easing disclosure, and enabling information dissemination to the community.

5.2.1.1 Strengthening resilience

The digital storytelling data shows that these learners do not consider themselves as powerless; the participants seem to breathe resilience. They de-stigmatise and re-define the realities of HIV- and AIDS-related stigma in a rural context with all its complexities. As has been highlighted in Gubrium (2009), digital storytelling has the potential to influence health and resilience through the sense of ownership of the story and being able to tell one's own story and to reflect on the story with others. This is illustrated in the way the different participants alluded to being proud of who they are; taking care of themselves; not being ashamed of poverty; and holding onto their dreams of the future.

> *I believe that as a person one should not be looking at what the other person may have, be satisfied with what has been given to you and the life that you have because that is what also leads people to contracting the HIV virus…*
>
> *You have to be proud of who you are, even if you are HIV positive you are human…*
>
> *…the thing is that we should be satisfied of what we are…*
>
> *You do not have to engage in risky behaviour because you want or need money but you have to be proud of yourself even if you are poor...*
>
> *If you coming from a poor family you must accept who you are than being afraid being stigmatised for poverty and later for HIV…*
>
> *Take care of yourself and forget about what other people are saying because you can live a long life. Whatever name they give to you as label, just ignore…*
>
> *I hope that those who do not have parents could take care of themselves…*
>
> *…when you are poor you can stay poor, you don't have to go and do something.*
>
> *We are capable of running our lives because we can recite what tradition says*

> *about the Bible, it says that our body is God's temple, therefore, we should respect ourselves and take care of our body.*
>
> *...and that a person, in life you shouldn't listen to what people are saying about what you are doing because a lot of people don't want to see other people succeed…*
>
> *…there are successful people that have passed through way more difficult situation than they have. So, young people should get up and work so that they can succeed in life…*
>
> *…let's not be distracted by what people say or do as that will not help us fulfill our dreams…*
>
> *Young people should just stop expecting things from other people, they must take their lead to better things…*

Resilience can be defined as being able to cope with disruptive, stressful or challenging life events, drawing on protective and coping skills (Cyrulnik, 2009). Theron and Theron (2010) add that resilience is the successful adaptation to the environment despite exposure to risk, while Donald et al. (2006) describe it as the ability to cope and bounce back from difficulties. Resiliency theory assumes that, against all odds in life, individuals can regain their lost social comfort, depending on how they manage stress, and the level of social support they receive (Theron & Theron, 2010). Resiliency recognises that in spite of adolescents being subjected to stigmatising and being stigmatised, there are some who rise above that situation. Although resilience is not at the centre of this study, I take cognisance of it as "[c]onnecting resilience with how a person interacts with his/her community is consistent with symbolic interaction theory that creating and maintaining meaning within a particular environment is central to all human relationships" (Behrman, 2012, p. 9).

The resilience in the learners was striking as was the fact that they showed hope and optimism in living with the given realities of HIV- and AIDS-related stigma. These findings concur with the fact that youth can "respond to structural influences, they can make their own decisions with respect to a number of major, as well as minor, life experiences, and they can actively shape some important dimensions of their experiences" (Evans, 2002, p. 261). Thus, "meaning is not fixed, and immutable; it is fluid, modifiable and open to reappraisal" (Chamberlain-Salaun, Mills & Usher, 2013 p. 5). Put simply, the stories enable the learners' resilience and their taking up of their own agency. Moreover, comments such as the following show that the stories allowed them, at an individual level, to act, supporting the idea that people are active agents rather than passive respondents to external stimuli (see Lee, 1990).

> *Mina ngiyakholelwa ekutheni uma ngabe bekukhuluma kabi bekuthuka bekusho nokuthi ngeke ube nempumelelo empilweni, ngiyakholwelwa ukuthi uma bekuthuka bakunika amandla okuthi uqhubekele phambili.*
>
> *[Even though people may wish that you do not succeed in life, I think that you should take it as a positive reinforcement.]*
>
> *...futhi uma ngabe usutholile ukuthi une HIV/AIDS ungazibulali, futhi ungaphuzi uphuzo oludakayo, yiba nesibindi, ubhekanenenkinga yakho.*
>
> *[...a person living with HIV does not have to commit suicide, or abuse drugs. Have courage and face the problem that is facing you.]*
>
> *I am also seeing that many people have got the tendency of that when you are poor then you should expect people to care for you, of which is wrong. You are the person who stand up for yourself and do what you think is best for you and stop wanting money you would have to give your body for… it doesn't mean that your parents' dying is the end of the world.*
>
> *You should know who you are and where you come from, and what you need from life...*
>
> *Be confident of who you are and stop paying attention to people, like if people are laughing at you. It's good to focus on school which is the only way for you to succeed in life…*
>
> *It's just that in life you meet many challenges in order to succeed…*

The evidence in this study signifies that the “younger generation [is] becoming pro-active in the face of risk and uncertainty of outcomes, and are making pragmatic choices for themselves which enable them to maintain their aspirations despite the persistence of structural influences on their lives” (Evans, 2002, p. 249). This study has revealed that the youth can challenge poverty and wealth inequalities at a structural societal level which remain an overarching challenge in addressing HIV and AIDS in youth (Bhana & Petersen, 2009). It was encouraging, though, to hear what the participants had to say, as is reflected in this unsolicited poem. It was written by one of the participants who wanted to contribute solutions in a creative way.

> *Accept who you are*
> *Be a person you want to be*
> *Stay positive with your life*
> *Be a confident person and a critical thinker*
> *Love yourself and respect yourself too*
> *Learn to accept your situation, find help from project of HIV+*
> *Never give up, face the challenge*
> *Do not listen to people who want to destroy your life*
> *Do not forget that we have to pray*
> *Be faithful to your partner*
> *Never have sex without protection*
> *Life is too serious to be taken serious*
> *Trust in yourself, be faithful in yourself*
> *Be free, use your human rights in your community*
> *Fight for life, never mind people.*

The use of animal metaphors, and the related symbolism, also reveals something about the participants’ resilience. An interesting comment from one participant shows a tension between using animals as metaphors and equating an HIV-positive person to an animal.

> *Kubalulekile ukuthi sifundise umphakathi ukuthi umuntu one HIV akasisona isilwane kodwa ungumntu usaphila ufana nathi, akusho ukuthi uma une HIV sekufanele ulahlwe, uthukwe*

> *[It is important that we teach the community that an HIV positive person is not an animal but a person like everybody; it does not mean you are supposed to be ill-treated*.]

I also asked the participants why they chose the animals they chose and what the animal meant to them. The following quotations, from Snail, Lion and Mosquito, show the reasons participants put forward.

> *As a snail, I have a humble personality. When people kick me and confuse my direction, I am the one who apologise by returning to my shell and stop for a moment. But my antennae (which give me direction and determination) would come out again and I will continue with my journey. Even if I am in conflict with other people, that is what I do, apologise, but would continue with what I believe is good for my life.*

The participant further said:

> *What I can say is that we show what kind of community we come from. We show that in growing up we faced many challenges, the people we meet, and the way in which we present ourselves…*

When I asked the participant who chose to represent himself as a lion why he did so, he referred to how lions draw strength from being together in a pride:

> *Do you know that some people do not know the flexibility the lion has? Some people think a lion only attack[s] but lions go in a peck [pack] to make sure they protect each other. They can attack enemies and also what is important is that they provide for their young ones.*

The participant who chose to represent himself as a mosquito, also introduced the notion of resilience in the telling of his story, thus showing his own agency:

> *Like a mosquito, which is born without wings and the wings develops late but still the body is bigger than the wings, that is the way I symbolize, with all the challenges I have and that I have nothing for now. I will fly high with my wings and make sure that I live it big in the future and protect myself from those who*

> *block my way with the sting that I have. I want to fly high in the presence of HIV and AIDS and the stigma and produce what people will like.*

These utterances by learners confirm the notion that human behaviour is influenced by the meanings ascribed to objects or people (Blumer, 1986). In this case, learners chose animals they felt revealed certain traits that helped them to express how they make sense of stigma. It is worth mentioning that the participants' use of animals in storytelling — in this case offering their experiences of stigma (either their own or that of others) — is not new in African cultures. In the context of this study it enabled me to understand the participants' meaning making through engaging them in a social practice they were familiar with. An interesting project I referred to earlier, "*Storytelling in the waiting room*" (Zeelen et al., 2010) confirms how storytelling can help break the stigma surrounding HIV and AIDS. The storyteller used dialogue between animals to create openness about the disease. The pioneers of the project assumed that such stories would encourage people to internalise the messages rather than just taking in information about HIV and AIDS cognitively (Zeelen et al., 2010).

The digital storytelling, in its use of animal metaphors, enabled the participants to reflect on the experiences of stigma, thus showing their resilience.

5.2.1.2 Promoting education

Participants, in taking up the notion of agency, recommended education and HIV education as a way towards understanding and addressing HIV- and AIDS-related stigma. They, too, like Bhana (2008) and Kelly (2002), believe that education is fundamental to addressing HIV- and AIDS-related stigma. First, the learners themselves ensure that they themselves are educated, and second, that they contribute to a community dialogue in which positive and non-stigmatising practices are discussed. Education in general is regarded as very important.

> *Education comes first, afterwards you can enjoy your life, that is having girlfriends and boyfriends.*
>
> *You have to focus on your studies and be what you are …*
>
> *Sometimes in life you find some difficulties but you have to focus on your study*

> *and don't think boyfriends can change, they are all the same, just be what you are...*

Participants in this study showed that they were aware of their own agency. Through the digital storytelling process, the agency of participants featured in ways that, as Gubrium, (2009) points out, a pre-structured research agenda could not demonstrate. Agency is understood as the input from the young people as individuals, "emphasising those aspects of social engagement which are predominantly individual, creative," and "proactive and [which] involve resisting external pressures" (Evans, 2002, p. 261). Agency in this context refers to understanding one's situation; taking action to change it and becoming resilient in the process and in being personally and actively engaged in taking initiative and control of a situation (Donald et al., 2006). They were aware and had become more aware of their own knowledge and aware that they could use the knowledge to educate others.

"Digital storytelling, as a method for community participants to produce something concrete and tangible out of their experiences", constitutes "a 'forum' for advocacy on issues of concern" (Gubrium, 2009, p.189), in this instance HIV- and AIDS-related stigma. I noted how participants themselves animated the meaning making of their experiences, and participated in creating shared meanings. Digital storytelling can be a powerful tool for opening up ideas and strategies for communication, exchange, and "dialogic awakening" between the researcher and community partners (Ohler, 2006, p. xx), and between the participants and the community. Digital storytelling enables the defining and articulation of meaning to be redistributed.

Education is not seen as an event, but as a process which needs time, financial and social support and commitment from families and the entire community. Educational initiatives have shown promise in reducing HIV- and AIDS-related stigma and the promise of digital storytelling as a tool for engaging with stigma and taking action in educating the community could be a critical way of addressing HIV- and AIDS-related stigma (Surkan et al., 2010). This was well articulated by the learners:

> *…what I have learnt is that there are still some people who lack information on HIV, I mean people who don't understand HIV… we have to educate those who don't understand HIV…*

> *…we have to educate those people who take care of people who are HIV positive and those who live with those children who lose their family because of HIV…*
>
> *…These stories we can use to educate people…Use these stories to educate, they have messages good for our people*
>
> *…I think all the people must fight against this disease, they must learn more about it and to the people who more about this HIV, they must try to sit down with people that lack information on HIV...*
>
> *…call for HIV workshops, campaigns…and use the digital stories maybe one at a time…*
>
> *…have an HIV motivational speaker…*
>
> *Find a counsellor who will speak to the people about HIV…*

Although some authors such as Deacon et al. (2005) argue that providing young people with factual information about HIV does not equate to stigma decline, some studies have shown that levels of AIDS-related knowledge is inversely correlated with stigma (Kalichman et al., 2006). Again, there is substantive evidence on knowledge that has been documented about the futility of education when it comes to addressing stigma, and the fact that education only is not able to address this (Bhana, 2008). The participants, however, point to how the education should be carried out: one should “sit down with people who lack HIV information”. This suggests a collaborative sharing and learning from each other, not a uni-directional transmitting of knowledge. This resonates with participatory work done with community health care workers where the community members, too, indicated that there should be a sitting down together (De Lange & Mitchell, 2012).

In South Africa, a notably large-scale educational programme using peer education methods has been initiated by *Rutanang* (a Sotho word for ‘learning from each other’), collaboration between government, NGOs and educational institutions (Bhana & Petersen, 2009). There have been a number of other education programmes in sub-Saharan Africa which have used learners to educate their peers in high schools (Bastien, 2008). Education programmes using the peer educator concept such as “the ‘popular opinion leader’ model,” has been tried “as a mechanism for facilitating a change in social norms, with promising outcomes” (Mathews in Bhana & Petersen, 2009, p. 62). “The popular opinion leader model has its roots in diffusion of innovation theory with the idea that a popular, respected and influential member of a group network can influence [education] to invoke a ‘tipping’ in the social norms” (Bhana & Petersen, 2009, p.62).

HIV- and AIDS-stigma education programmes must, however, be specific and must focus on community needs. As such, digital storytelling seems to be able to draw on the stories from within the community to educate those within the community, making this relevant and appropriate for the community.

5.2.1.3 Easing talking about disclosure

Digital storytelling was seen as a tool for easing disclosure amongst the participants as they were sharing issues based on their experiences or on their understanding of the experiences of others in the school and community. The participants felt that disclosure was the starting point for them to know what was happening in their communities, and they felt enabled to talk about the challenge of disclosing. This was indicated by extracts from their writing such as these:

> *We have to know that HIV is like every disease that is out there… I understand the story…*
>
> *…because things like this we find them mostly in our community, in our families because us black people we are so scared to come out and tell the truth…*
>
> *Mosquito has a big problem with his cousin because he did not know about his life while he was staying at his aunt place. His aunt eventually tells her children that his biological parents passed away and he felt bad when he got the story….*

It is debatable whether disclosure can normalise HIV as a disease since people still fear the negative consequences of disclosure such as being more vulnerable after disclosure (Gilbert & Walker, 2010; Obermeyer & Osborn, 2007; Kehler, 2013). In this study, the issue of disclosure seemed to uncover a point of tension: the participants show that there is a need for disclosure while at the same time there is fear of the response of the other when disclosing. Their foray into the issue of disclosure also opens up thinking about why disclosure is necessary, and whether it is to benefit the HIV positive person or to protect the community (Kehler, 2013). As long as HIV is associated with immoral behaviour the issues of disclosure and confidentiality will continue to pose challenges. The ideal, then, would be to create a safe space for disclosure so that HIV, just like fatal illnesses such as some forms of cancer, could become more normalized (Roura et al., 2009). The participants, however, did not discuss whether the HIV- positive person has a right to choose whether to disclose or not (Kehler, 2013).

The impact of othering on practices of disclosure is illustrated in some extracts. The words I highlight below are personal pronouns, but the participants could have referred to those with HIV as "people living with HIV" without fear of stigmatisation as one participant did:

> *We should not exclude **people living with HIV**, we must love and support them because they are not different from us*.

If is encouraged, there should be no fear and shame when we talk about the illness, even as we are being sensitive. While the participants were advocating for normalising of the disease, the way the solutions were given, such as providing support and care, still implied othering.

> *What we need to do is to take care of **them** [infected and affected], give **them** what is needed at a particular time and support **them**…*
>
> *The only thing we are supposed to do is to support **them** and give **them** hope*…
>
> *Asingahlukumezi abantu aba HIV+, Asibathande, sibasaphothe bayafana nathi.*
>
> *[We must not give HIV+ people tough time, let us support **them**, as part of our community]*

The difficulty of normalising HIV and AIDS became clear in the voice of the participants. While they are calling for an openness and acceptance, the othering still exists in their language even though they are against stigmatising. This resonates with a study in which “some parents and guardians began asking healthcare providers to avoid using the words HIV and AIDS around their school-age children” (Wiener et al., 2007, p. 3). This shows how the young people end up avoiding the use of such words. The way we speak about infected people is sometimes inadvertently stigmatising. While support and caring is suggested, there is still a divide between ‘them’ and ‘us’.

This digital storytelling narrative shows, on the one hand, that the participant knew that disclosure caused stigmatisation, and on the other, that disclosure and openness could help to address stigma:

> *It is hard for me to go to the clinic and get my ARVs because I always hear people, adults, even those with HIV, gossiping about me when I am in the clinic to get my treatment. …My friend’s mother works in the same clinic and helps me with my needs such as the ARVs and the food that we get from the clinic. I always throw it [food] away in fear of bringing it to the school since I start at the clinic then to [go] school. The other students call me names and judge me because of my status. I fear carrying the food parcel because is known that it is donated to the HIV positive people although I need the food, this affects me at school even my school work has declined…*
>
> *I wish people can come to a better understanding about HIV and stop stigmatising so that I can feel accepted especially [because I am orphaned] orphans.*

Although there is treatment and support in place, the issue of disclosure remains a challenge because of stigma. Worldwide, HIV related stigma cause difficulties in the managing and provision of HIV treatment (Calin, Green, Hetherton & Brook, 2007; Obermeyer & Osborn, 2007). This also affects the attitudes for people who provide HIV-related care as pointed out by Steward et al. (2008). The issue of disclosure remains a complex issue since those who acknowledge that HIV exists, according to Babalola, Fatusi and Anyanti (2009), often do not refer to it as HIV or AIDS but call it ‘this thing’, ‘this disease’, ‘this animal’ or just a ‘sickness’ that does not have a name. This shows that something needs to be done to address and halt stigma, so that people can talk openly about HIV and AIDS, disclose their status, and access the care and support the require.

> …o*nly to found [find] out that she was HIV positive and she found out that when she went to take [do] a[n] [HIV] test at the clinic. She does not go out anymore and hardly even go to school*.
>
> *…emva kwezinyanga ezimbili ngahamba ngayohlolela igciwane lengculazi. Ngathola ukuthi ngiHIV positive. Emva kwalokho ngagula kakhulu ngaze ngehla ngisho nasemzimbeni. Abangani bami bangibuza ukuthi kwenzenjani njengabantu ebekade sitshelana nabo izimfihlo, ngabatshela ukuthi nginegcewane legculazi. Kusukela ngalelo langa angizange ngibabone bengivakashela nasesikoleni abasafuni ukuhamba nami.*
>
> *[…after two months I went to do an HIV test, I found out that I was HIV positive. After I knew about my status I got sick and I lost weight. My friends were worried about me and they asked me what was going on with me since we never keep any secrets among ourselves. I told my friends about my HIV status. After that they never paid me a visit at home and they stopped to hang out with me at school*.]

Even though the participants did not resolve the issue, the digital storytelling enabled them to think about and discuss the issue of disclosure.

5.2.1.4 Halting Stigma

During the discussions the participants showed that it is also within them to choose to stop stigma although they were a small group. This reminds me of Margaret Mead's words, "Never doubt that a small group of thoughtful committed citizens can change the world… Indeed, it is the only thing that ever has" (quoted in Palmer, 1992, p. 5). They articulated their views that they should set an example by providing care and support and by being non-judgmental.

In their discussion on solutions the participants pointed out that one way of eliminating stigma lies in showing support and providing supportive care in their communities. They believe that if there could be support and care for those who are affected and infected by HIV, the tide can be turned. This was picked up on when participants indicated the need for support for self, others and the entire community.

> *I have learnt from the sessions that HIV positive people need support and that they are our brothers and sisters, we have to cover them with warm blanket…*
>
> *The only thing we are supposed to do is to support them and give them hope about their lives…*
>
> *…be helpful to people, love them, care and respect…*
>
> *…to tell young people more about HIV and AIDS, like if you are HIV positive, it is not over about your life and show them love, support them. Singababandlululi (We should not discriminate them), they are still humans, (bangabantu) just like you and me…*
>
> *…People must not abuse orphans and label them using the disease that killed the parents...*
>
> *…It is important to find support system than to engage with risky behaviours…*

The learners see the agency in themselves and their being able to contribute in providing care and empathy for HIV-infected and HIV-affected people. This resonates with Ogden and Nyblade (2005) who point out that a key determinant of effective HIV prevention and AIDS care is the existence of a humane and supportive environment for people with HIV and AIDS. This includes the school where a child spends most of her time, and which should be a humane and supportive environment. Sheen's work (2013) confirms that peer acceptance and social support is shown to mitigate the effects on children infected and affected by HIV and AIDS. From the learners' quotations it seems easy to suggest that people must be empathetic to those who are affected and infected by HIV, but it is clearly a process that needs to be worked on.

The learners also suggested that people should stop being judgemental and not use false beliefs as a basis for judging. For example, in the early days of HIV infection, people who had it, or AIDS, would lose weight and become very thin until recently that there is ARVs in place. The loss of weight, (whether the person was HIV-infected or not), was a signifier of the illness and was used to stigmatise the person who had lost weight. The learners' approach to the experiences of stigma and being judged was that they themselves could begin by being non-judgemental.

> *I have learnt that if you are skinny, that does not mean you are HIV positive…*
>
> *We don't have to judge a person by looking at him or her…*
>
> *The other thing that I have learnt is that you don't have to stigmatise people because of their status because we are the same…*
>
> *…they are still human being like us…*
>
> *People should just stop stigmatising …*
>
> *…solution is that do not discriminate a person because you see him or her becoming thin because you cannot know what is affecting him or her....The solution is that do not judge a book by its cover…*

These extracts from what the participants wrote, all point to the notion that judging by individuals can be addressed through individual agency and by taking action through their own participation, their refusing to judge, and in empathising with people infected and affected by HIV and AIDS.

5.2.1.5 Dissemination to the community

The community should be involved to get an insight into the different cultural and contextual meanings of HIV- and AIDS-related stigma. This could provide essential information, which is community-based and contextual which could serve as the focus of the stigma intervention. Drawing on information about stigma which is context-specific is crucial for the effectiveness of an HIV- and AIDS-related stigma intervention (Bos et al., 2008). This was crystallised in these participants' statements:

> *When I listened to the stories I felt the need of the availability of information through people of rural areas…*
>
> *What I have learnt in this session from other friends gives me more understanding and more information about HIV, I feel I can go to my community and share with them these stories and maybe it can change the way they treat people with HIV…*
>
> *We, especially us the youth, to educate older people in the community…*

> *HIV and stigma is a problem in our community, they stigmatise others and we must involve the community to stop stigma.*
>
> *I think that South Africa, Africa or the whole continent must sit down and try to look at if all the people really understand what HIV is, especially to the people that are living in the rural areas because in rural areas they lack information about this virus.*

Consistent with the body of community-based participatory research, the above points to the need for models of research as interventions that take greater account of the complex nature of stigma, its multilevel nature, and how it plays out in a particular context. Involvement of the community may even require being involved in the preparation and implementation of a collaborative program proposal and could draw on real and relevant stories from the community to tailor the programme (Bos et al., 2008). Addressing HIV- and AIDS-related stigma may call for “collective action to initiate critical thinking about the role of social institutions in the marginalisation and social exclusion” (Campbell et al., as cited in Bos et al., 2008, p. 457) of the people affected as a means of stigma reduction initiative at school and at community wide level. HIV- and AIDS-related stigma in sub-Saharan countries is quite a complex psycho-social phenomenon that is related to culturally and context-specific beliefs and values (Bos et al., 2008). As such, it has been documented that HIV- and AIDS-related stigma interventions programmes in communities can be effective only “when based upon a context-specific needs assessment” (Bos et al., 2008). It is also important to have a spirit of working together amongst those — stigma researchers, affected and infected people, and relevant parties — who develop the programme and to implement it (Bos et al., 2008), as the following extract from a participant points out.

> *…and to the people that know more about this HIV virus, they must try and sit down with the people that research about HIV…*

In this study participants stand by the importance of community involvement in local responses to HIV- and AIDS-related stigma, through the use of digital storytelling, which brings the specific stories of the community to the fore. Although social environments cannot be changed to maximally support community involvement, researchers with participants could do something towards the possibility of working with the community (Campbell et al., 2010). The entire community should be involved in stigma reduction strategies which are participatory and which draw on the agency of the community.

5.2.2 Theme five: Enabling a critical space for participation

Digital storytelling enables space for critical participation, in which participants can engage in a meaningful way with the issue at hand.

5.2.2.1 Democratic space for engagement

Mitchell (2008) and De Lange (2012) address the notion of democratising research. They both indicate that 'democratising research' is not a new concept, and that it has been referred to broadly as research that enables academic engagement and participation in community life, which, in turn, enables research participants to guide the direction the research inquiry takes and then, again in turn, enables researchers to take up their social responsibility in society. The notion of democratising research (Cole & Knowles, 2008) therefore 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" (De Lange, 2012, p. 5). They will help generate, analyse, represent and disseminate the data derived from their communities. This data will enable them to take action and thereby make a difference in the communities where the research takes place.

Digital storytelling, used with CBPR in this study, enabled participants to participate in their own language and to discuss local community issues which affect their lives. The participants were familiar with their own contexts and they addressed issues which concerned their life situations and struggles, and offered some thoughts about solutions. Digital storytelling increased their space for sharing views, learning from each other, and reflecting and thinking about solutions to addressing HIV- and AIDS-related stigma as these extracts from their writing show:

> *Today it was cool because we listened to our stories and together we raised our views about each and every story…*

> *What was good was that we even used our own language for discussion and we spoke about things we all knew…*
>
> *…but overall this project taught me a lot…*
>
> *I learnt that we think differently about stigma thing and that we get stigmatised by our family members.*
>
> *I had experienced a number of the things we were sharing with the others but I had no chance of sharing it or telling others yet they also see these things…*
>
> *Kulesession sifunde okuningi ngizwile izindlela eziningi abanti abastigmatiser nagazo abantu abanegciwane, abanezihlobo ezinaleligciwane nabasiza abantu abanegciwane…*
>
> [*In this session I learnt a lot including the different ways in which people stigmatise people with HIV, affected by HIV and those who help people with HIV*].
>
> *It was great opportunity for us because we were given a chance to think for ourselves, and discussed issues where we needed clarity…*
>
> *I actually like that after listening to the stories we asked to provide solutions which can work in our communities…*
>
> *HIV brought a lot of issues in our communities….A lot of things I have experienced in my life but did not take notice of and did not take action, but now I understand and I will try and do take notice of them in future.*

The above extracts show that the participants were interested in, and motivated by, the way they engaged with digital storytelling. This corresponds with the findings of Davis (2004) and Hoffer and Swan (2006) regarding students' engagement with digital storytelling. They affirm that "digital storytelling, unlike traditional instructional strategies, engages students in the "language of their generation" (Lowenthal, 2009, p. 298). Enabling participants to have maximum participation and to take a lead in the research process shifts a "researcher-centric construction of the social world to that of the participants" (Clark et al., p. 14). The data generated by these participants represents “an intersection between personal biography, culture, positionality, politics, and aesthetics” (Clark et al., 2010). According to Banks (2001, p. 179), “social research has to be about engagement not exercises about data generation”. In this study it was possible to engage the participants through the fact that digital storytelling offers an appropriate and exciting way to captivate their interest. Participants felt that the digital storytelling provided a social space in which they felt safe to discuss the often unspeakable topic of HIV and AIDS (Campbell et al., 2010; De Lange, 2012).

The space for engagement seemingly enabled a sense of ownership. It is important to note that while working with digital storytelling the participants commented that the work was meaningful because the stories were produced by them, and it was their issues that were raised. They clearly felt they had opportunity to provide an opinion, to contribute to solutions, and to be heard.

5.2.2.2 Sharing of experiences

The participants pointed to the need to talk to others about the issues they do not usually talk about, such as HIV- and AIDS-related stigma, and how digital storytelling enabled them to talk about their experiences and how their looking at each other’s stories evoked empathy.

> *If I listen to these stories I get something that make me feel happy because now I know more about HIV and AIDS stigma…*
>
> *Today we also listened to our stories, we wrote about we learnt about the stories and I felt sad when I was hearing those stories…*
>
> *How I felt when I was listening to these stories…I felt so sad because I heard so many stories which sadden me like that people still stigmatise and that makes me feel sad…*
>
> *When I listened to these stories I felt amazed because I never thought our minds would come with up with such a thing….*
>
> *When I hear all these stories including mine, I feel so emotional. It was painful stories.*

> *This person's story is sound and so painful because this person had to leave school because he wanted to help his family…*
>
> *I felt good at the same time that it changes the way I think about people affected by HIV I really changed my life…*

The points made above are in line with Zeelen et al. (2010) who argue that it is logical to assume that digital storytelling can be a powerful tool to contribute to increased openness about HIV and AIDS and the sharing of information. One of the benefits of digital storytelling is the ability to reach the many unheard and unseen learner voices and feelings (Bull & Kajder, 2004). Digital storytelling amplifies participants' voices but also allows them to project their feelings. In a study by Pillay, the participating learners confirmed that "stories provide a way for individuals to cope with group and interpersonal tensions, feelings of anger and loss, and questions of purpose and meaning in a culturally approved manner" (Pillay as cited in Zeelen et al., 2010). One benefit which also stands out for digital storytelling is its unique way of giving voice to, space for, and validation of, participants' emotion (Bull & Kajder, 2004). Also with issues of emotions, digital storytelling has the potential of bringing closure to young people's challenges and issues in their lives (Lowenthal, 2009). In a school most attention is usually paid to the cognitive development of the learners, and often too little attention is paid to their emotional well being. That the participants could share not only their experiences, but also the emotion around stigma and expose their own vulnerabilities is seen as valuable in beginning to address HIV- and AIDS-related stigma.

5.2.2.3 Trying out digital media

Media refers to the transmission channels used to deliver information or data. The term is often used as synonymous with mass media or news media, but may refer to any means of information communication (American Psychological Association: media, (n.d). Media has evolved over the years from analogue to digital media (Qvortrup, 2006), with digital storytelling part of the trend.

These participants indicated that their digital stories, as digital media, can be a tool for inquiry, representation and dissemination in addressing HIV- and AIDS-related stigma in a rural community. In this way their voices could be heard, the digital stories could be used to educate others, and they could be used to reach a wider audience. The young people, even though from a rural area, had a strong sense of technology and digital media as an appropriate means of communication.

Making voices heard

Although the participants come from a rural context, they were adamant that they could use the digital stories as a tool for evoking discussion around HIV- and AIDS-related stigma, that they could be disseminated in the media, and that their community's access to cellphones could be used as a significant mode of communication. This was confirmed by extracts from their writings in which they were suggesting disseminating the findings to surrounding schools and to the community.

> *We can go visiting schools making young people aware, showing them these stories on HIV and AIDS…*
>
> *We can visit other schools and show them what we have done and then discuss, maybe they come out with other stories and then say other solutions…*
>
> *I see that a community meeting should be called, and we get there and show them our stories so that they can understand…*
>
> *I think that it would be appropriate to go to our communities, to teach the elderly, especially because they are the people that sometimes find themselves with challenges.*
>
> *I think we can go to our community and target older people, schools and other young people through cellular phones…*
>
> *What we can do is publishing it in newspapers, in the media, on radio and on TV…*

As was seen in the research done with girls in Rwanda, MacEntee and Mitchell (2011) point to the girls as knowledge producers with their participation central to the research. In this study, the learners, too, were knowledge producers and through the digital storytelling of their experiences, real or imagined, heard about or witnessed, of HIV- and AIDS-related stigma, they represented their own stories in a way that makes their voices clearly heard. They felt that these could be disseminated in the community to inform and further engage individuals, families, schools, peers, and also policy makers. While the suggestion of showing the stories in the public domain was not an integral part of the research, disseminating the stories could be a valuable aspect of community-based participatory research.

Using digital storytelling, also in peer to peer education as a form of social learning, has proved to be an effective way of exchanging and engaging with information especially in the rural South African context (Zeelen et al., 2010). This also ensures that the children are acknowledged for their knowledge production and efforts in the research process which happens in their own contexts.

The participants' agency in wanting to share their knowledge and their self-made artefact with the community is consistent with CBPR which is characterised as community owned and managed research (COMR) (Schulz, Israel & Lantz, 2003). In line with this, Griffith et al. (2010) argue that CBPR is about balancing knowledge generation and intervention for the mutual benefit of all partners through shared decision-making power, starting with a topic identified as problematic by the community.

Using media to educate

The discussion that the participants had on how action can be taken to communicate the knowledge produced in their digital stories, demonstrated a keen sense of technological possibilities as well as those of mass media.

> *We then looked at how we can help each as the youth with the challenges we face, we looked at how we can communicate…*
>
> *I think the cell phone idea can work faster because we can do that any time. The other youth can add more and say more like we also doing in this project…*
>
> *We know about these technologies and a cell phone is used to set time to take ARVs and it can still be used even now for spreading the information…*

> *…amongst us as young people, we could chat and send each other messages with our phones on Facebook…*
>
> *I am saying although not everyone has these [sophisticated] phones here we can use social networks like twitter, mix it, face books and send the stories and also discuss more…*
>
> *We can also do what the other students did during the world aids day and show it to parents when they are attending the world aids day… you remember when you were for the other project?*
>
> *The problem is that we do not have but even those who have we can start with them. It was interesting even to see that it is easy to use technology, look the computer, I never used before but I was able to do my story…*
>
> *If many people can understand the pain and suffering from HIV stigma they can change the way they think, it is just that it will take time to reach everyone…*

Media-based strategies to combat HIV- and AIDS-related stigma are useful and there is a need to intensify the use of such methods (Babalola et al., 2009). In terms of using mass media, Bhana and Petersen (2009, p. 64) report that, in the South African context, “at a community level there have been a number of national mass media campaigns aimed at changing social norms as well as increasing information and awareness at an individual level, using print, radio and TV media”. They further draw attention to other TV programmes, such as the Soul City Project (initiated in 1994), LoveLife (initiated in 1999) and Khomanani (initiated in 2001). Other programmes are “Gazlam, Tsha Tsha, Takalani Sesame and Beyond Awareness, all in South African Broadcasting Commission Television” (Bhana & Petersen, 2009, p. 64). These programmes possibly point to the value these digital stories might have for the school and the community.

The importance of communication through digital technologies as a tool to engage with and effectively address the unnecessary fears about HIV, thus fostering acceptance of people affected and infected by HIV, is clearly raised by the participants. Mitchell and De Lange (2013) have, for example, used cellphones to produce cellphilms with teachers in two rural communities as a tool to engage the teachers in thinking about their own responses to HIV and AIDS issues, such as learners using condoms. The cellphilm work enabled teachers to reflect on their own stances, and through a ‘speaking back’ approach required them to consider how they might change their responses. The participants in my study were eager to show their digital stories to peers and to the wider community. It was suggested that they go to schools in their community to show the stories to their peers and thus trigger dialogue so that other young people could also contribute to the dialogues. Social media such as Facebook and Twitter is commonly used by adolescents nowadays (Boyd, 2009; Turkle, 2011). Statistics tell us that South Africa has one of the lowest Internet access rates compared to other world countries, but of those that do have access to the Internet, most of the people say that their primary use of the internet is social networking (Hutchins & Rowe, 2012). Furthermore, South Africa’s Internet access statistics revealed in its general household survey for 2012, on 22 August 2013, that less than 10 percent of South African households had access to the Internet at home (Statistics South Africa, 2013). The survey also showed that less than seven per cent (6.3 percent) of households did not have access to cell phones (Statistics South Africa, 2013). In spite of the limited access to the Internet, the participants saw the potential of digital technology in their agency to contribute to addressing stigma in their community.

Going on line

Digital storytelling is seen as communicable, accessible, and contextualised to communities including local rural South Africa communities where a considerable number of people are affected and infected by HIV. This is illustrated by this participant’s response:

> *Sibuye sabonisana njengentsha ukuthi singenze njani ukuthi lihambe lelivangeli lokungacwasani lifinyelele emphakathini wethu nezinye izindawo lapho kunabantu abasha…*
>
> [*We also got an opportunity to reflect on the stories and came up with suggestions of how we can make sure that these stories reach our communities and other audiences worldwide for the youth to access.*]

The digital format of the stories makes it possible for dissemination online. The learners were excited when it came to the possibility of showing their digital stories to a global audience. Lowenthal (2009, p. 299) claims “that this alone makes digital storytelling more powerful than other forms of storytelling”. Lowenthal (2009) argues that uploading digital stories online serves other educational purposes. The significance of storytelling lies in both the telling and retelling and digital storytelling allows the participants to tell their stories time and time again. In this study it was interesting that participants wanted their stories posted and accessed so that people could listen to them. The learners from the same rural community working with Mitchell, Pascarella, De Lange and Stuart (2010) uploaded their work online and also indicated that they wanted other learners to learn from them.

It would have not been possible to suggest the use of social networks and certain types of media if the content had not been captured electronically. Digitised data can be preserved for long-term use and can be easily accessed. This would not have been possible if the stories were in hard copy format. The digital stories can be retrieved when needed without relying on memory, which might even distort information.

Rural youth are socially connected via cell phone, twitter, mixit, Facebook and so on. Such media therefore hold the potential for use in various ways to address issues concerning HIV and AIDS (MacEntee, Labacher & Murray, 2011). Yahanet is one example of a vibrant web space that provides a virtual global networking platform that connects youth groups and individuals around the world who are addressing, or would like to learn how to address, HIV and AIDS issues through arts and media (MacEntee et al., 2011). It therefore makes sense to work with the participants to consider the use of the digital stories on such social networking platforms.

5.2.2.4 Bridging the digital divide

The notion of a digital divide refers to the gap between those who have and those who do not have access to computers and the Internet (Compaine, 2001; Warschauer, 2004. However, the notion of the digital divide as a gap limited to the availability of computers and the Internet is challenged by some researchers. Warchauer (2004) argues that the availability of computers only cannot bridge the digital divide but instructors and teachers must be in place otherwise the computers and the Internet may remain un-accessed or not used. Also, the facilities must be functioning at all times. In rural areas the Internet goes down and, because technical support is far from the area, this may cause delays in fixing this problem (De Lange et al., 2010). Warschauer (2004) also argues that if the end-users are not well prepared for the use of Information Technologies the divide remains a challenge.

Central to the use of information communication technology are multiple literacies, including writing, reading, listening and thinking, as well as being able to connect to related issues and stories enhanced by Information and Communication Technology (ICT). The way knowledge is communicated is changing because of new technologies, and because of shifts in the use of the language within different cultures. Therefore, new and multiple literacies must also be used and developed (Dunham, Brake, Kernohan & Savery, 2011). The term multiple literacies also refers to language, visual and media literacy. Text is combined with sound and images and is incorporated into movies, billboards, television, and in almost any site on the Internet (Dunham et al., 2011).

The extracts below from the participants' writing confirm that digital storytelling allows for multiple forms of literacy such as writing, telling, thinking, listening, drawing, using cameras, and using computers.

> *In this session we learnt so many things that we did not know. I learnt how to write a story which also must be told in two minutes…*
>
> *We also had to refine our stories so that they are clear…*
>
> *Working individually and in pairs allowed us to write our stories and also being able to narrate to your partner, who allowed you to think before you write and also listen to the person you work with.*
>
> *I really enjoyed the drawing, taking photographs and also using the voice recorder to make the stories…*
>
> *I learnt so much in the process, I can use it in future, the recording of the voices, taking photographs and the computer, although I was using it for the first time.*

> *In this session I learnt about many different things to be addressed before shooting using a camera or a video.*
>
> *I noticed that getting photos related to your story needs creativity and also that it is more elaborative if your photographs follow your story, show how your story looks like…*
>
> *In this session I learned so many different things, I learnt how to use a computer with headphones…*
>
> *Today I learnt a lot and also I had to use a computer which I never used before. But more importantly I had to hear what other learners feel about what we did….*
>
> *We really had a wonderful time in using computers and to see our stories, now like a movie, and we were able to view them and I felt like doing it over and over again and I liked the computer…*

The quotations above show that literacy is no longer simply viewed as reading and writing, as Lowenthal (2009) argues. In the twenty-first century, “students need to be able to employ a number of different literacies” in order to be effective communicators (Porter as cited in Lowenthal, 2009 p. 299). Digital storytelling, therefore, helped to provide participants with skills such as using their language and using computers, and thinking critically about the issue of HIV- and AIDS-related stigma in crafting digital storytelling (Kajder, Bull & Albaugh, 2005). In addition, this study reveals that “digital stories increase the meaning making potential of a text” by giving participants “a different kind of meaning making and a different way of knowing” (Hull & Nelson 2005, p. 225). The participation of the learners allowed me to introduce them to technologies they were aware of but had not yet used. The technology used in the storytelling process is fairly complicated, but the learners, who had not had prior access to such technologies, fared very well in using the technology to create their stories.

5.2.2.5 Remembering new stories

Looking at the process of digital storytelling it was clear to me that throughout the process more stories were evoked. The participants refer to the digital stories as real — this is what happens in their communities. They also highlight that the digital storytelling of the other participants triggered memories of other stories intersecting with HIV- and AIDS-related stigma, such as issues of stigma associated with rape, suicide because of stigma, and gender issues. The digital storytelling also allowed me a pedagogic moment in which to teach about ethics.

> *What happens in our communities is amazing, I learnt a lot because I did not know some of the things which happen in our community and that there are issues which are stigmatising which can lead to you contracting HIV…*
>
> *Out there in our communities there are still people who discriminate people who are HIV positive and what really surprised me was that even our families do discriminate in such a way that they separate utensils, dishes I mean everything, even today!*
>
> *Some of the stories would remind you of other experiences you have but did not write a story about, but during reflection we were able to discuss at length…*
>
> *I have got different stories about stigma which happen in the community with different people. I feel happy about these stories because they talk about the things that happen in our community and that we also do but sometimes without intention but now we spoke about it…*

The process involved in digital storytelling allows for a number of ways to understand the phenomenon of HIV- and AIDS-related stigma. It also allows participants to raise other HIV- and AIDS-related stigma issues which may not have been crystallised in their stories. To discuss and reflect is a main strength of community-based participatory research (Hartley & William, 2009; Lowenthal, 2009; Zeelen et al., 2010) and the use of digital storytelling enables the participant to use, discuss and reflect on the familiar stories from their own community. The participants also indicated that HIV- and AIDS-related stigma is the main problem but that it is also linked to other stigmas that could affect people severely such as, for example, being too ashamed to report rape or being so ashamed that the stigma drives them to commit suicide.

> *Stigma that is related to HIV to my community is main problem and it leads to many things which could affect many individuals…*

Rape is condemned by society but victims are stigmatised and some rape victims therefore prefer to remain silent. This is indicated in this extract from a participant's writing:

> *People are always stigmatised. Like they don't choose to be raped but they are still stigmatised. That will lead to them being silent and contract HIV when they could have used treatment.*

The quotations from the writings of the participants show that digital storytelling triggered thinking about issues related to HIV- and AIDS-related stigma, such as the fact that rape victims feel vulnerable but do not report or seek help because rape is stigmatised. Perceived personal vulnerability is seen as a risk factor because it reduces the possibility of taking the necessary precautions which come after being raped (Phaswana-Mafuya & Peltzer, 2006). Children often do not tell anybody that they had been raped because of the way sex is culturally constructed (Moletsane, 2003), but also because of the fear of being blamed, stigmatised or hurt. This leads to negative consequences such as HIV contraction which, in turn, is stigmatised.

Another issue that was raised was that of suicide arising out of the fear of being stigmatized and having to deal with the consequences. This was echoed by participants:

> *What I have learnt HIV and AIDS stigma is that many people are shy of their results that leads them to committing suicide. Many people do not want to accept their status.*
>
> *Sometimes you find people killing themselves because they are HIV positive… they fear the stigma and the discrimination*
>
> *Akumele ukuthi uma usunesifo se HIV ne AIDS sekufanele uzibulale noma ubone ukuthi usibhebhethekise lesifo.*
>
> *[If you are HIV positive there is no reason to kill yourself or spread the virus. If you find out that you are HIV positive, it does not mean that you should kill yourself.]*

This highlights the fact that despite the support and treatment that is in place, stigma has negative impacts and leads to people committing suicide.

Another issue — that of sexual orientation — was raised:

> *I also learnt that HIV is also found in the gay and lesbian community and they are more stigmatised.*

The gay and lesbian community is stigmatised even by two of my participants:

> *Another thing is the issue of gays, hey, Ma'am, it's hard to get used to them… even if we shouldn't discriminate them, but how can you as a guy sleep with another guy?*
>
> *....one can't get used to it. That is why people discriminate and this AIDS was first found in them…*
>
> *I live in a community where the gays and lesbians are part of the community. There is something that some of the members of the community are against off. They discriminate these people because they believe that they are not real people as a result of their sexual practices.*
>
> *I am not happy as well with gays and lesbians because of their sexual behaviour. But the big issue is that the gays have sex with the females as well. This sexual behaviour leads to the spread of the HIV virus.*

The findings show that the learners are aware of the interconnectedness of HIV and AIDS, gender-based violence and sexuality and how these work together to exacerbate stigma. This also points to how the content and type of stigma differs across various cultures and socioeconomic contexts (Deacon & Stephney, 2007; Norman, Abreu, Candelaria & Sala, 2009).

Working with learners and working with a sensitive topic like HIV- and AIDS-related stigma in creating a visual artefact — digital stories — required careful thinking from me. It was, however, interesting that the reflection exercise enabled the participants to reflect on the ethical issues they had become aware of in creating digital stories. This is revealed in extracts such as these:

> *I liked it when we photographed pictures to illustrate our stories. Others did drawings and cartoons and pictures were not supposed to show faces of people.*
>
> *There is no need to take a picture of a person to represent your story but you can use any background...*
>
> *It is not necessary to take a photo of a person but you can use cartoons.*
>
> *If you take pictures related to your story you don't have to photograph people's faces, their cars without their permission….*

Mitchell (2008) highlights the importance of alerting participants to visual ethical issues. She further notes that there is a possibility that participants might not be complying with issues of ethics such as informed consent, anonymity and confidentiality. However, the key argument in this study is that the methods used enabled participants to raise issues which affect them and which provide solutions to these issues.

5.3 SYNTHESIS

The two themes which respond to the second question, on how digital storytelling can enable learners to take action in addressing HIV- and AIDS-related stigma, have been presented. What is primary is that the process involved in crafting digital storytelling and drawing on CBPR opened up comfortable and flexible spaces in which the participants (the young learners) could identify the different and sometimes paradoxical ways in which they view lived, witnessed, heard about or imagined stigma experiences. They draw on the issue of agency and engage with the stigma stories contextually.

CHAPTER SIX

SUMMARY, CONCLUSIONS, IMPLICATIONS AND CONTRIBUTION OF THE STUDY

6.1 INTRODUCTION

The aim of the study was to explore secondary school learners' experience — whether lived personally or imagined, whether heard about or witnessed — of HIV- and AIDS-related stigma in school in a rural community, through digital storytelling. This study also aimed to explore how digital storytelling can be used to address stigma. HIV- and AIDS-related stigma remains a critical challenge in effectively addressing HIV and AIDS. While this is a global phenomenon, it is key to address HIV and AIDS in South Africa, the country with the proportionately greatest number of people living with HIV and AIDS in the world. The voices of young people, the population group most at risk and often marginalised, are central to this study. I therefore show here, with reference to the five themes, how the following critical questions have been answered:

- What can digital storytelling reveal about secondary school learners' experiences of HIV- and AIDS-related stigma in schools in a rural community?
- How can digital storytelling enable secondary school learners in school in a rural community to take action to address stigma?

The summary is followed by conclusions and the implications I drew from these conclusions. I also offer the theoretical and methodological contribution of the study and outline the limitations to the study as well as offering suggestions for further research.

I think it appropriate to restate, briefly, the research design and methodology and revisit my ontological and epistemological stance, all of which throw light on the conclusion and implications established in this study. I chose qualitative research and used a critical perspective to explore the twelve secondary school learners' narrated experiences of HIV-and AIDS-related stigma and how digital storytelling can enable them (and us) to take action. This qualitative approach allowed me to explore the phenomenon of HIV- and AIDS-related stigma. The participatory nature of the study also allowed for interaction among participants and for generating digital stories about their understanding of various experiences of HIV- and AIDS-related stigma. The critical frame made space for the participants to reflect on their experiences of such stigma, discuss experiences witnessed and/or heard about in the rural community, and draw on their own experiences of stigma to envisage possible solutions. Their views, as insiders in the rural community, could contribute to changing the community in small ways, in order to try to reduce “entrapment, domination or dependence within society, and ultimately try and provide participants with autonomy and freedom” (Cohen et al., 2007, p. 26). I kept in mind that a critical paradigm supports the notion of change, in particular that of research as social change (Shratz & Walker, 1995).

My ontological stance is that HIV- and AIDS-related stigma exists and is experienced in multiple ways in the lives of people, considered, in this instance, by secondary school learners in a rural community. As such, my epistemological stance is that the participants construct their understanding of their experiences of HIV- and AIDS-related stigma in their own lives and in those of others, and that these experiences offer many subjective truths. Therefore, my methodological stance in choosing to study HIV- and AIDS-related stigma draws on a community-based participatory methodology, in which I used digital storytelling, complemented by focus group discussions and reflective writing, as a participatory method, so as to understand the secondary school learners’ experiences and their understanding of the experiences of others. It also enabled me to use the digital storytelling with them as a tool for using research to effect social change. The learners themselves, as participants in the process with its emphasis on participatory action, and its focus on their experiences, knowledge of the experiences of others, and of what needs to happen, is more likely to have a greater effect on social change (Wang, 1999). This also allowed for self-tailored, context specific knowledge production which enabled insiders’ voices to be elicited by the insiders themselves and not by an outsider (Mnisi, 2009).

Given the research question, the research paradigm and methodology, it was expedient for me to use symbolic interactionism as a perspective from which “explore how meanings are created, assembled, negotiated and modified by members of a society” (Plummer as cited in Brickell, 2006, p. 417). This symbolic interaction theory fits the study since it “presumes meaning to be an emergent property of human interactions, not something intrinsic to an individual or a situation” (Blumer as cited in Brickell, 2006, p. 417). Accordingly, people construct the *meaning* of “their social world and [their] own lives through [their] interactions with other people, gathering together and negotiating meaning as they participate in social life (Blumer as cited in Brickell, 2006, p. 417). Meaning, therefore, is not fixed since it evolves from interactions within an environment and with people. The second core principle is *language*, which is significant in thought and social action and is used to assign shared meanings and interpretations of significant symbols (Blumer, 1969). Language becomes equally important in the third core principle which is that of *thought*. I chose symbolic interactionism as the explanatory framework for looking at questions of stigmatisisation, particularly at HIV- and AIDS-related stigma, because, like all other social phenomena, it is a product of social processes such as interaction and socialisation.

6.2 SUMMARY OF FINDINGS ADDRESSING THE RESEARCH QUESTIONS

6.2.1 Research question one: What can digital storytelling reveal about secondary school learners’ experiences of HIV- and AIDS-related stigma in schools in a rural community?

The study has established that these learners experienced HIV and AIDS-related stigma, whether real or imagined, lived or witnessed, as a hardship, as a cycle of silent suffering, and as a result of aspects of ‘culture’ fuelling stigma.

6.2.1.1 HIV- AND AIDS-related stigma is a hardship

The study showed that the learners’ experiences are that stigma is a hardship and that it is pervasive at all levels of their ecology. It happens at the level of the family: while the affected families are stigmatised by other people, they also stigmatise their infected family members. Stigma is also rife among peers and friends, part of a structure on which most adolescents rely for belonging, affirmation and support. The existence of stigma in the nested layers of the ecology spreads to the wider community which also stigmatises. These experiences, or the fear of having them, eventually have an impact directly on the individual, in this case a learner who is part of the family, school and community. The findings point to the possibility of dispelling the notion, in the context of HIV- and AIDS-related stigma, of the family as providing care, friendship and social support, of school as an institution of learning but also as providing care and support, and the community as one of *Ubuntu*, providing collective care and support for the child in need. Hardship from the various layers of the ecology has an impact on the individual intrapersonally, leading to the loss of self-respect, the loss of self-acceptance and the lowering of self-esteem, and interpersonally, leading to social isolation and the loss of trust in people. The effects of HIV- and AIDS- related stigma on the intrapersonal and interpersonal may further exacerbate the hardship by contributing to the engagement in behaviour which further places the individual at risk.

6.2.1.2 Caught in a vicious cycle of silent suffering

This theme foregrounds the silent suffering experienced by young people because of HIV- and AIDS-related stigma. The learners' accounts of different experiences reveal that there is no support for young people, who in most cases in this study would be orphans living in poverty. This material poverty is seen to contribute to the engagement of young people in risky behaviour, which is also stigmatised, and which further increases vulnerability to HIV. It therefore seems that material poverty contributes to perpetuating HIV- and AIDS-related stigma since in an era of materialism and consumerism, poverty itself seems to be further stigmatised. The children and youth usually keep silent about the suffering because they perceive a lack of confidentiality which runs through all ecologies including health centres where they have to seek medical help. The lack of support and caring in the structures such as the family, school and healthcare centres prevents people from accessing services and also from disclosing to the family. This study shows that stigmatisation is facilitated by the rumour and gossip about those who are living with HIV and AIDS, which goes around at all levels of the community such as the family, peer groups, school and the wider community. This leads to the fear of disclosure even though it is clear that the learners believe that disclosure is the right thing to do. HIV- and AIDS-related stigma, in connection with orphanhood and poverty, further perpetuates itself and this, in turn, perpetuates infection.

6.2.1.3 ‘Culture’ fueling stigma

The study also established that not talking about things of a sexual nature has negative implications and can fuel the fear and ignorance about HIV and Aids. This, it is believed, can potentially perpetuate the stigma around the condition. More than that, it also transpired that learners’ experiences, imagined or real, lived or described as an extrapolation from those of others, showed that stigma is exacerbated by religious beliefs and proscriptions and that HIV- and AIDS-related stigma is not castigated by religious leaders. The abstinence-before-marriage principle propagated by most belief systems contributes to silence about, and stigmatisation of, early sexual debut. The Zulu cultural practice of virginity testing is used to ensure that young girls preserve their virginity, but this fuels the stigmatisation of those who are no longer virgins. The stigma attached to the loss of virginity leads to the female youth preserving their virginity by engaging in often unprotected anal sex which might lead to the further spread of HIV. The way people respond to social issues such as HIV- and AIDS–related stigma is clearly influenced by cultural practices and religious beliefs of the communities in which people find themselves.

What has become clear in this study is that terms and their meanings play a key role in the stigmatising of people infected and affected by HIV. It is how people talk about HIV and AIDS, how they talk about the treatment, how they talk about the other — the one who is infected — that contributes to stigmatising in the community. If a person contracts HIV, derogatory terms are used to express how bad the person is and to point to the shame that the person has brought to the family and to the entire community. Learners referred to several derogatory words and substitute words that are used within a community to talk about HIV and about those living with the virus, and also to further stigmatise the infected and affected in their own community. These terms are understood by the internal members of the community. In the context of this study, it is believed that these shared meanings provide a frame of reference that guides the way members behave towards those to whom the terms refer.

6.2.2 Research question two: How can digital storytelling enable secondary school learners in school in a rural community to take action to address stigma?

This study has established that digital storytelling can enable learners to take action by taking charge of stigma and creating a space for participation. As Cornish (2006), points out, is vital that participatory projects give marginalised people concrete experiences of exerting their agency.

6.2.2.1 Enabling taking charge of stigma

The findings from this research show that digital storytelling is a relevant method for tapping in to the experiences of the secondary school learners in schools in an affected rural community, and for addressing HIV- and AIDS-related stigma. The findings revealed that digital storytelling can strengthen resilience in learners and encourage educating the self and others on the issues of HIV- and AIDS-related stigma, and so contribute to a safe and supportive community space. Moreover, digital storytelling can be used to contribute to halting stigma by breaking the vicious cycle of silence. This is because through digital storytelling, people get to listen to, and engage with issues raised in the digital stories, such as the need to provide care and support and to reconsider the judgementalism shown towards those infected and affected by HIV. Digital storytelling was also seen as enabling disclosure since “[i]t creates an opportunity to go beyond silence and rumour” (Zeelen et al., 2010, p. 395) and bridges the gap perceived to exist between *them* and *us* in the context of the rural school settings. Digital storytelling also enables the dissemination of information to the community. Digital storytelling therefore creates a safe environment for the engagement of the entire community in discussions about HIV- and AIDS-related stigma.

6.2.2.2 Enabling a space for critical participation

The study reveals that digital storytelling creates a democratic space for participants’ engagement. It allows for the participation of young people in addressing HIV- and AIDS-related stigma in recognising youth as legitimate actors. The sharing of experiences of HIV- and AIDS-related stigma, whether real or imagined and whether heard or witnessed, helped participants to get a better understanding of such stigma in their community. Moreover, the tool enables engaging with digital media and new technologies that allow the voices of young people to be heard, and that allows them to contemplate going online with their digital stories. Adopting methods which create spaces for critical engagement, a sense of ownership of the problem in question (HIV- and AIDS-related stigma), and a sense of confidence in their ability to contribute to solving these problems is vital. Digital storytelling goes beyond all this since it also bridges the digital divide especially in a rural context such as that in which this study was conducted. The processes involved in digital storytelling enable leveraging multiple literacies such as talking, thinking, writing, and using computer technology while simultaneously addressing HIV- and AIDS-related stigma. Digital storytelling also triggered new and related stories about issues other than those to do with HIV- and AIDS-related stigma, such as sexuality, gender issues, gender-based violence, and ethics around engaging with sensitive topics. Clearly the process of digital storytelling deepened and extended the engagement with HIV- and AIDS-related stigma into these other areas.

6.2.3 Conclusions

It is clear that HIV- and AIDS-related stigma remains a hardship in the different layers of ecology that make up a community. While it seems that many people are still ill-informed or misinformed about HIV and AIDS and the stigma surrounding it, the lack of understanding and support compels silences which not only exacerbate the pain, but also the stigma, creating a vicious cycle between HIV and AIDS and HIV- and AIDS-related stigma in this rural context. A ‘culture’ that does not encourage dialogue about issues of a sexual nature, including HIV and AIDS, fuels stigma, thus putting the youth further at risk.

The findings might not necessarily throw new light on the experiences of stigma, but they do show the multi-faceted ways in which these learners represent the experience of HIV- and AIDS-related stigma in their rural community through digital storytelling which makes the stories real and relevant. Digital storytelling is a ‘bottom–up’ effort to address stigma, with the youth offering ideas for action to engage with and address the issue. This is a useful entry point for taking action, because the participants recognise the "embeddedness of stigma in collectively negotiated social representations and practices which are constructed, reconstructed, reproduced or challenged in the ongoing interactions of communities of peers going about their lives on a day-to-day basis" (Campbell et al., 2007, p. 413). This leads me to conclude that efforts to tackle stigma should build on the experiences of young people and on their understanding of how members of their own communities experience this problem, and on solutions formulated by these very people who are at the frontline of perpetuating and/or suffering from stigma.

6.3 Implications of the findings

In this section I offer implications for the findings with regard to HIV- and AIDS-related stigma for the individual, the family, the learners' peers, the school, and the community.

6.3.1 HIV- and AIDS-related stigma is a hardship

While it would be ideal to suggest that communities should revive the spirit of *Ubuntu*, the idea of being a 'being-with-and for-others' which prompts people to care about each other including young people who are affected or infected, it is clear that HIV- and AIDS-related stigma remains a challenge in this age of AIDS. It does, however, imply that the community, such as the elders, could provide safe houses where advice is on offer so that the young people might know where to locate help. These safe houses could act as centres for young people where they could always access trustworthy adults and get an opportunity to engage with such sensitive issues. Another strategy would be to have one-stop care centres staffed by social workers, educational psychologists, and health professionals located close to the schools to address the hardship.

The findings imply that the communities must go back to the practice of having the whole village contribute to the development of the child. Young people must not suffer in silence. Given that the stories of the learners are true representations of what is happening in their communities, the community, through its existing structures, must act. In the true African spirit it indeed takes a whole village to raise a child. It has always been known in Africa that it takes a village to raise a child. If the practices implied in this belief could be revived by having the authorities such as the Kings and the Chiefs, who wield influence over the people of their village, encourage care and support and the showing of empathy to the young people who experience stigma, huge strides could be made.

It is a reality in many communities that the family structure is disrupted by the illness and/ or death of a parent or both parents. This leaves the children stigmatised and vulnerable, and they often have no one to head up their households. While the Department of Social Development can provide the necessary grants which could help alleviate poverty, the children left behind need to be assisted to apply for the grants. Here, too, the establishment of a one-stop centre in the community could assist. But, while material poverty can be addressed in this regard, the emotional well-being of the child is central to her or his holistic well-being. In this regard, the social support from family is necessary since social isolation and hopelessness are major factors that contribute to depression caused by HIV and the stigma attached to it (Brouard, 2005; Rao et al., 2012). The family itself could be helped by other family members who have been equipped to be supportive. Retired professionals or other available professionals in the community could assist by teaching and promoting anti-stigmatising programmes.

School, where learners spend most of their time, and which is a space for teaching and learning, ought to be a supportive and caring space, free of stigmatising, and a place of hope for a better future. It is therefore important for the school principal, the school management team, and the teachers to listen to the learners' concerns about their own lives and ensure that schooling provides holistic development for the learners. A policy for educators in South Africa, (Department of Education, 2000), which has been replaced by The Minimum Requirements for Teacher Education Qualifications, (Department of Education, 2011), clearly states that an educator is not merely a subject specialist, and it defines one of the roles of an educator as needing to play a community, citizenship and pastoral role. An educator has to promote a healthy classroom environment by helping those who experience barriers to learning, whether in the classroom or in the community (Donald et al., 2006; Olivier et al., 2007). Therefore, professional development to help educators understand and change the face of HIV and its related stigma is required. Teachers must create a safe teaching and learning space for engaging with the learners in an authentic way.

In order for teachers to be able to do this, the Department of Education must scale up professional development programmes that will enable educators to address stigma. They, too, face challenges in addressing HIV and AIDS and its stigma in the class room, and, at the same time they, too, have families with all their related challenges. This requires a ‘starting with ourselves approach’ (see Van Laren, 2010): teachers must first address their own biases and stigmas before they can assist the learners. The Department of Education must strengthen its partnerships with related departments, local non-government organisations, the community structures, and peer educators.

Given that the experiences of stigma include hardship at the individual level, in dealing with HIV- and AIDS-related stigma, the individual has to be able to draw on knowledge, skills and inner strength to withstand the effect of stigmatising statements whether used intentionally or unintentionally. This also implies that the family, school, and community, where possible, should provide the individual with opportunities to develop inner strength, self respect, and positive self-esteem. Programmes to encourage young people to develop strong interpersonal and intrapersonal skills could be put in place at school and at community level.

6.3.2 Caught in a vicious cycle of silent suffering

Poverty has been put forward as a pervasive problem and it is also stigmatised. The poor socio-economic conditions that exist in an unsupportive environment and that are exacerbated by community gossip make for a vicious cycle of silent suffering. This has implications for the elimination of poverty amongst young people, and this could be addressed by the Department of Social Development to ensure that each child with material needs be allocated his or her child grant, which would go some way towards addressing some needs. The school, too, should ensure that children who do not have the necessary school requirements are not discriminated against. Rather, procedures should be put into place to allow learners from poor backgrounds to access basic school requirements. This could include school feeding programmes that ensure some food security, clothing banks for accessing pre-owned school uniforms and so on. A school environment which is welcoming and supportive could provide a safe haven for vulnerable children, especially where the conditions at home are challenging. The HIV and AIDS committee in collaboration with the Life Orientation teacher and the peer educators could initiate a simple anti-stigma programme, perhaps a buddy system and one that focuses on the strengths that each learner brings. Similarly, the teacher in each class could ensure the learners' acceptance of each other and she or he could have a zero tolerance response to stigma. The school as a key structure in the rural community could engage community members in discouraging stigmatising and being supportive of vulnerable children.

6.3.3 'Culture' fuelling stigma

In rural African communities culture is key and this could be used to drive stigma or to denounce it. Because culture shapes language, it can be used to ensure "that new discourse in the HIV field does not stigmatise, but rather … catalyzes empowerment for our community members" (Dilmitis et al., 2012, p. 1). If community awareness is raised about how language matters and if the impact on how learners who are infected or affected think about themselves, as individuals within their families, peers, schools and within society (Andersen & Taylor, 2011; Dilmitis et al., 2012), could be shown, the stigma could begin to wane. A simple shift in language could speak volumes not only about where the learners are but where they would like to be. Teachers in the school, by using inclusive language, can "break down barriers which 'other', and build greater mutual respect and understanding" in addressing HIV- and AIDS-related stigma (Dilmitis et al., 2012, p. 1). It is therefore important to understand how words and their meaning affect the thoughts of others, and acknowledge how the use of some terms in a language can be damaging, or constructive and enabling: a term that is used in one context may be stigmatising in another.

Culture must be understood as evolving and moving with time. Some unrealistic beliefs must be reviewed through the voices of the learners and they must be heard as well on what they think can work for them. Traditional beliefs that result in not talking about sex issues put children at risk in that the youth may be misinformed about HIV and AIDS. The information should be accessible through a sound sexuality education curriculum and be taught by teachers who understand their own biases and prejudices and who have been exposed to effective training by facilitators who are experts in the field of sexuality education and participatory methodologies. If this is done effectively at school level the breaking of the silence can filter down through the entire community. Schools, since they exist within communities, have always been used to disseminate information to local communities. The youth can play a pivotal role in disseminating such information. Young people, too, can look into culture and see what is still there to engage their generation and make meaning for them.

6.3.4 Enabling taking charge of stigma

The implications for the study require that individuals, families, schools and the entire community tap into traditional methods such as storytelling but also that they move with the times. The study has shown that digital storytelling may strengthen resilience and trigger agency as the individual self and the community become educated on HIV- and AIDS-related stigma. The stories that were told around the fire in the old days proved to have an impact on educating the community. Therefore the families and the school may want to go back and strengthen the use of storytelling in the form of digital stories which use modern technology which is liked and used by young people.

6.3.5 Enabling critical space for participation

If stigma is spread through gossiping which is a kind of a ‘storytelling’, people talking about their experiences of stigma could then be explored and addressed by the narrators and the listeners. These narrators and listeners would understand that while some of these experiences of stigma are not seen as such in other societies, the terms and their meanings and what people think of the stories, counts in their context. In the context of school, learners know more than their educators do about the peer stigma they experience or hear about or witness because, as learners, they interact with their peers. Educators must then find appropriate ways to get to know what is known by the learners. The information can be used to craft relevant and contextual policies for the school. Learners in rural contexts must be given the opportunity to explore technical facilities such as computers and cameras so as to bridge the digital divide between them and researchers, but the latter should also incorporate capacity building into their research design so that they leave something of value behind. It is the learners’ time and era to communicate using such facilities irrespective of their rural context. This enables them to actively engage with the issue at hand.

6.4 CONTRIBUTION OF THE STUDY

6.4.1 Theoretical contribution

This study is located in the field of Psychology of Education so the significance of capturing the learners' voiced perspectives on various experiences of stigma makes an important contribution to the literature on HIV- and AIDS-related stigma in the world of secondary school learners in schools in a rural context.

There is a body of knowledge available that shows that youth and children experience HIV- and AIDS-related stigma, either when they are living with HIV infected parents, or if they have parents who have died from AIDS related illnesses. Having family members who are infected also leads to such stigma as does being infected. There is a paucity of studies on HIV- and AIDS-related stigma experiences of secondary school learners in schools in a rural community, and how they see this HIV- and AIDS-related stigma being addressed. It is necessary to understand their experiences and their perspectives on the real or imagined experiences of others, so that appropriate assistance can be provided.

This point concurs with that of Stadler (2003) and Zeelen et al. (2010) who note that just as the 'telling' is a powerful channel, "rumour and gossip" might be "used for better purposes such as providing the community with the right information through [digital] storytelling which people can share with each other from mouth to mouth", in so doing the silence around HIV issues might be broken and people might start talking openly about this disease (Zeelen et al., 2010, p. 394).

The dynamic nature of the construction of stigma points to its being a social process: stigma, and any analysis of it, is necessarily intertwined with interactions and is nested within a larger social context. Stigma regarding HIV and AIDS is experienced on both a personal and community level and may result in silences at both these levels (Daniel, Apila, Bjørgo & Lie, 2007). The processes of stigma construction, therefore, are seen to exist within and between these micro (individual) and macro (collective) levels of society. Silence about HIV and AIDS affects children's perceptions of illness and stigma. Piko and Bak (2006) state that children's beliefs about health risks are developed through their own experiences. Since most of these children's experiences of illness revolve around infection, they are likely to relate to illness in terms of contagion and contamination. This feeds into the notion that HIV-related stigma is a socially shared knowledge about the devalued status of people who are thought of as living with the contagion and contamination of HIV (Herek, 2002). This is then manifested in “prejudice, discounting, discrediting, and discrimination directed at people perceived to have HIV” and the “individuals, groups, and communities with whom they are associated” (Herek, 2002, p. 1; Steward et al., 2008, p. 2).

According to symbolic interactionism, people live in a world that is socially constructed. Language, meaning and thought are part of a particular situation or phenomenon, such as HIV- and AIDS-related stigma, and are thus central to the stigmatizing. Whether HIV- and AIDS-related stigma emanates from fear or from any other psychological response, it is dependent on the meaning given to the situation to be feared or otherwise responded to. The language used determines the meaning of the situation and whether it is socially acceptable or not. Thought is also an important principle since the processing of whether one can stigmatise or feel stigmatised is processed through thought. The language, meaning and thought given to a phenomenon by people who live in a particular context are better understood by them than by an outsider. What a person considers to be ‘bad’ and ‘good’ is dependent on what a particular community regards as good and bad. Therefore it is important to be guided by the insiders if we are to generate interventions to understand stigma and ultimately address it. “The mobilisation of HIV vulnerable communities to participate in research as intervention provides valuable opportunities through which people can develop a stronger sense of agency” (Campbell & Cornish, 2010, p. 1571). These authors further argue that the symbolic context is comprised of the meanings, ideologies and worldviews circulating in society. When “these meanings are about specific communities, they may convey respect or stigma, which in turn affects how those communities are treated by others, and how they feel about themselves” (Campbell & Cornish, 2010, p. 1574). However, knowledge and meaning making among the school children and youth have more often than not been neglected, yet there is a need for the knowledge to be meaningful to the people who will consume it. Gibbs, Crone, Willan and Mannell (2012) argue that many intervention programmes fail probably because they omit the understanding of the southern African context and target.

In keeping with Campbell and Cornish (2010, p. 74) I uphold that “marginalised and stigmatised social groups are often particularly vulnerable to HIV [and] AIDS, and challenging stigma is a crucial early step” in mobilising local people and establishing their local, rightfulness to ownership. Therefore context is important to consider when researching stigma. A community is a social structure, things are shared and the meaning making is done collectively. For that reason, this study used CBPR methodology to try to tap into the learners’ experiences of stigma in their community. It used digital storytelling as a data generation method where they collaboratively and collectively made meaning. The participants suggested solutions to the problems they identified in a participatory way. Participants, in listening to all the stories created by others made meaning from what they heard in these stories and came to a real understanding of how stigma plays itself out in the lives of other people. They suggested tailor-made and context-specific solutions. They recommended ways of disseminating the stories through media and social networks via cellphones. Such a strategy, although small to begin with, can grow until a tipping point is reached.

The new meaning given by the learners in their stories and their suggestions can be shared by those accessing the information and then they can also comment on the issue. This might change the meaning these new listeners attribute to HIV and their thoughts about stigmatising, thus possibly contributing to social change. One thing that is promising is that in this study the content was created by insiders. It was not a case of having outsiders give advice or prescribe to insiders. It is encouraging to see insiders expressing hope instead of hearing outsiders recommending on behalf of the communities they work with.

Several studies claim that the availability of ARVs brought about a decrease in HIV- and AIDS-related stigma (Deacon & Stephney, 2007; Campbell et al., 2011). However, the participants reveal that in their community it is the stigmatising and the language used that give a different meaning to the availability of ARVs and also to disclosure.

6.4.2 Methodological Contribution

In Chapter One I made it clear that there is a growing body of knowledge around HIV- and AIDS-related stigma, and that South African and international studies have used digital storytelling to explore issues concerning HIV and AIDS. However, I did not find other studies on young people and HIV- and AIDS-related stigma which used CBPR and digital storytelling to explore and address stigma experiences.

Methodologically, this study contributes to the body of work that helps to make marginalised voices heard on issues that affect them in their communities. It also contributes to understanding how children and youth could be included in debates about issues that affect their lives (Griffith et al., 2010; Israel et al., 2005; Flicker et al., 2007; Deacon & Stephney, 2007). Of particular importance is that all school children have access not only to education, but to education that is equal to that which is offered in urban schools (UNICEF, 2012). Learners, as knowers of their own lives and contexts, are not innocent and without knowledge and ideas, but are best positioned to critically engage with the issues which affect them. Excluding their voices ignores the richness of them.

Community based participatory research was used with methods that have been applauded by Griffith et al. (2010, p. 204) and Israel et al. (2005) because they acknowledge the local communities, and build on their strengths and resources in knowledge generation. This also enables dissemination of the new knowledge to the community. CBPR is an interactive process that incorporates *research, reflection and action.* In this way, learners in the community were engaged in addressing a problem, that of HIV- and AIDS-related stigma, as identified by the community members themselves. This points to the importance of research as intervention and suggests that HIV- and AIDS-related stigma interventions must be more participatory in nature and must be culture sensitive at the community level in seeing local people as the experts in their own realities and as the protagonists of sustainable social change.

Working with this group of learners in exploring and addressing HIV- and AIDS-related stigma is a continuation of work started in 2004, in the *Learning Together: Towards an integrated participatory approach to youth, gender and HIV/AIDS interventions in rural KwaZulu-Natal schools* (CVMSC, n.d; De Lange et al., 2003;) and in the later *Digitization and Data Management with visual Data in Social Research: Giving life (to data) to save lives*" (CVMSC, n.d; De Lange et al., 2007) that focused on the challenge of stigma as identified by school teachers in the community. Using CBPR provided an opportunity for young learners to tell the story of stigma from their own perspective and to interact with the dominant stories. In this study, participants had the opportunity to document their responses to experiences — their own, imagined ones, those heard about or those witnessed — and then had the chance to revisit them and through the use of this CBPR, to collectively deepen their awareness of the problem and to offer solutions towards addressing this stigma. Digital storytelling builds on the idea “that humans are story-telling organisms who, individually and socially lead storied lives” (Connelly & Clandinin, 1990, p. 2). Therefore, digital storytelling is seen to have the potential for use in educational research aimed at social change. It works with the real stories of participants’ lives; their engagement with them, and the facilitated viewing of the digital stories among peers, in the school, and in the community can contribute to shifting the thinking about HIV- and AIDS-related stigma.

Children who have been given an opportunity to tell their own stories have offered powerful testimony. Digital storytelling, as a visual and arts-based method, is one of the most compelling approaches that children and youth have of expressing what they have experienced or what they see or think others have experienced. These digital stories are interesting in a number of ways. First, they highlight several perspectives on HIV- and AIDS-related stigma, with their stories serving as evidence of experiences, real to them personally or otherwise, in their own context. Second, when a community is regularly confronted with stories like these, they could begin to respond differently to people living with HIV.

In South Africa where the use of mobile media is central to the way information is communicated in both urban and rural areas, digital stories, as digital data, can be easily transferred through popular social networks. Clearly, the rural context can also draw on mobile media to address HIV- and AIDS-related stigma. “HIV and AIDS has become part of the repertoire of normal misfortune” (Jewkes, 2006, p. 431) and the rural context holds potential for researchers to research the multiplicity of social reaction to HIV and AIDS, including HIV- and AIDS-related stigma. As a researcher who sees significance in digital storytelling for making the voices of the marginalised, in this instance the learners, heard, I must consider the questions: “By whom is this heard?” and “ What would those who hear, do?” The agenda here is to get the learners heard by their peers, the school, and the entire community in such a way that it influences local policy and practices, which in turn can lead to widespread social change. This study also eschews the practice of outsiders giving voice to the marginalised, especially the learners, who are often regarded as children who know nothing and who cannot take action.

In drawing together the theoretical and methodological contribution, I try to show (see Figure 6.1) how locally relevant digital stories of learners from within the community can become the stories of the community, and be used to communicate and to address HIV- and AIDS-related stigma in a real and relevant way within the same community. The bi-directional arrows show how the stories emanating from the community could also be used to enable the disrupting of the way in which the participants and the community think about and use language to talk about infected and affected people, and make meaning of HIV-and AIDS-related stigma. By way of replacement they could begin to construct new meanings of affected and infected people, in this way take action to change the stigmatising practices seen in the lives of individuals, in the school context as well as in the rural community.

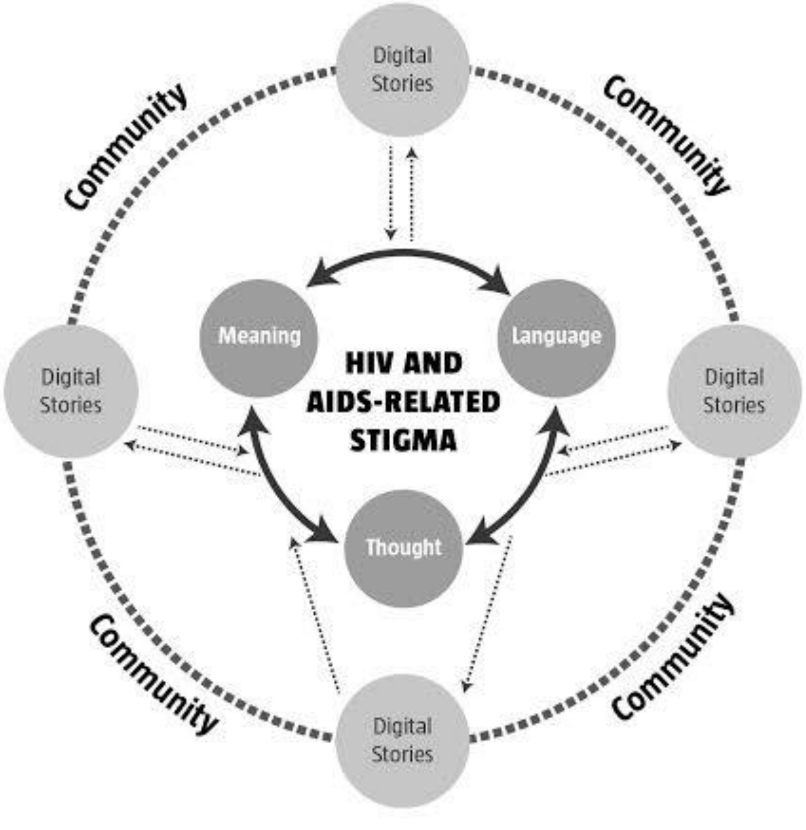


Figure 6.1: Digital storytelling to address stigma in school and community

Throughout the methodology chapter I pointed out the possibility of digital story telling as a strategy to address stigma and bring about social change.

6.5 LIMITATIONS OF THE STUDY

I acknowledge that this is a small qualitative study with only twelve participants and hence the findings cannot be generalised. I have, however, provided a rich and thick description enabling other researchers to consider how the findings may be applicable to their own work.

This qualitative study is positioned within a critical paradigm with a research-as-social-change focus that draws on participants and their voices to enable critical engagement and give them the opportunity to exercise their agency in taking action. I have, however, relied on self-reporting data from the participants and cannot easily document or measure long term change.

On the subject of the language used, I must point out that the participants were all isiZulu speakers while I speak Siswati, but I could engage with them. I gave them the option of doing their digital storytelling in isiZulu or in English. This points to two possible limitations: first, those who used English might have been limited in expressing themselves. However, the use of the visuals in the digital storytelling facilitated expression; and second, those who used isiZulu had to have their stories translated into English, which might have caused a loss in translation. I had them translate their own stories into English but then had someone who speaks both isiZulu and English ensure that the translations were indeed correct.

The interpretation of visual images used in the digital storytelling drew on the participants' own interpretation and on my interpretation of them. The analysis could have been strengthened had I analysed the use of the visual content and the use of metaphor. However, the different data sets from the participants' reflective writing and from the focus group discussions revealed enough to help crystallize the findings.

6.6 SUGGESTIONS FOR FURTHER RESEARCH

The suggestions for further research are presented in the light of methodology, sample, context and content.

- A study that could take this work further could include the use of social network platforms to communicate information and opinion on HIV- and AIDS-related stigma to young people who are known to use these social networks as platforms for discussion about, and debate on, current issues.
- A study could look at 'giving life' to the digital stories of this study through digital archiving, that is, storing the stories, enabling access to the stories and sharing the stories with the rural community.
- A study which furthers the analysis of the visuals of the learners by focusing on semiotics and metaphors and symbolism in these visuals, which are part of the digital stories, could be undertaken.
- A study that uses digital storytelling to explore HIV- and AIDS-related stigma with a different target group such as family members of infected people, teachers, and community health workers could be undertaken.
- A study that uses digital storytelling to explore HIV- and AIDS-related stigma with single sex groups could be done.
- A study that discusses HIV- and AIDS-related stigma using other visual participatory methodologies could be compared with this digital storytelling one.
- A study that focuses on urban learners and their perspectives on the experience of HIV- and AIDS-related stigma, rather than on rural ones, could yield useful information.
- A study that focuses on a group of learners from senior primary schools to explore their experiences of stigma — real, imagined, heard about or witnessed — would add to the larger body of research on HIV- and AIDS-related stigma.

6.7 SYNTHESIS

This study reflects findings which mostly concur with those outlined in the literature on studies done on HIV- and AIDS-related stigma particularly in sub-Saharan Africa and South African rural contexts. The study explored with a small sample of secondary school learners from two schools in a rural community their experiences — lived or imagined, real or otherwise, heard about or witnessed — of HIV- and AIDS-related stigma and how they can take action in addressing such stigma. Located within a critical paradigm and drawing on CBPR, digital storytelling enabled the learners to make their voices heard and to exercise their agency towards taking action to address this stigma.

The secondary school learners from schools in a rural community wrote, told, recalled or made up stories about HIV- and AIDS-related stigma experiences and used technology such as digital voice recorders, cameras and computers to create their digital stories. They also analysed their own digital stories and spoke about individual agency and about becoming sensitised towards solutions. This method of digital storytelling in the social sciences is critical when it comes to communicating findings to be used in the school and community in which the research took place. The idea is that small groups of learners identify problems in their own life worlds and generate locally relevant solutions, through digital stories which can be spread throughout their own communities so as to fulfil the purpose of participatory research in drawing on indigenous methods (such as storytelling) and enabling personal agency.

In this thesis I have argued that contextual stigma directed to people fits in with the language, meaning and thought that a community constructs around stigma. I also claim that digital storytelling enables the exposure of particular stories of stigma that learners experience, witness or hear about in the context of a school in a rural community. At the same time, the digital storytelling enables a change in the language, meaning and thought around stigma. What is more is that this particular digital storytelling is about sharing stories about, and experiences of HIV- and AIDS-related stigma and how these stories can be used as part of the solution. If such stories can be told, people can spread them just as gossip is spread but in this case such spreading would work towards positive social change. Therefore, I conclude that in order to confront the challenges raised by the perpetuation of stigma, efforts must involve the communities and must tap into their own experiences of perpetuating or enduring stigmatisation.

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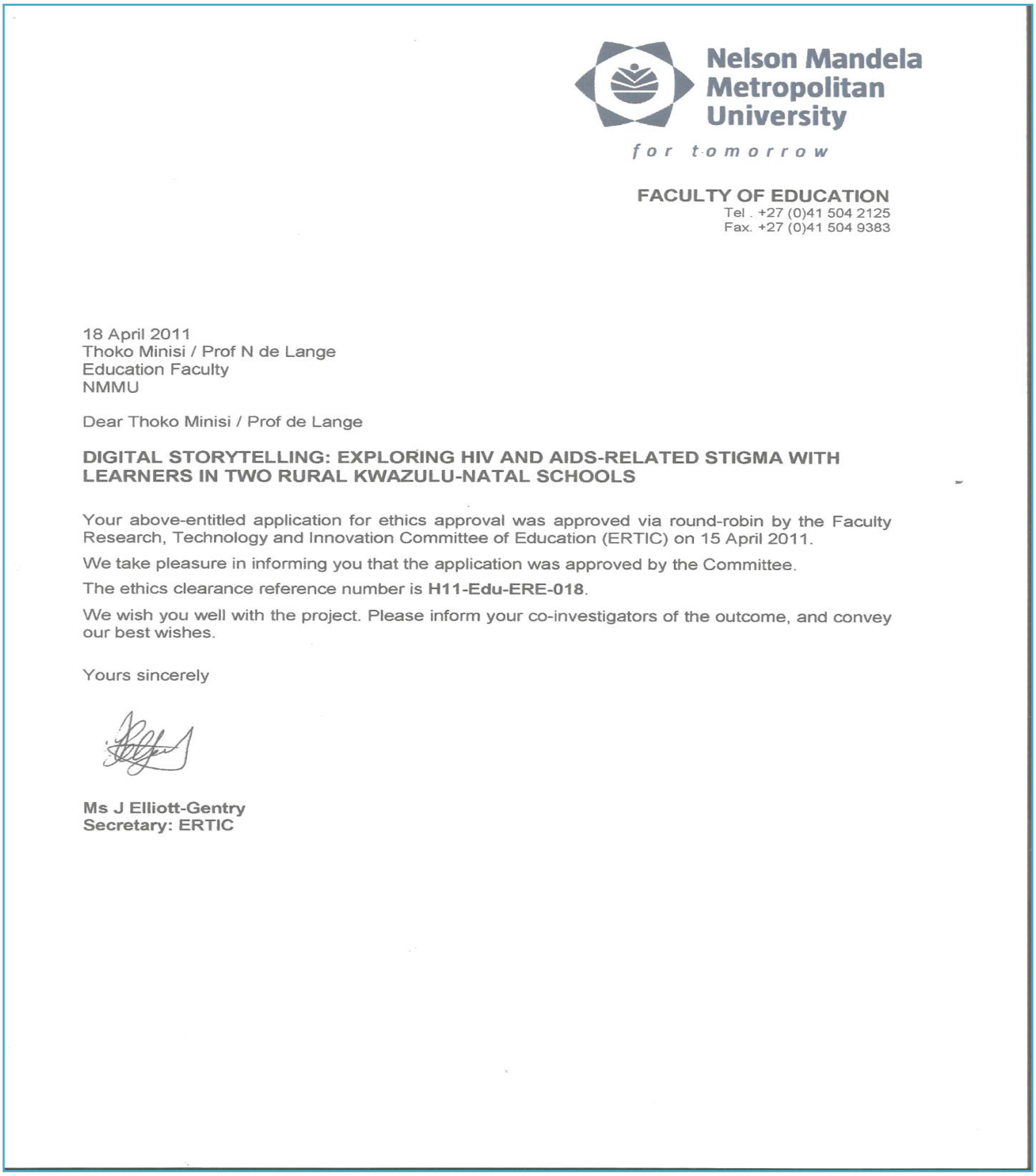
APPENDIX A: ETHICAL CLEARANCE CERTIFICATE



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18 April 2011
Thoko Minisi / Prof N de Lange
Education Faculty
NMMU

Dear Thoko Minisi / Prof de Lange

DIGITAL STORYTELLING: EXPLORING HIV AND AIDS-RELATED STIGMA WITH LEARNERS IN TWO RURAL KWAZULU-NATAL SCHOOLS

Your above-entitled application for ethics approval was approved via round-robin by the Faculty Research, Technology and Innovation Committee of Education (ERTIC) on 15 April 2011.

We take pleasure in informing you that the application was approved by the Committee.

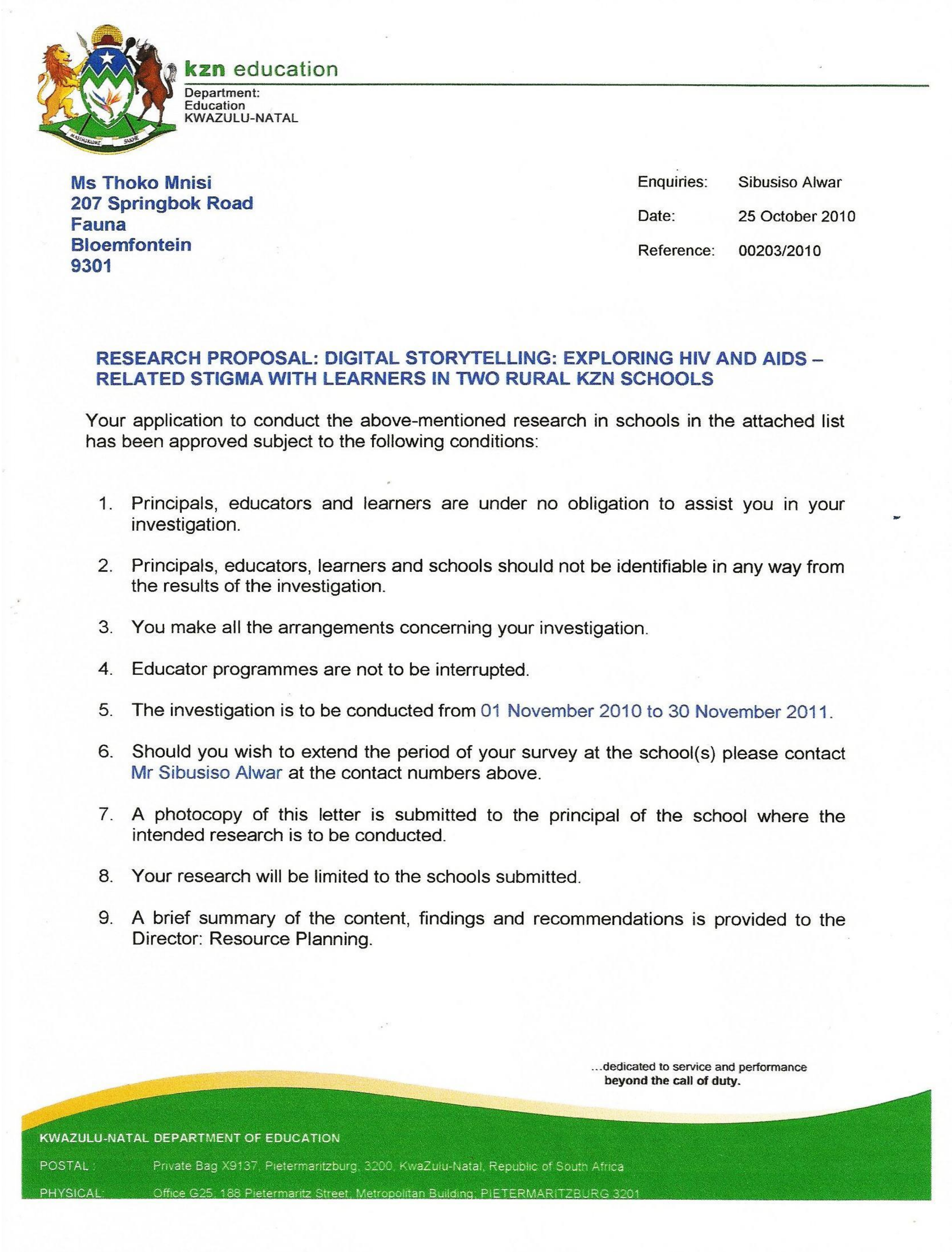
The ethics clearance reference number is **H11-Edu-ERE-018**.

We wish you well with the project. Please inform your co-investigators of the outcome, and convey our best wishes.

Yours sincerely

Ms J Elliott-Gentry
Secretary: ERTIC

APPENDIX B: LETTERS FROM THE DEPARTMENT OF EDUCATION



kzn education
Department:
Education
KWAZULU-NATAL

Ms Thoko Mnisi
207 Springbok Road
Fauna
Bloemfontein
9301

Enquiries: Sibusiso Alwar
Date: 25 October 2010
Reference: 00203/2010

RESEARCH PROPOSAL: DIGITAL STORYTELLING: EXPLORING HIV AND AIDS – RELATED STIGMA WITH LEARNERS IN TWO RURAL KZN SCHOOLS

Your application to conduct the above-mentioned research in schools in the attached list has been approved subject to the following conditions:

1. Principals, educators and learners are under no obligation to assist you in your investigation.
2. Principals, educators, learners and schools should not be identifiable in any way from the results of the investigation.
3. You make all the arrangements concerning your investigation.
4. Educator programmes are not to be interrupted.
5. The investigation is to be conducted from 01 November 2010 to 30 November 2011.
6. Should you wish to extend the period of your survey at the school(s) please contact Mr Sibusiso Alwar at the contact numbers above.
7. A photocopy of this letter is submitted to the principal of the school where the intended research is to be conducted.
8. Your research will be limited to the schools submitted.
9. A brief summary of the content, findings and recommendations is provided to the Director: Resource Planning.

...dedicated to service and performance
beyond the call of duty.

KWAZULU-NATAL DEPARTMENT OF EDUCATION
POSTAL: Private Bag X9137, Pietermaritzburg, 3200, KwaZulu-Natal, Republic of South Africa
PHYSICAL: Office G25, 188 Pietermaritz Street, Metropolitan Building; PIETERMARITZBURG 3201

kzn education
Department:
Education
KWAZULU-NATAL

10. The Department receives a copy of the completed report/dissertation/thesis addressed to:

The Director: Resource Planning
Private Bag X9137
Pietermaritzburg
3200

We wish you success in your research.

Kind regards

R. Cassius Lubisi (PhD)
Superintendent-General

kzn education
Department:
Education
KWAZULU-NATAL

Ms Thoko Mnisi
207 Springbok Road
Fauna
Bloemfontein
9301

Enquiries:	Sibusiso Alwar
Date:	25 October 2010
Reference:	00203/2010

PERMISSION TO INTERVIEW LEARNERS, EDUCATORS AND DEPARMENTAL OFFICIALS

The above matter refers.

Permission is hereby granted to interview Departmental Officials, learners and educators in selected schools of the Province of KwaZulu-Natal subject to the following conditions:

1. **You make all the arrangements concerning your interviews.**
2. **Educators' programmes are not interrupted.**
3. **Interviews are not conducted during the time of writing examinations in schools.**
4. **Learners, educators and schools are not identifiable in any way from the results of the interviews.**
5. **Your interviews are limited only to targeted schools.**
6. **A brief summary of the interview content, findings and recommendations is provided to my office.**
7. **A copy of this letter is submitted to District Managers and principals of schools where the intended interviews are to be conducted.**

The KZN Department of education fully supports your commitment to research: Digital Storytelling: Exploring HIV and Aids – Related Stigma with Learners in Two Rural KZN Schools.

It is hoped that you will find the above in order.

Best Wishes

R Cassius Lubisi, (PhD)
Superintendent-General

...dedicated to service and performance
beyond the call of duty.

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APPENDIX C: PARENT LETTER

207 Springbok
Road Fauna
Bloemfontein
9301

13 November, 2010

Dear Parent

Digital Storytelling to explore HIV and AIDS-related stigma with secondary school learners in a rural community in KwaZulu-Natal

My name is Thoko Mnisi and I am currently studying towards a PhD in Education at the Nelson Mandela Metropolitan University. As part of the requirements of the degree, I am required to complete a research thesis. My study aims to explore through digital story telling the learners' experiences of stigma in two rural schools. This also aims at sensitizing the schools towards taking action in addressing stigma.

In order for the study to be a success, I require female and male learners between the ages of 13 to 18 years, from grade 8 and 9 to participate in the research. I would be grateful if you would consent to your son/daughter participating in my study.

If you choose to allow your son/daughter to participate in this research, he/she will be invited to participate in **two phases** of data generation which involve **producing the digital stories.** I will begin with the briefing on the production method and working with the participants. Participants will then share their stories by listening to each other's stories. This will be followed by recording a first-person voice-over narration. Thereafter, the participants will take photos and make drawings with which to illustrate their stories. This will be fin ished by using software to make the digital stories. The second phase two will involve **reflecting on the stories.** In this phase, learners will be watching the digital storiesto elicit what they learn from watching the stories and what they could do. Completion of the process will take four days of five hours and will be done in school.

Participation is completely voluntary, and you have the right to withdraw your son/daughter (and your son/daughter has the right to withdraw him/herself) at any time. Confidentiality and anonymity will be maintained at all times and in the analysis of the data and the completion of the PhD and future publications.

A summary report of the findings will be made available to the participants.

If you would like any further information or are unclear about anything, please feel free to contact me via e-mail: mnisi.thoko382@gmail.com or telephonically 0844001137.

Your cooperation and your son/daughter's participation is valued and appreciated.

Kind regards

THOKO MNISI_______________________________________

Researcher

PROF. NAYDENE DE LANGE____________________________

Supervisor/promoter

DECLARATION BY PARENT OF PARTICIPANT

I, ________________________ (I.D. number___________________________)

in the capacity of parent/guardian of

_______________ ___________ (I.D. number ___________________________)

hereby confirm as follows:

		(Please initial against each paragraph)
1	My child was invited to participate in the above mentioned research project, which is being undertaken by Ms T. Mnisi, who is a student in the Faculty of Education at the Nelson Mandela Metropolitan University.	
2	This research aims to explore learners' experiences of stigma in two rural schools. This also aims at sensitizing the schools towards taking action in addressing stigma. The information will be used as part of the requirements for a PhD in Education. The results of the study may be presented at scientific conferences or in specific publications.	
3	I understand that I will need to complete the consent form and return it to the researcher on completion. In addition, my child will be required to participate in **two phases** of data generation which involve **producing the digital stories and reflecting on the stories**.	
4	My child's identity will not be revealed in any discussion, description or scientific publication by the researcher.	
5	My child's participation is voluntary. My decision whether or not to allow my child to participate, or my child's decision whether or not to participate, will in no way affect his/her present or future school career or lifestyle.	
6	No pressure was exerted on me to consent to my child's participation and I understand that I may withdraw my child, or he/she may withdraw at any stage without penalties.	
7	Participation in this study will not result in any cost to my child or myself.	

I CONSENT VOLUNTARILY TO ALLOW MY CHILD TO PARTICIPATE IN THE ABOVE-MENTIONED PROJECT.

Signed at: ___________________ on: ________________________ 2011.

Signature of parent or guardian of participant: ______________________

APPENDIX D: PRINCIPAL'S LETTER

• PO Box 77000 • Nelson Mandela Metropolitan University

Nelson Mandela Metropolitan University
for tomorrow

13 November, 2010

Dear Principal

Digital Storytelling to explore HIV and AIDS-related stigma with secondary school learners in a rural community in KwaZulu-Natal

My name is Ms Thoko Mnisi and I am a PhD student at the Nelson Mandela Metropolitan University (NMMU). I am conducting research on **Digital Storytelling to explore HIV and AIDS-related stigma with secondary school learners in a rural community in KwaZulu-Natal** in the field of Educational Psychology under the supervision of Professor N. De Lange. The Provincial Department of Education has given me approval to approach schools for my research. A copy of the department's approval is attached to this letter. I invite you to consider taking part in this research. This study also meets the requirements of the Research Ethics Committee (Human) of the NMMU.

Aims of the Research

The research aims to:

- Explore through digital storytelling the learners' experiences of stigma in two rural schools.
- Sensitize the schools towards taking action in addressing stigma.

Significance of the Research Project

The research is significant in three ways:

- The participatory nature of the study will provide opportunity for amplifying the often silenced voices of learners' understanding, experiences and addressing HIV and AIDS-related stigma - through your storytelling - by identifying the problems and providing solutions towards taking action.
- This process of digital story telling will extend your experience beyond the acquisition of new skills, such as technical (use of digital and video recording camera, and social skills) and possibly contribute to social change.

Benefits of the Research to Schools

- The results of the study will be disseminated to the participants, the school involved the community and the Department of Education.
- The results can inform towards forward planning in terms of intervention programmes.

Research Plan and Method

The learners will be required to participate in **two phases** of data production which involve **producing the digital stories and reflecting on the stories.** I will facilitate during the process of data production which will take four days of five hours during school vacation. Permission will be sought from the learners and their parents prior to their participation in the research. Only those who consent and whose parents consent will participate. All information collected will be treated in strictest confidence and, neither the school nor individual learners will be identifiable in any reports that are written. Participants may withdraw from the study at any time without penalty. The role of the school is voluntary and the School Principal may decide to withdraw the school's participation at any time without penalty. If a learner requires support as a result of their participation in the survey steps can be taken to accommodate this.

School Involvement

Once I have received your consent to approach learners to participate in the study, I will

- arrange for informed consent to be obtained from participants' parents
- arrange a time with your school for data collection to take place

- obtain informed consent from participants

Attached for your information are copies of the Parent Information and Consent Form and also the Participant Information Statement and Consent Form.

Invitation to Participate

If you would like your school to participate in this research, please complete and return the attached form.

Thank you for taking the time to read this information.

Ms Thoko Mnisi	Prof. N. De Lange
Researcher	Supervisor
NMMU	NMMU

• PO Box 77000 • Nelson Mandela Metropolitan University

• Port Elizabeth • 6031 • South Africa • www.nmmu.ac.za

Nelson Mandela Metropolitan University

for tomorrow

Digital Storytelling to explore HIV and AIDS-related stigma with secondary school learners in a rural community in KwaZulu-Natal

School Principal Consent Form

I give consent for you to approach learners in Grades eight and nine to participate in the **Digital Storytelling to explore HIV and AIDS-related stigma with secondary school learners in a rural community in KwaZulu-Natal**

I have read the Project Information Statement explaining the purpose of the research project and understand that:

- The role of the school is voluntary
- I may decide to withdraw the school's participation at any time without penalty
- Learners in Grades eight and nine will be invited to participate and that permission will be sought from them and also from their parents.
- Only learners who consent and whose parents consent will participate in the project
- All information obtained will be treated in strictest confidence.
- The learners' names will not be used and individual learners will not be identifiable in any written reports about the study.
- The school will not be identifiable in any written reports about the study.
- Participants may withdraw from the study at any time without penalty.
- A report of the findings will be made available to the school.
- I may seek further information on the project from Ms Thoko Mnisi on 0844001137.

____________________________ ____________________________

Principal Signature

APPENDIX E: LEARNER ASSENT FORM

Ms Thoko E. Mnisi
Cell: 0844001137
207 Springbok
Road
Fauna
Bloemfontein
9301

13 November, 2010

Dear Learner

I wish to invite you to participate in the study **Digital Storytelling to explore HIV and AIDS-related stigma with secondary school learners in a rural community in KwaZulu-Natal**

You will participate in producing digital stories with other 10 volunteer learners from your school. This will start with a first phase of briefing on the method of digital storytelling. You will then be involved in actual activity of writing your story script based on your experience of HIV and AIDS-related stigma (not necessarily your lived experience). You will then share your stories and listening to each other's stories. You will then recor the first-person voice-over narration. Thereafter, you will take photos and make drawings with which to illustrate your work. The second phase will involve **reflecting on the stories.** In this phase, you will be watching thedigital stories to elicit what you have learnt from watching the stories (if anything) and what action you could suggest or take. There are no risks involved in this study, however if you feel uncomfortable at any time, please inform me, Ms Mnisi, the researcher, or your parent so that I can arrange for you to be excused.

I believe that the participatory nature of the study will provide opportunity for voicing your understanding, experiences and addressing HIV and AIDS-related stigma - through your storytelling - by identifying the problems and providing solutions towards taking action. This process of digital story telling will extend your experience beyond the acquisition of new skills, such as technical (use of digital and video recording camera, and social skills) and possibly contribute to social change.

Anonymity and confidentiality will be ensured as no names and faces of persons will be revealed. Data generated will be stored in the digital archive and given strict confidence. It can only be accessed by the group of researchers for research purposes. Neither the school nor individual learners will be identifiable in the research reports that will be written and published.

I am not aware of any instrument which might cause harm, however psychological support will be in place.

If you have any problems with the study or want questions answered, you can contact the following people:

The researcher:	Ms Thoko Mnisi Cell: 084 400 1137
Promoter:	Prof. N. de Lange 041-5044519

Voluntary Participation (What if I do not want to do this?)

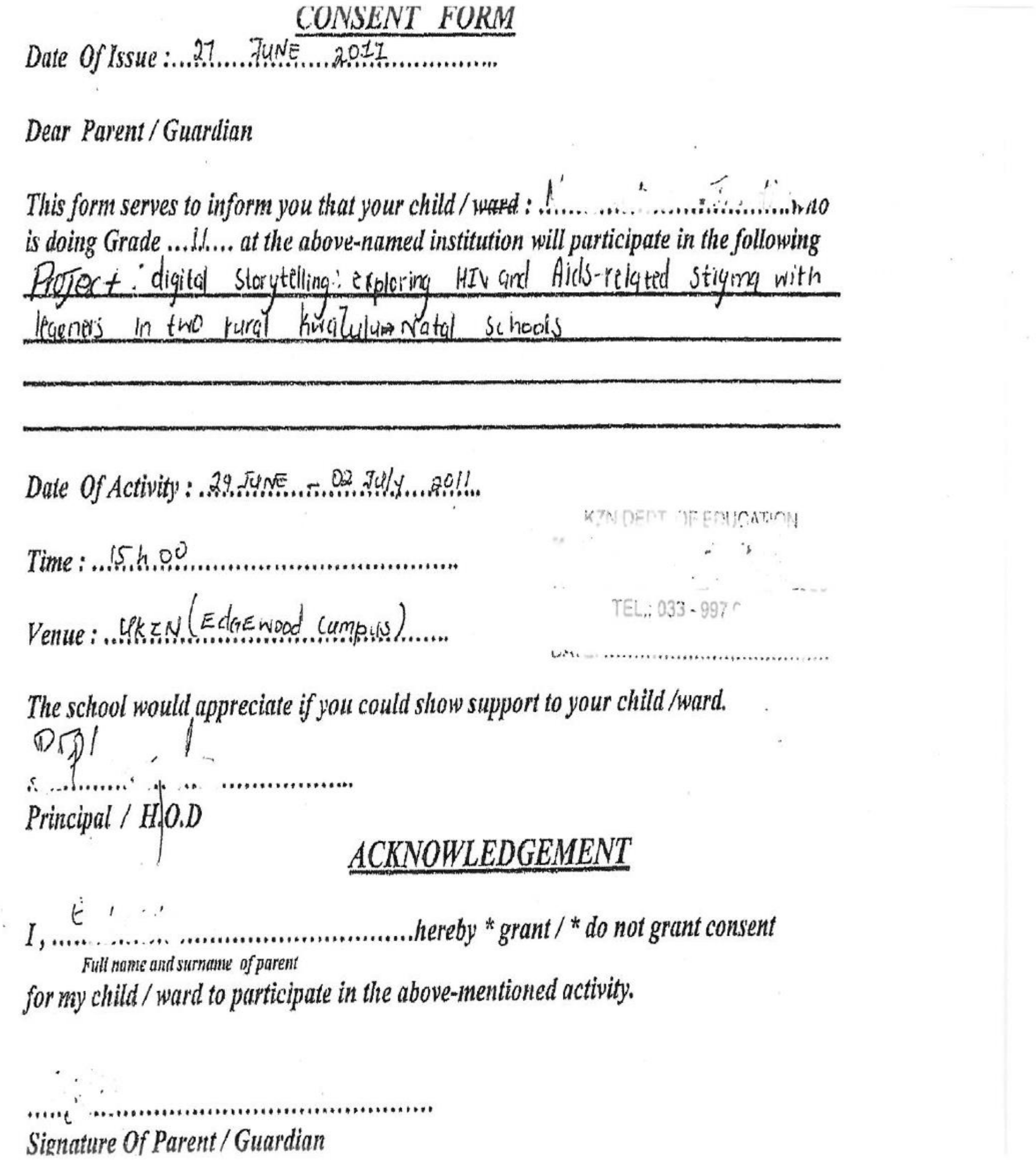
Your participation is voluntary and you will be free to withdraw at any stage of the research without any disadvantage.

Do you understand this study and are you willing to participate?

☐ YES ☐ NO

Signature of Learner ____________________ Date ____________________

APPENDIX F: PARENT CONSENT FORM



CONSENT FORM

Date Of Issue :...27....JUNE.....2011...............

Dear Parent / Guardian

This form serves to inform you that your child / ~~ward~~ : ....who is doing Grade ...11.... at the above-named institution will participate in the following

Project : digital storytelling: exploring HIV and Aids-related stigma with learners in two rural KwaZulu-Natal schools

Date Of Activity : ..29 JUNE ... – 02 July ... 2011...

Time : ...15 h 00..

Venue : ...UKZN (Edgewood campus).......

KZN DEPT OF EDUCATION

TEL.: 033 - 997

The school would appreciate if you could show support to your child /ward.

....

Principal / H.O.D

ACKNOWLEDGEMENT

*I, ...hereby * grant / * do not grant consent*

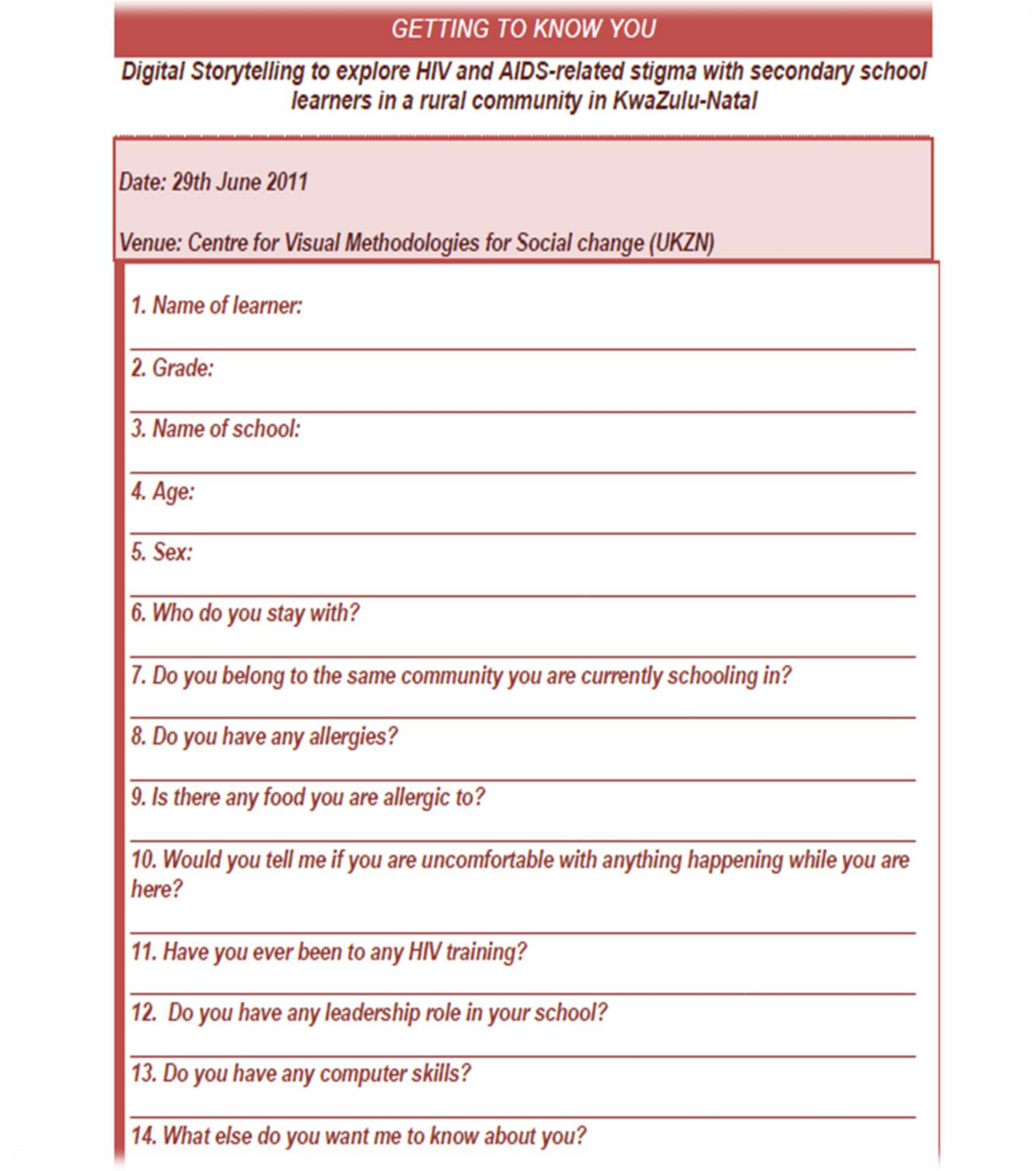
Full name and surname of parent

for my child / ward to participate in the above-mentioned activity.

..

Signature Of Parent / Guardian

APPENDIX G: GETTING TO KNOW YOU



GETTING TO KNOW YOU

Digital Storytelling to explore HIV and AIDS-related stigma with secondary school learners in a rural community in KwaZulu-Natal

Date: 29th June 2011

Venue: Centre for Visual Methodologies for Social change (UKZN)

1. Name of learner:
2. Grade:
3. Name of school:
4. Age:
5. Sex:
6. Who do you stay with?
7. Do you belong to the same community you are currently schooling in?
8. Do you have any allergies?
9. Is there any food you are allergic to?
10. Would you tell me if you are uncomfortable with anything happening while you are here?
11. Have you ever been to any HIV training?
12. Do you have any leadership role in your school?
13. Do you have any computer skills?
14. What else do you want me to know about you?

APPENDIX H: THE PROGRAMME OF DATA GENERATION WORKSHOP

Date: 29th June 2011	
ACTIVITY	TIME
Dinner and registration	18h00
Knowing you better	19h00 – 20h30

Date: 30th June 2011	
ACTIVITY	TIME
Breakfast	07h00 -
Ice breaker	09h00 – 09h15
Animal Choice	09h15 – 09h20
Understanding stigma activity by participants	09h20 – 09h40
Discussion	09h40 – 10h00
Stretching	10h00 - 10h05
Presentation by researcher - Participatory Discussion (participants while researcher facilitates)	10h05 – 10h30
BREAK	10h30 -11h00
Briefing on the production method	11h00 – 11 h15
Presentation (researcher and the educator)	11h15 -11h45
Drafting the Story	11h45 – 12h45
LUNCH	13h15 – 14h00
Reflection session (individually written)	14h30 – 14h45
House keeping	14h45 – 15h15
Working individually on generation drawings and photos they will use to illustrate their stories	14h15 – 16h15

Date: 1st July, 2011	
ACTIVITY	TIME
Welcome and reflection	09h00-09h15
Refining stories in terms of clarity	09h15-10h15
BREAK	10h15-10h45
Story recording	10h45-11h45
Working individually on finalising drawings and photos they will use to illustrate their stories	11h45-13h00
LUNCH	13h00-14h00
Downloading visuals (photos and drawings)	14h00 – 14h30
Participants add visuals and sound tracks	14h30 -15h30
DVD making (all twelve stories)	15h30 17h00
Individual reflective piece	17h00 -17h15

Date: 23rd September, 2011	
ACTIVITY	TIME
Welcome and house keeping	14h00-14h05
Login on computers and inserting DVDs	14h05-14h15
Giving prompts and clarity on activities	14h15-14h25
Story viewing	14h30-15h00
Written reflections	15h00-15h15
SNACK BREAK	15h15-15h40
Focus Group Discussion	15h40 – 16h00