# BEYOND DATA PRODUCTION: EXPLORING THE USE OF A DIGITAL ARCHIVE IN ADDRESSING HIV-RELATED STIGMA WITH EDUCATORS IN TWO RURAL SCHOOLS IN KWAZULU-NATAL

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# DECLARATION

The research report for this dissertation was carried out by Thoko Esther Mnisi under the supervision of Professor N. de Lange in the Faculty of Education, University of KwaZulu-Natal. This study represents original work done by the author and where the work of others has been used, acknowledgement was made. I declare that this dissertation has not been submitted for a degree at any other university.

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T. E. Mnisi

1 December 2009

# ACKNOWLEDGEMENTS

# REFERENCING STYLE

The author wishes to orientate the reader to the writing conventions that have been used in this dissertation. The dissertation uses the American Psychological Association (APA) 5$^{th}$ style for referencing which is the University of KwaZulu-Natal requirement. The beginner's guide to APA reference style prepared by Sharon Ritchie and Faye Garnham (Universal College of Learning) library and revised in 2004 has been adhered to.

**When one author is cited:**
Janekho (2002) suggests the business-operating environment has not changed dramatically with the advent of the Internet. Customers still demand quality service and products.
**or**
The business-operating environment has not changed dramatically with the advent of the Internet, as customers still demand quality of service and products (Janekho, 2002).

**Where there are more two authors cited:**
According Smith and Stewart (1999) there is a difference between HIV and AIDS.
**or**
There is a difference between HIV and AIDS (Smith & Stewart, 1999).

**Where there are more than two authors but less than six:**
Polit, Beck and Hungler (2001) list a range of potential sources for research. (First time citation).

Furthermore Polit et al. (2001) argue that…. (For the second time)

**Where there are six or more authors:**
 I cite only the last name of the first author followed by the words et al in the text, but list six in reference list.

Alston et al. (2002) argue that…
**or**
There is difference between … (Alston et al., 2002)

**Example reference list entry:**
Alston, A., Currie, H., Goldlovitch, G., Johnson, S., Powell, A., & Strang, P. (2002). *Medical practice management*. Wellington: Brooker.

Page numbers are only indicated where a direct quotation is used.

# ABSTRACT

This study outlines the use of a digital archive (a data set of staged HIV stigma photographs which were taken by Grade 8 and 9 learners) with educators in two rural schools in KwaZulu-Natal, exploring their views on using it in their teaching to address HIV and AIDS-related stigma. It responds to the need for creative and participatory methods in addressing HIV and AIDS. A qualitative, interpretive, exploratory and contextual design, using community-based participatory research methodology, was used to explore the digital archive, identify, and try out ways in which it could be used in addressing the pandemic. Data was generated using ICT-based focus group interviews involving fourteen male and female educators from two schools some - who have been participating in HIV research projects. I draw on a psycho-social framework within the ecosystemic approach, the values of community psychology and research as social change.

A digital archive has potential for communication and transferring information, especially in a rural area. It also shows potential to get both females and males to work together in addressing HIV-related stigma, hence reducing the gendered skewness of this pandemic. From the educators' responses to using the digital archive, themes emerged around working with the content of the archive, using the archive for teaching and learning, using the archive for engaging with stigma in the school and for change in the community. The findings suggest that the use of a digital archive in a rural context can enable educators to access and share digital material, which is locally produced, relevant and realistic, to address HIV-related stigma in the school. The tool in use can facilitate community participation and be used to deepen the understanding about HIV and HIV and AIDS-related stigma to a level that has impact on individual behaviour and ultimately on the community. Despite the potential there are still challenges such as lack of access to infrastructure, literacy, and relevant content. This work is exploratory and encourages further work to explore the implications and the trends on the use of a digital archive in other school settings.

## KEY WORDS

COMMUNITY

DIGITAL ARCHIVE

DIGITISATION

EDUCATORS

HIV AND AIDS-RELATED STIGMA

METADATA

RURAL SCHOOL

VISUAL DATA

# ACRONYMS

| | | |
|---|---|---|
| AIDS | - | Acquired Immunodeficiency Syndrome |
| CBPR | - | Community-Based Participatory Research |
| CVMSC | - | Centre for Visual Methodologies for Social Change |
| HIV | - | Human Immunodeficiency Virus |
| UNAIDS | - | Joint United Nations Program on HIV and AIDS |
| UNICEF | - | United Nations International Children's Emergency Fund |
| UKZN | - | University of KwaZulu-Natal |
| VCT | - | Voluntary Counselling and Testing |
| WHO | - | World Health Organisation |

# DEDICATION

In writing up this dissertation I used simple and comprehensive language to reach the community I have worked with. A community-based participatory research (CBPR) approach, which is an interactive process incorporating *research, reflection and action,* was adopted. This method has been applauded for engaging the community in addressing problems - which have been identified by them - hence bridging the gap between knowledge and practice in the community in improving health. I concluded and proposed that HIV and AIDS interventions must be more participatory and culture sensitive at community level, seeing local people as the experts in their own realities and as the protagonists of sustainable change.

I therefore dedicate this piece of work to the entire community of Vulindlela district in KwaZulu-Natal (more specifically the two schools which participated). I thank them for taking the lead in the research and producing ideas which can be transferred to other rural settings.

# CONTENTS

**PAGE**

# CHAPTER ONE
# ORIENTATION TO THE STUDY

# CHAPTER TWO
# EXPOSITION OF HIV- RELATED STIGMA

# CHAPTER THREE

# DIGITAL ARCHIVE AND ITS SOCIAL USES

# CHAPTER FOUR
# RESEARCH DESIGN AND METHODOLOGY

# CHAPTER FIVE
# FINDINGS AND DISCUSSION

# CHAPTER SIX
# CONCLUSIONS, IMPLICATIONS AND RECOMMENDATIONS

# LIST OF TABLES

# LIST OF IMAGES

# LIST OF APPENDICES

# CHAPTER ONE

# ORIENTATION TO THE STUDY

*...Can I add on that picture? I think I can bring to their attention that there are anti-retroviral now available so there is no need to wait until the classes are empty while there are ARVs. I can inform the learners that there is the treatment that prolongs [living with] HIV because many people are dying because they lack the knowledge. Then they can even spread the news at their homes that people must come out and get tested so that they get the treatment at the right time before we see empty classes. People should not be afraid to go and get the treatment...* [Participant]

## 1.1 INTRODUCTION

Once seen as a death sentence, HIV and AIDS is now viewed as a chronic but manageable disease. An issue of concern is that many people with HIV and AIDS seek help under cover of darkness, deeply ashamed of their plight (Deacon, 2005). It is therefore crucial to find ways to better comprehend and address the HIV and AIDS-related stigma especially in Southern Africa. Although the pandemic is a cause for concern worldwide, South Africa is most affected. In 2007, 32% of all the new infections and AIDS-related deaths occurred in South Africa, and more than half of the infected South Africans lived in KwaZulu-Natal (UNAIDS, 2008), this being the province in which this research is contextualised. The Department of Health (2007; 2008) also reported that the KwaZulu-Natal province has the highest HIV prevalence estimate compared to other provinces (See Figure1.1). Stigma and discrimination obstruct HIV and AIDS prevention efforts by limiting access to and use of HIV and AIDS-related services for prevention, treatment, care and support. While some affected people remain silent about the disease, it is quite encouraging that more and more scholars are not silent about the issues of HIV and the repercussions thereof. There is a plethora of literature on HIV and AIDS prevalence, the biomedical issues, the relationship of the disease to sexuality, the psycho-social effects related to stigma, and ways of addressing the 'scourge' (Deacon, 2005; DoH, 2007; Pembrey, 2006; Shisana, Ncayiyana, & Prince, 2008; Shisana et al., 2009; Singhal & Rogers, 2003).

Furthermore HIV and AIDS-related policies, also in the Department of Education, are filtering down to schools to address HIV and AIDS in the classroom.
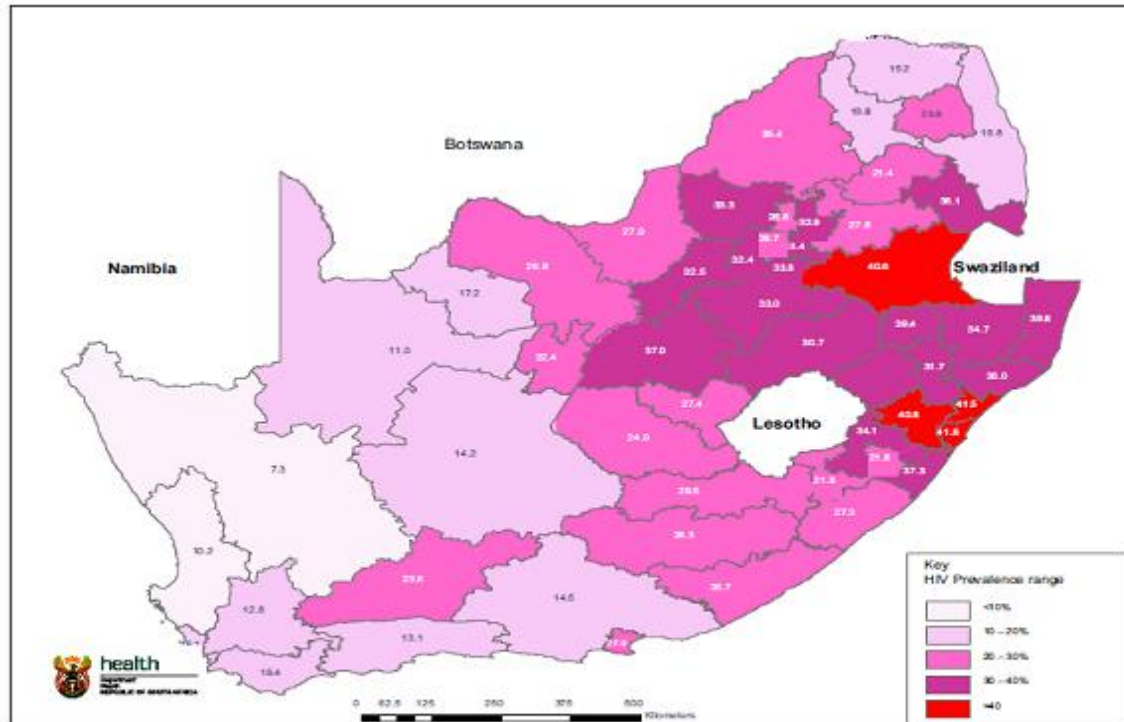


**Figure1.1: HIV prevalence estimates by district among antenatal attendees, South Africa (Department of Health, 2007)**

The pandemic requires the use of all resources and tools available, including visual and arts-based methods, because they are participatory in nature. The South Dakota-Department of Education (2004) defines visual and arts-based methods as a broad category that includes drawings, photography, electronic media like video and computers, dramatic performance, traditional and modern dance, music, poetry and recitals used as tools to entertain, teach and learn, foster creative self expression, and interpersonal communication, and understanding the relationship between visual art, history, culture and society. An example is a digital archive developed through Information and Communication Technologies (ICT) namely computers, combined with visual arts-based methods which was used successfully in addressing HIV in the "[1]Learning Together: Towards an integrated participatory approach to youth, gender and HIV/AIDS interventions in rural KwaZulu-Natal schools" (De Lange et al., 2003).

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[1] "Learning Together: Towards an integrated participatory approach to youth, gender and HIV/AIDS interventions in rural KwaZulu-Natal schools" (De Lange et al., 2003), hereinafter, "Learning Together" project. This is the project where the staged HIV-related stigma photographs from the digital archive were generated.

Such technologies can be used to deepen the understanding of the HIV-related stigma at a level that can have a positive impact on individuals and ultimately the community. The challenge also lies in opening up and extending access to ICT, in the case of this research, to educators and learners in a rural community. A digital archive or electronic 'library' for storing, managing, disseminating, and using data in addressing the pandemic has been created from photo-voice work in an earlier project (See Chapter 3).

This study outlines the use of a digital archive, that is, an electronic data set of staged photographs of HIV and AIDS-related stigma with educators in two rural schools, exploring their views on using it, and their trying it out in their teaching to address the issue.

## 1.2  STATEMENT OF THE PROBLEM

Considering the huge amount of visual data generated in an earlier research project, "Learning Together" (De Lange et al., 2003) from 2004 to 2006, the question raised was how such a volume of visual data could be stored, managed, and made accessible not only to all researchers in the team, but also to the participants themselves.

The team of researchers from the University of KwaZulu-Natal initiated the "Learning Together" project in the Vulindlela district, but the research focus was also driven by the community (educators, learners, community health workers and parents) who were equitably involved in the research process (De Lange et al., 2003). Visual and arts-based participatory approaches were used (involving photography, drawings, and video documentaries) with the aim of addressing issues around HIV and AIDS, youth and gender. A further aim was to foster collaboration and potential links between educators and community health workers (Ndlovu-Mamba, 2006) in addressing HIV and AIDS. Subsequently, participants identified stigma as a persistent problem and barrier to all the efforts towards combating HIV and AIDS in their community (Moletsane, De Lange, Mitchell, Stuart, & Buthelezi, 2007). As one way of addressing stigma, photo-voice was used where staged photographs were taken by Grade 8 and 9 learners in one of the participating schools. Once the photographs had been taken and developed, the learners selected the ones which they thought best depict stigma and wrote why they took them. As an intern at the Centre for Visual Methodologies for Social Change (CVMSC) I

worked on the digitisation of the dataset around stigma, and developed an interest in how the visual data could be used by the educators in the schools to address issues around HIV and AIDS-related stigma.

The drive behind this study comes from the recognition, as early as 1988, by the World Health Assembly (WHA), that the main barrier to prevention and care was stigma and discrimination against people living with AIDS (Nyblade et al., 2003). This was also identified by the participants in the "Learning Together" project (Moletsane et al., 2007; Wechsberg, Parry, & Jewkes, 2008). HIV and AIDS-related stigma is rooted in community norms of culture, sexuality, and behaviour as observed by Duvvury, Prasad and Kishore (2006), and therefore, rural communities in South Africa can become effective intervention points not only for HIV prevention but also for responding to the cultural norms which often worsen the plight of the youth (Wechsberg et al., 2008). The schools are regarded as part of the solution to social issues which affect the learners and are therefore regarded as entry points (Olivier, Wood, & De Lange, 2007). Educators can thus play an important role in school-based HIV prevention efforts if they are equipped with the necessary tools. Educators however, face numerous challenges such as working environments, and limited access to HIV materials which are relevant to their context (UNESCO, 2009).

In an effort to combat the pandemic, the Department of Education (2002) in South Africa proposed the integration of HIV and AIDS in life skills education to mitigate the effects of stigma on people living with HIV and AIDS. Following that, several researchers have written about how HIV and AIDS issues could be dealt with in the classroom using various methodologies, but still the stigma persists (Francis & Francis 2006; Francis & Hemson, 2006; Griessel-Roux, Ebersöhn, Smit, & Eloff, 2005; Moletsane et al., 2007; Stuart, 2006). These researchers conclude that education continues to have a significant role to play in the struggle against HIV and AIDS and further suggest that a holistic approach to HIV and AIDS education is a critical component in any strategy to reduce stigma. The Education Labour Relations Council (2005) also emphasises that there must be adequate strategies in place to address the complexity of the HIV and AIDS pandemic in educational institutions. One such strategy is intervention that draws on visual participatory methodologies such as drawing, photo-voice, and video documentary. It is to the best of my knowledge that in

the South African context, more specifically in the field of education, most of the HIV intervention programmes have not focused on using visual data and its metadata, nor drawn on a digital archive to address HIV and AIDS.

## 1.3  RESEARCH QUESTION

Considering the above, I then pose the question:

**"How could educators in rural schools access and use a digital archive (the visual data and its metadata) to address HIV and AIDS-related stigma?"**

## 1.4  RESEARCH AIM

The research aim is therefore to 'give life' to the visual data with which I worked and to possibly 'save lives' through a better understanding of HIV and AIDS-related stigma, by exploring how educators in rural schools could access and use a digital archive to address issues around this problem.

## 1.5  CONCEPT CLARIFICATION

The concepts involved in this study of using digital archives are clarified below.

**1.5.1 HIV and AIDS-related stigma** refers to all negative thoughts and feelings which people have about HIV and AIDS and the people living with the disease (Ogden & Nyblade, 2005), their families, and even about discussing it (Campbell, Foulis, Maimane, & Sibiya, 2005).  Stigma is a social construct which affects the life experiences of stigmatised people (Dovidio, Major, & Crocker, 2000), because it is perceived as a mark of shame where the carrier is blamed, devalued, and significantly discredited (Aggleton, 2000; Goffman, 1963).  Stigma is therefore described as a powerful tool for social control which can be used to marginalise, discriminate, label, and at the same time cause fear (Alonzo & Reynolds, 1995; Goffman, 1963).

**1.5.2 Visual data** refers to data (records) with observable stimuli: the external something that can be seen by eyes (Banks, 1998; Pink, 2007; Pink 2008).  Examples

of visual data are drawings, photographs, video work, collage, and so on (Karlsson, 2007; Prosser, 1998). Visual data from far places can be "leisurely perused" and they then tell a story (Prosser, 1998, p.101).

**1.5.3 Digital archive** is the outcome of digitising data. Hughes (2004) defines digitisation as a process by which analogue content is put into a binary code to be readable by a computer. Digitisation has the potential to transform scholarly use of data in digital libraries, but the full potential of such material can be realized only if the resulting digital objects are easy to access and manipulate and are accompanied by sufficient metadata to support extraction of the data (Linden & Green, 2006). Digitisation enables user groups such as children, youth groups, teachers, researchers, historians, and the general public to examine images on the web rather than to examine physical volumes in a library (Park, Mitchell, & De Lange, 2008). These collections of data then become digital archives (Beagrie & Pothen, 2001).

**1.5.4 Metadata** is described as "data about data" (Laddad, 2005, p.5) or descriptive information about a resource. Metadata is "structured descriptions, stored as computer data that attempt to describe the essential properties of the other discrete computer data objects" (Gill, 1998, p.2 as cited by Park et al., 2008).

**1.5.5 Educators** are people whose jobs are to teach learners to improve and extend knowledge and develop skills (Wehmeier, 2000). The Norms and Standards for Educators policy in South Africa (Department of Education, 2000) clearly states that an educator is not merely a subject specialist, and defines one of the roles of an educator as supporter: community, citizenship and pastoral care. An educator has to promote a healthy classroom environment by helping those who experience barriers to learning, whether in the classroom or through community interaction (Donald, Lazarus, & Lolwana, 2002). An educator is defined by the roles of being an interpreter and designer of learning programmes, a researcher and a lifelong learner (Donald et al., 2002). The policy also highlights the roles as a necessity in meeting the varied demands around HIV-related stigma and increasing wellness within the school and community.

**1.5.6 Rural school** refers to a school in a remote area which is informationally and infrastucturally underdeveloped (Pansiri, 2008). In this research, a rural school does

not suggest 'remote' in a demeaning and marginalising way but rather a particular geographical location, often with high levels of poverty, disease and "other social ills" (Chikoko, 2008, p.78).

**1.5.7 Senior secondary school** in South Africa is also referred to as a high school. A school in general is an institution which provides schooling for all the grades from R-12 (South African Schools Act, 1996:84). A senior secondary school would cater for learners between the ages 13-19 years doing grade 8-12.

## 1.6  THEORETICAL FRAMEWORK

For this study, I draw on Hitchcock and Hughes' (1995) view of a theory, seen as being concerned with the development of systematic construction of knowledge of the social world. Furthermore, Visser (2007, p. 20) views a theoretical framework not as "absolute laws", but believes that it is a framework that could be refined or replaced by more appropriate theories. The complexity of HIV-related stigma and the use of a digital archive in this study require more than one theoretical framework: a psycho-social framework within an ecosystemic perspective, to understand stigma; and research as social change, including the values of community psychology.

Current literature on stigma draws on research conducted before HIV, and the studies refer mostly to the definition of stigma, discrimination, and the causes and effects thereof (Deacon, 2005; Nyblade et al., 2003). Dovidio et al. (2000) explain that 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. The choice of the values of community psychology (Seedat, Duncan, & Lazarus, 2001; Ratele et al., 2004), seems to be the ideal approach concerned with transforming the way in which psychological problems are conceptualised and understood. De Lange, Greyling and Leslie (2005) point out that HIV and AIDS and HIV and AIDS-related stigma find causes in the whole ecosystem, and therefore the solution should be located in the whole *ecosystem.* Moletsane et al. (2007) concur that if there is no new way of addressing HIV-related stigma, the impact of HIV-related stigma will continue to affect schools,

communities, individuals, and groups. It is for these reasons that I believe in order to understand the complexity of stigma there is a need to explore stigma within ecosystemic layers, allowing people who construct HIV as stigma to better understand and change, hence my employing visual data (within digital archives) as a tool for social change.

The study focuses on HIV-related stigma, but particularly on how educators can use a digital archive to address issues around this. It is for this reason that the study is also informed by the work of Schratz and Walker (1995) who include different tools and approaches to visual methodologies , the work of Martin (2004) who believes art has the potential to effect social change; of Troer (1995) who created and exhibited photo collages that link stigma associated with AIDS to the stigma suffered by TB sufferers; and Wang (1999) and Ewald (2001) who through photo-voice allowed Chinese women and children to take photographs of their lives and speak about why they took them. Some visual researchers such as De Lange et al. (2003) and Stuart (2006) have made reference to the above scholars. Mitchell and Weber (1999) argue that captions and inscriptions (recording what was said by the photographer of the picture taken) are important aspects of the social uses of photography. In the dataset of staged stigma photos which I will use, the learners also wrote short narratives to complement their photos. I will be looking at the social uses of digital archives (photographs and their metadata) at the level of the school and will work with educators.

Since stigma has to do with discrimination against a person by members of mainstream society I also adopt the *values underpinning community psychology*, as one of its goals is to "induce social change" (Duffy & Wong, 2000, p.16). Community psychology is defined as understanding people within their social worlds and using this understanding to improve people's wellbeing. It is about understanding and helping; focusing on social issues and other settings that influence groups and organisations (Visser, 2007). In this case, the focus is at school level. The goal is to optimise the wellbeing of communities and individuals to innovate alternative interventions designed in collaboration with affected community members (Duffy & Wong, 2000). A community psychology approach embedded in an *ecosystemic approach* (Donald, et al., 2002), can make a valuable contribution as

it includes the wider context, in this case, that of HIV-related stigma which is not merely an individual's problem but has its origins in a broader social context (Eloff & Ebersöhn, 2004). Some of the values and goals of community psychology are the promotion of health and wellbeing, caring and compassion, self-determination and participation, respect for diversity and human dignity, and social justice (Dalton, Elias, & Wandersman, 2001; Visser, 2007).

## 1.7 RESEARCH DESIGN AND METHODOLOGY

### 1.7.1 Research design

A qualitative, interpretive, exploratory and contextual design which was determined by the research problem will be adopted; in this case exploring the use of a digital archive with educators in rural schools to address issues around HIV-related stigma. Qualitative approaches allow for deliberation and creativity of participants in their actions; they "make meaning in and through their activities" (Cohen, Manion, & Morrision, 2007, p.20). This was suitable for the research because an exploration of different ways of using a digital archive to address HIV-related was required. The participants understand their context and are able to construct their worlds (Denzin & Lincoln, 2003) in the attempt to address needs which are best known by them. They are deliberate and creative in their actions, act intentionally, and make meaning through their activities (Cohen et al., 2007). Description and understanding are the ultimate intent of qualitative research and that is why the data collection methods engaged must allow and create rapport, mutual trust, and honesty between the researcher and participants (Tedlock, 2003).

### 1.7.2 Research methodology

For this research project a community-based participatory research methodology (CBPR) informed by the theoretical frameworks, will be adopted. Community-based participatory research aims to bridge the gap between knowledge produced and practices used in communities to improve health (Clinical Information, 2004). Also, O' Fallon, Tyson, & Dearry (2000) defines CBPR as an interactive process, incorporating research, reflection, and action as a cyclical process. In this study I took previously

produced visual data to the community who had participated in the research, so that they could access and work with their data, to improve the health of the community. Parker and Aggleton (2003) propose including/involving the intended beneficiaries such as local residents and organisations in all strategies related to HIV. Strategies that recognise the unique strengths which each participant brings (Eloff & Ebersöhn, 2004), like CBPR, have been used in interventions for stigmatised mental health illnesses (Cowie, Boardman, Dawkins, & Jennifer, 2004) and therefore CBPR is useful when working with HIV-related stigma. Secondly, in the process of exploring what educators can do with the data, community-based participatory research methodology enables the researcher and the community to collaborate in research which can lead to community change (Marsden, 2002). It benefits the community and develops knowledge applicable to their settings although the knowledge can be transferred to other settings (Macaulay, 2007). It is important to note that CBPR focuses on research which is of importance to the community and seeks to combine the knowledge with action, with the intention of achieving social change (Cornwall & Jewkes, 1995). More often the cultural norms become a barrier to HIV prevention strategies and exacerbate gendered HIV-related stigma (Stuart, 2006). CBPR can help overcome cultural challenges to conducting research and enable scientific research in culturally diverse or unique communities. This is also relevant to the research as I was working with educators in rural schools.

### 1.7.2.1 Research setting

This research utilised secondary data of HIV-related stigma staged photographs which had been taken by Grade 8 and 9 learners in a rural school in the Vulindlela district, where HIV and AIDS prevalence is high. Digitisation of photographs took place at the CVMSC which is housed in the School of Language, Literacy and Media Education (SLLME) in the Faculty of Education at UKZN. This digital archive was to be used with educators from two schools in the Vulindlela district which had been involved in an earlier "Learning Together" project (De Lange, et al., 2003). Having access to computers is therefore necessary. One school has a fully equipped computer room with computers connected to the Internet while the other school does not. This posed a challenge which had to be overcome and which I explain in chapter 4.

### 1.7.2.2 Sample

I will purposively sample the participants (Nieuwenhuis, 2007) as I intend to work with educators who are directly responsible for raising awareness and prevention of HIV and AIDS, assisting the infected and the affected, and dealing with the trauma of illness and death (Bhana, Morrell, Epstein, & Moletsane, 2006), and also addressing the issue of stigma. CBPR is usually used within a community with a common problem, interest or goal; in this instance, addressing HIV-related stigma. A sample of 14 educators from two schools in Vulindlela District, where the data had previously been generated, will be selected and invited to participate. Some of the participants had been part of the "Learning Together" project where HIV-related stigma was identified as a barrier to HIV intervention programmes. The selection of this specific group of people will be deliberate as they had been involved in a specific programme related to the study (Denscombe, 2005). The choice of the participants was driven by the knowledge they have.

### 1.7.3 Data generation

The CBPR requires constant engagement with participants. This will be achieved by using the digital archive and allowing the participants to engage with it through prompting, in what I call an ICT-based focus group interview.

### 1.7.3.1 ICT-based focus group interview

Focus group interviews have the potential to encourage debate among participants about a particular topic and participants are able to build on each other's ideas which generate in-depth views (Morgan, 1997; Nieuwenhuis, 2007). A focus group interview is therefore cautiously designed to obtain perceptions in a specific area of interest in a liberal, non-intimidating environment (Kreuger, 1994; Nieuwenhuis, 2007). It is a tool for studying ideas in a group on a topic determined by the researcher (Morgan, 1997). At the other end of the continuum are researchers who regard focus group interviews as a suitable vehicle for participatory research (Short, 2006). A focus group interview has the potential to obtain data that could not be easily obtained with observation and individual interviews (Morgan, 1997). Participants will be able to generate different

ideas on the use of the digital archive as they enhance each other's ideas in suggesting several uses of the digital archive, simultaneously discussing the issue of stigma.

## 1.7.3.2  The process of data generation

### *Exploring the archive*

Firstly, a "workshop" will be conducted on what a digital archive is, what it contains and how to access it.  Each participant in the focus group will get an opportunity to access the data and then to study the data set which shows the nature of stigmatisation in this rural school, through the eyes of grade 8 and 9 learners.

### *Using the archive in designing lesson plans*

Secondly, the educators will be prompted to discuss how digital archives and its metadata could be used in the classroom in facilitating the understanding of issues around HIV-related stigma. At this point educators will be helped to open the digital archive, scroll through it, and choose a photograph they want to use in their classrooms to address stigma.  The focus will be designing their own exercises that could be tried with learners.

### *Implementing the lesson plans*

Thirdly, educators will try out their designed lesson activities with their learners.  The sessions will be conducted by one educator at each school.

### *Reflecting*

The video recording of the lesson will be watched by the participants, followed by a focus group discussion, reflecting on their views on using the digital archive in the lesson.  This again allows for refinement of thoughts on the use of the digital archive with the learners in their rural schools.

### 1.7.4 Data Analysis

Qualitative data analysis is primarily an inductive process of organising data into categories and identifying patterns among the categories (De Vos, 2005). This process of interpreting data is done for the purpose of drawing conclusions which reflect the interests, ideas, and theories of the study (Babbie & Mouton, 2004). The data from the focus group interviews, will answer the critical question of how digital archives can be used optimally, and will be analysed using Tesch's descriptive analysis technique to identify units of meaning and look for emerging themes as described by Creswell (1994). The focus of the study is on the educators and their views on how the digital archive might be used in addressing HIV-related stigma in rural schools. The raw data will be transcribed from audio-tape and video-tape to text. It is from the transcribed interviews that a thorough analysis will be done to come up with themes. Kvale (1996) states that transcribed interviews make analysis more amenable.

### 1.8 DELIMITATION OF THE STUDY

This study is located in the field of educational psychology, while the tool in use (a digital archive) is borrowed from the Library and Information Management Science. The theoretical frameworks are derived from the field of educational psychology, as the focus is on exploring with educators, how they might use a digital archive to address an issue such as HIV and AIDS-related stigma which affects the learning and development of learners. The study is contextualised as research is undertaken in schools in a rural setting (Balfour, Mitchell, & Moletsane, 2009; Chikoko, 2008).

### 1.9 COURSE OF THE STUDY

This chapter introduced the study by stating the problem, aim of the research, the critical question, and the theoretical frameworks employed. The chapter further briefly outlined the research design and methodology, sample, data production process, and how the data was analysed.

Chapter two provides an overview of two broad bodies of literature: the HIV-related stigma discourse and the use of digital archives. Local and international literature has

been explored and it informed the choice of the two theoretical frameworks against which the data analysis was done. Intervention strategies have been highlighted including policies in place which filter through to the education system. The history of the use of digital archives has been explored and how it could be used in the classroom context, more specifically in addressing issues around HIV-related stigma. I acknowledge that there was not much literature on the use of digital archives (in particular) in addressing HIV-related stigma especially in the context of education.

Chapter three focuses on digitisation and the digital archive. The chapter addresses issues related to the use of the digital archive as a research tool in the study. It stems from the recognition of the success of other tools which have been used to address HIV and AIDS-related stigma. I describe how I compiled the digital archive using secondary data from a photo-voice data set. I illustrate the overall approach and report on first experiences using a sample collection from the "Learning Together" project which is hosted on the website of Digital Innovations South Africa (DISA) in the University of KwaZulu-Natal. The online data was then used for my data production process.

Chapter four gives an outline of the research design and methodology. A full description of the research setting, research tools, the participants and their roles, the researcher's role, and details of each session is provided. I include a section positioning myself as the researcher. This chapter in essence provides details of how the research process unfolded and how the data was analysed.

Chapter five discusses the findings and how they relate to the literature reviewed. The findings are presented thematically and direct quotes from participants are used to support the interpretation. Also, the audit trail is included to show how the themes emerged.

Chapter six contains conclusions, implications, recommendations, and suggestion for further research. I also theorise the pedagogical possibilities and social uses of digital archives. At the end I list some of the limitations of the study.

## 1.10  SYNTHESIS

This research explores the use of a digital archive with educators in rural schools in addressing HIV-related stigma.  This research hopes to deepen the understanding of HIV-related stigma using online visual data that had been produced by the members of the school community themselves in an attempt to address the problem.  The understanding is hoped to be an indicator of "what can be?" to educators, learners, the community, and ultimately policy makers.

The next chapter will discuss local and international literature on HIV and AIDS-related stigma and in doing so the causes, prevalence, types of stigma, effects, and how scholars have addressed such issues, will be explored, pointing at the knowledge gap which this research tries to bridge.  Particular attention is given to theoretical frameworks and concepts that have been used in addressing the 'scourge'.

# CHAPTER TWO

# EXPOSITION OF HIV-RELATED STIGMA

*...enter the field with timely knowledge of the related field literature before conducting the field research...* (Babbie, 2001)

## 2.1  INTRODUCTION

In this chapter HIV-related stigma will be discussed, beginning with the origins and definition.  I also review literature to understand the phenomenon.  Efforts and intervention strategies are highlighted including policies filtering through to the education system.  The history of the use of digital archives broadly how it could be used in the classroom context and more specifically to address issues around HIV-related stigma, is explored.  The study focuses on two broad bodies of literature: HIV and stigma, and the use of digital archives within research as a social change framework.  The theoretical frameworks which guide the study, and how they complement each other, are outlined.

## 2.2  HIV-RELATED STIGMA

### 2.2.1 The origin of the term 'stigma'

Historically the term 'stigma' referred to a tattoo mark branded on an individual's skin for wrong-doing.  This was a practice during the early Greek civilization (Singhal & Rogers, 2003).  That physical mark served as identification to the general public to easily identify a blemished individual to be avoided.  Goffman (1963) describes stigmatised people as individuals with spoiled identities and rendered unworthy by others because they possess an "undesired difference" (Singhal & Rogers, 2003 p.249).  Stigma is a term that involves both deviance and prejudice but goes beyond both in that it extends to more general attributions about character and identity (Singhal & Rogers, 2003).

Stigma has been a feature of many diseases, either terminal or associated with sex (Deacon, 2005). Goffman (1963) has become a point of departure for studies related to stigma. His studies on stigma relate to mental illness, physical deformities, and socially deviant behaviours. Most researchers use Goffman's (1963) social theory to understand the stigma of medical conditions ranging from obesity, stuttering, mental illness, and tuberculosis, to sexually transmitted infections including HIV (Brown, Trujillo, & Macintyre, 2001). Stigma has always existed, with HIV and AIDS being the latest disease to be stigmatised (Dovidio, et al., 2000). Moreover, stigma has been labelled as the most important social and psychological issue of the HIV experience (Dovidio et al., 2000). It serves as an effective form of "social psychological policing" by punishing those who have breached the unequal power of gender, generation, and ethnicity (Campbell, et al., 2005, p.6).

## 2.2.2 Defining stigma

According to Deacon (2005, p.15) definitions are important because they "structure how we think about a phenomenon". In an attempt to define HIV-related stigma, I draw on definitions from different scholars. Goffman (1963) describes stigma as an attribute that is deeply discrediting and results in detaching a person or group from the whole (valued less than normal people) (Brown, et al., 2001; Dovidio et al., 2000). Herek and Glunt (1988) define HIV-related stigma as directed at persons perceived to be infected with HIV regardless of their confirmed serostatus. The latter confirms that even those who are not HIV positive are not spared stigmatisation. They form part of the population which Mann (1987) regards as unfairly stigmatised. Singhal and Rogers (2003) refer to the example of a woman who chooses not to breastfeed her baby and the community perceives her to be HIV positive and stigmatises and discriminates against her for this choice, even though she might not be infected with HIV. This kind of stigmatisation is also gender related and will be taken up further when discussing the relationship between HIV-related stigma and gender (c.f. 2.2.7).

Abdool Karim and Abdool Karim's (2005) notion of stigmatisation includes those who are not infected but affected, for example youths whose parents had died of AIDS. The study builds on Moletsane's (2003) work, investigating those who are affected. Thus the effect is twofold in that the parents have passed away, and that there is also the

stigma of having had parents who had died of AIDS. Ogden and Nyblade (2005) describe how stigma plays itself out in people perceived to be HIV positive and individuals, families, friends, and the community with which they are associated and Campbell et al. (2005) concur that even those talking about it are stigmatised. This includes prejudice, discounting, discrediting, and discrimination (the entire range of negative thoughts and feelings) that the stigmatiser directs towards the stigmatised (Nyblade et al., 2003). According to UNAIDS (2008) discrimination follows stigma and is regarded as the unfair and unjust treatment of an individual based on his perceived HIV status.

Goffman (1963) focuses on the individual aspects of stigma and in the case of HIV-related stigma was critiqued by Herek and Mitnick (1996) who recommend that empirical research on AIDS stigma be carried out by social and behavioural scientists. The argument is based on that fact that AIDS-related stigma represents a set of shared values, attitudes and beliefs that can be conceptualised not only at the individual level but at cultural level. At the level of the individual it takes the form of behaviours, thoughts, and feelings that express prejudices against people infected by HIV and their families, including those who are affected (Campbell, Maimane, Nair, & Sibiya, 2005). Herek and Mitnick (1996) argue that understanding stigma requires the understanding of both the cultural and the individual level as by definition stigma is a relational construct. Subsequently, Parker and Aggleton (2003) offer a framework that emphasises stigma as a social process that produces and reproduces relations of power and control. In their analysis they combine stigma and discrimination, and see it as a tool used by dominant groups to produce, legitimise, and perpetuate social inequalities; exerting social control through the exclusion of the stigmatised group in such a way that the latter cannot fight the stigma.

Academics from different disciplines such as bio-medical, education, and social sciences have engaged in intellectual and research exchange with regard to issues around HIV and AIDS-related stigma, such as Alonzo and Reynolds (1995); DoH (2007); Duffy (2005); Jewkes (2006); Leickness et al. (2007); Moletsane et al. (2007) Parker and Aggleton (2003) and Shisana et al. (2009) but stigma persists.

Alonzo and Reynolds' (1995) research on the trajectory of HIV-related stigma provides evidence on how it affects people living with HIV psychologically, socially, and sometimes physically (Dovidio et al., 2000). Singhal and Rogers (2003) identify the effects of stigmatisation by analysing several cases and further suggest communication strategies to overcome HIV-related stigma. Campbell shows how people living with HIV are stigmatised at all the ecosystemic layers: *"I have an evil child at my house"* (2005) and *"Letting them die"* (2003), and suggests intervention methods in her chapter, "*The collective action in the prevention of HIV/AIDS in South Africa*" (2004).

The Foundation for AIDS Research (2008) shows evidence that stigma clings stubbornly to women living with HIV and AIDS. Beyond mere defining and finding causes for [2]internalised stigma, Leickness et al. (2007) investigate the effects of internalised HIV-related stigma and conclude that there is correlation among depression and internalised stigma. Rintamaki and Weaver (2008) call for, in particular, research that explores the intersection of communication and psychosocial outcome. In summary, valuable work has been done on HIV-related stigma; I detail the foundational work thematically below. The next section examines HIV and AIDS-related stigma as the most stigmatised disease.

### 2.2.3  HIV-related stigma as a social phenomenon

An Africa-study synthesis compiled by scholars from Ethiopia, Tanzania, Vietnam and Zambia has tried to understand HIV and AIDS-related stigma (Ogden & Nyblade, 2005). They consider HIV-related stigma a social phenomenon involving the interplay between social and economic factors in the environment and the psycho-social issues of affected individuals. In their findings it becomes apparent that ignorance about the means of transmission plays a vital role in causing stigma. Values, norms, and moral judgment are other factors associated with the stigma. Unlike other diseases like cancer or diabetes, HIV and AIDS are associated with immorality (Moletsane, 2003). All these have negative consequences on people living with HIV and AIDS, as well as their families, and hinder treatment and prevention efforts (Ogden & Nyblade, 2005). The authors also concur with the idea that the three aspects of stigma which Goffman (1963)

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[2] Internalisation consists of a wide range of emotions or feelings e.g. feeling threatened, inadequate, lonely, anxious, insecure, and guilty (Donald et al., 2002).

distinguishes are related to HIV and AIDS. These are described as "abominations of the body" which for example could be physical deformities and disfigurements; "blemishes of individual character" such as mental disorders, addictions, and dishonesty; and "tribal identities" which of course refer to the race, nation, religion, and sex. Dovidio et al. (2000, p.2) further identify six dimensions of stigmatising conditions which are concealability, course of the mark, disruptiveness, aesthetics, origin, and peril. The extent to which the stigmatising characteristic is necessarily visible, 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 the state of the stigmatised. 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 issue of concealment and disclosure is 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, that is, diabetes, cancer, or tuberculosis. In the South African context, in KwaZulu-Natal, most people would say a person has 'idliso' (Govender, 2006) implying that a person has been poisoned. Those whose illnesses are invisible will be spared social rejection (Dovidio et al., 2000). HIV infected people have even 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. This 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 AIDS (Acquired Immune Deficiency Syndrome). It differs from one individual to another and the outward symptoms may be frightening and associated with death. Some people may have several bouts before they die and some may only be ill once and die, which makes the duration of the illness indefinite. Some people can lie in hospital beds for months, causing families and friends no longer wanting to be associated with the HIV patient, and even leaving the body unclaimed in morgues (Campbell et al., 2005).

HIV and AIDS-related stigma have been perpetuated by religion and moral issues. In areas where religious institutions have influence, for example rural communities, greater stigmatisation is reported (Kalichman & Simbayi, 2004; Paruk, Mohamed, Patel, & Ramgoon, 2006). HIV is stigmatised because of the moral denouncement of behaviours through which the virus is mainly transmitted, that is, sex.

Since its outbreak, the HI virus 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 expose other people to danger of contracting the disease.

The stigmatising mark (congenital, accidental, or intentional) can also involve the person's responsibility for creating the mark. People living with HIV are thought to be responsible for having contracted HIV (Francis & Hemson, 2006) and associated with behaviours performed of one's own free will, 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 the people are more stigmatised because the condition is not accidental. It is also seen to be a result of personal irresponsibility and it is believed that it can be avoided (Avert, 2008). However, Alonzo and Reynolds (1995) note that individuals with the illness do not experience the same degree of stigma; there are also some who are regarded by society as 'innocent' victims of HIV and AIDS. This includes children who contract HIV from their mothers, transfusion recipients, and rape victims, and thus they may be stigmatised less harshly.

Another dimension involves the perceived danger of the stigmatising condition to others. 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 perpetuates the stigmatisation of the illness (Alonzo & Reynold, 1995; Moletsane et al., 2007; Parker & Aggleton, 2003). Although it is becoming known that HIV can only be spread through blood transfusion, 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 (Govender, 2006). A study conducted by Francis and Francis (2006) illustrates that people are afraid of HIV, often irrationally, so that whenever an HIV positive learner goes to the toilet the other learners would use Jeyes Fluid to 'clean' the AIDS. Stigmatisation therefore also results from the perceived danger of the disease. Studies show that some families chase away their family members or do not allow them to use utensils, while some couples break up (Avert, 2008).

In addition of the dimensions of stigma discussed above, Dovidio et al. (2000) argue that visibility and controllability are the most important dimensions of stigma for the stigmatiser and the stigmatised person. Similarly, UNAIDS (2008) in the guidelines for addressing causes of stigma and discrimination, identified three key causes, that is, linking people with HIV to behaviour that is considered to be improper and immoral; fear of acquiring HIV through the everyday contact with the infected people; and a lack of awareness and knowledge about stigma and discrimination and its effects. This refers back to the suggestion by Campbell et al. (2005) that the issues of HIV and stigma should be addressed simultaneously. Understanding the dynamics of HIV and its effects could perhaps show which dimensions of stigma have to be addressed. Alonzo and Reynolds (1995) conclude that HIV and AIDS are a manifestation of an extraordinary illness in terms of its potential for multidimensional stigmatisation.

Regarding the concept of discrimination, most of the literature suggests that stigma emanates from stigmatisation (Dovidio et al., 2000). Deacon (2005) contends that discrimination is a result of stigmatisation. She suggests that internalised stigma can be the result of discrimination which emanates from the HIV positive person expecting to be stigmatised and in that case the stigma and discrimination takes place vice versa. Francis and Francis (2006) explain that discrimination is something people do to disadvantage people living with HIV; one of the effects of internalised stigma is discrimination that originates internally with the HIV positive person, without other people having to do anything to disadvantage them.

### 2.2.4    HIV-related stigma as a worldwide concern

HIV-related stigma is a matter of global concern and researchers such as Ogden and Nyblade (2005), Rogers and Singhal (2000, p. 245), Stuart (2006), concur that "stigma

is everywhere". In a recent study conducted by Phaswana-Mafuya and Peltzer (2006) results indicate the existence of stigma across all ages and in different contexts like family, school, work, health centres, and community levels. The world is more than 20 years into the HIV crisis with no cure and relatively few sustainable prevention programmes. However, support and medication are becoming more available such that HIV once seen as a terminal illness is now regarded as chronic but manageable illness. Positive living is being emphasised; however, the persistence of stigma related to HIV disrupts the social interactions of the stigmatised with other people. Although the rate of HIV and AIDS deaths shows a decline in developed countries, infection rates are still very high in developing countries, with the African continent leading worldwide (Singhal and Rogers, 2003). Closer to home, KwaZulu-Natal has a high prevalence of HIV (Department of Health, 2008; Makubalo, Nedshidzivhani, Mahlasela, & du Plessis, 2003; Morrell, Unterhalter, Moletsane, & Epstein, 2001) with the youth the most infected group of the HIV positive population (Department of Health, 2006). Despite the alarming and growing AIDS crisis, the world is not very successful in changing behaviour and putting forward communication strategies to combat HIV (Stuart, 2006). She adds that many communications are culturally inappropriate and offend public sensitivities which make it difficult to deal with a topic that involves sex, stigma, and death. It is however, notable that a current study shows KwaZulu-Natal, the context of the study, to have the third lowest levels of stigma out of the nine provinces (Schierhout, Delate, & Ridgard, 2008). However the stigma is multifaceted and deserves to be contextually understood, as must the type of stigma one is referring to, be considered.

**2.2.5   The effects of stigmatisation**

It is well documented that many people affected with HIV and AIDS in southern Africa experience poverty and isolation hence the inability to provide for basic needs such as food and even shelter (Campbell, 2003; Francis & Hemson, 2006; Parker & Aggleton, 2003). Considering that people live in fear of rejection by their families, communities and formal health services, they are likely to choose to die without seeking help. The stigma and the terror that surrounds HIV, as people imagine it, often causes people affected by HIV to be reluctant to seek treatment or support. Furthermore, HIV-related stigma prevents many people from coming forward for testing and counselling. 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, 2005; Singhal & Rogers, 2003).  Campbell (2003) writes that those who disclose their status often become victims of partners, family members, and communities where HIV is frowned upon.

Stigma is not only a challenge to the stigmatised or the stigmatiser but also a challenge to one's humanity (Dovidio et al., 2000).  The person who is stigmatised on one hand is devalued and his social identity is spoiled, on the other hand the stigmatiser views stigmatisation as dehumanisation, threat, aversion and sometimes depersonalisation of others.  From that notion Dovidio et al. (2000) conclude that stigmatisation is personally, interpersonally, and socially costly.  Subsequently, Deacon (2005) suggests that understanding is needed of the role of the individual in stigmatisation without resorting to defining stigma as the problem of an individual.  It is therefore vital to examine how HIV is stigmatised personally, interpersonally and socially, and in so doing I shall draw on some cases as evidence of stigma.

### 2.2.5.1  At individual level

The psychological and social consequences of stigma involve responses in both of the perceiver and stigmatised people themselves (Dovidio et al., 2000, p.5).  Manifestations of stigma, according to Campbell et al. (2005), are rooted within the individual psyche.  At the level of the individuals who are HIV negative or assume that they are, it takes the form of behaviours, thoughts and feelings that express prejudice against people infected by HIV, their families, including those who are affected (Campbell et al., 2005).  In regard to those who know they are HIV positive, Aronstein and Thompson (1998) mention panic, anger, shock, fear, shame, denial, changes in physical appearance, and suicidal thoughts.  These are brought about by the fear of not knowing how long one will live, fear of a painful death, blame and fear of stigma, reaction of disbelief regarding the status, and a desire to protect the family from the pain of prolonged illness.  Linsk and Mason (2004) add sadness, isolation, and uncertainty of the illness process.  They further state that the affected members' family face feelings similar to those of the infected member.  The fear, isolation, and the attempts to avoid personal stigma spreads from the level of the individual to every other member of the family.

The problem of stigmatisation, from the understanding of these authors, manifests itself in the individual psyches irrespective of the individual serostatus.

**2.2.5.2 In the family**

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), as African traditions emphasise complex family and community relations of support. The importance of the role played by the family in providing care and support for people living with HIV and AIDS cannot be denied. Not all families adhere to this due to what Herek and Mitnick (1996, p.4) term "secondary AIDS stigma," where those who are close to the HIV infected person like family members, partners, and loved ones 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 (Dano, 2007). Uninfected members may not offer support because of the fear of being linked to the virus. Campbell et al. (2005), in her findings, report that stigma also manifests in the family, and reveals that families stigmatise their members, gossip about their children who have the disease and call them evil children. Moreover, family members do not want people to know there is a sick person in the house, and will hide the person and prevent anyone from helping. In another paper titled *Understanding and challenging stigma,* Campbell et al. (2005) refers to stigma as all the negative thoughts and feelings that people have about HIV and AIDS which includes those who have it, their families, and even discussions about it (c.f. 1.5.1).

This notion of not discussing HIV and AIDS happens when a member of the family passes away and the cause of the death is kept a secret if the cause was AIDS. Because of the stigma the family also lives with a conspiracy of silence which slows down the healing process and isolates the family from traditional forms of support (Linsk & Mason, 2004). Gilbert (2001) asserts that the youth, unable to mourn openly, 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 Kenneth Kaunda (Singhal & Rogers, 2003) and Nelson Mandela in (Mandela, 2005) leading the way when they publicised the cause of their sons' deaths. Such examples of public disclosure are the only way to reduce the stigma since it humanises HIV and the AIDS epidemic.

### 2.2.5.3 At work

Phaswana-Mafuya and Peltzer (2006) indicate that there is stigma attached to HIV and AIDS at the workplace, and reveal that some work places stigmatise by compulsory testing for those who apply for jobs. There are also some cases of people fired from work after they disclosed their status, for example, a female teacher who disclosed her status to the principal as she would be absent to treat opportunistic diseases, was fired (Natal Witness, 22/10/01). Another example is of patients stating that they would not like to be treated by an HIV positive dentist (The Foundation of AIDS Research, 2008). Therefore, professionals in such a position would not disclose their status, for fear of losing clientele.

### 2.2.5.4 At health care

The kind of treatment which patients get from health care centres may deter them from accessing medical support. In India, in the early years of the HIV pandemic, patients' beds would be marked "HIV positive" (Singhal & Rogers, 2003) and their medical charts marked in red as a warning to hospital staff. Deetlefs, Greeff and Koen (2003) found that South African nurses' attitude towards HIV patients was negative. A study of HIV-related stigma in five African countries, that is, South Africa, Swaziland, Lesotho, Malawi, and Tanzania, also showed that there is stigmatising in health centres (Holzemer et al., 2007). In addition, specially allocated VCT and HIV and AIDS treatment rooms may cause stigmatisation where lack of space compromises confidentiality (Population Council and Health Systems Trust, 2006). Steinberg (2008) asserts that the general procedure of taking more time while counselling an HIV positive patient give other patients a 'clue' that the person in consultation is HIV positive. He further asserts that people prefer to die at home than to go for free anti-retroviral treatment out of fear of being stigmatised.

### 2.2.5.5  At school

The prevalence of HIV stigma is evident in South African schools as well as in other countries.  Singhal and Rogers (2003, p. 273) relate a story of a Brazilian HIV positive girl who was orphaned after her mother passed away.  She was then adopted by a "wealthy couple" who tried to enrol her in an elite school, but was denied admission - on the grounds of her status - which forced the family to sue the school.  Nkosi Johnson from South Africa was accepted at school only because he was under the custody of a Mrs Johnson, who could fight with the authorities (Singhal & Rogers, 2003).   Legal advice can only be sought by people who are financially stable.  In both cases the children obtained access to education only after legal action which ordinary citizens cannot afford.

Learners are stigmatised and discriminated against by both educators and peers (Francis & Francis, 2006).  One educator asked an HIV infected learner to share with the class how she got infected and warned the class not to get close to her.  This is similar to learners using Jeyes Fluid to clean the toilet every time an HIV positive learner uses the toilet.  In Nigeria, Jegede-Ekpe revealed her HIV status while still studying at a nursing school.  The principal tried to expel her from the school, her dorm-mates locked her out of the female's bathrooms, and relegated her to menial chores (Fleshman, 2004).   But she fought for her right to continue studying. These examples demonstrate that speaking out (disclosure) is not easy and may remain uneasy if revealing your HIV status is regarded in a negative way.

### 2.2.5.6 At community level

A community can also stigmatise an illness and in the South African context HIV is referred to by different names such as "Umlazi 3", "House in Verulam", "Amagama Amathathu" (Francis & Francis, 2006) and some call it "this animal" (Govender, 2006). Steinberg (2008), in his book, *The three letter plague* describes how the community stigmatises those who undergo HIV tests in Lusikisiki.   This is similar to the findings from the Populations Council and Health Systems Trust (2006) that people feel uncomfortable using VCT services where local community members are employed, fearing the compromise of confidentiality.  In Brazil too, people choose not to register

for free anti-retroviral drugs out of fear of being stigmatised (Sighal & Rogers, 2003). In Columbia when people were forced to undergo an HIV test, those who were found to be HIV positive were evicted from the area (Singhal & Rogers, 2003). Closer to home, Gugu Dlamini was killed by members of the community after divulging her HIV status (Francis & Hemson, 2006; Moletsane et al., 2007). In August, 2008 the newspapers and radio stations reported a case where a 37-year old woman in the Eastern Cape committed suicide and also killed four of her children after being continuously harassed by the community for her assumed HIV status (Booi, Ngcukana & Pather, 2008). The Chairman of the National AIDS council lamented that South Africa has high levels of stigma and discrimination and suggested that strategies to deal with stigma be put in place (Booi, et al., 2008).

## 2.2.5.7 Culture

A community is guided by cultural practices (Cross & Capentier, 2009; Dalton et al., 2001). In sub-Saharan African countries' cultural practices make it taboo to discuss sex issues with children, as it is regarded as a sensitive issue (Pattman, 2003). In the case of HIV and AIDS, a disease contracted mainly through sex, talking about it is circumvented, exacerbating stigmatisation and increasing the chances of the youth contracting it.

Cultural practices also intersect with gender issues as the African culture is characterised by patriarchy and condones the idea that males can have multiple sexual partners (Nyblade, et al., 2003). This does not only undermines any attempt to change sexual behaviour in an effort to fight HIV and AIDS, but also increases the potential of females to become infected and subsequently stigmatised. This is more so because masculine identity is constructed as macho sexuality; as Campbell et al. (2003) suggest, it is acceptable for males to have more than one partner to satisfy their sexual appetite in 'flesh-to-flesh' sexual contact. Guma and Henda (2004) note that girl children, according to the sub-Saharan African culture are brainwashed by the gender roles and identities of inferiority, obedience, submissiveness and silence. Ogden and Nyblade's (2005) *Common at its core* research report suggests that in instances where it is obvious that the woman is innocent and not responsible for transmission of the virus, the man is protected and the woman stigmatised, because the man is regarded as superior.

## 2.2.6 Relationship between HIV-related stigma, sexuality and gender

As has been alluded to before, there is a link between HIV, sexuality, and gender, and issues of sexuality and gender cannot be separated when addressing HIV issues. The HI virus itself was first associated with gayness and sex, and gender issues are always crystallised in that females are more vulnerable compared to males (Campbell, 2003; Morrell et al., 2001; Stuart, 2006; UNAIDS, 2008). The statistics given by the South African Department of Health (2003; 2007; 2008) also show that females have a higher rate of infection than males. They term HIV and AIDS-related stigma as a dual humiliation in that it was initially identified in a group already marginalised before they contracted HIV (Campbell et al., 2005). Women, youth, stigmatised groups, that is, gay men, sex workers, drug users, and the poor, often fall in this category of the socially disadvantaged. Despite the fact that females are more vulnerable to HIV (Campbell, 2003) and that they are more stigmatised, whenever they carry condoms to protect themselves they are perceived to be 'hunting' for sex. UNAIDS (2007) concur that women experience more stigma and discrimination than men. Nyblade et al. (2003) observe that women are likely to experience the most damaging forms of stigma, which includes violence.

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 and testing, or refusing sex; this includes married and unmarried women. The impact of HIV on women is severe in that women are economically, culturally, and socially disadvantaged and this lack of resources, treatment, and support makes it difficult to cope with the stigma (Avert, 2008; UNAIDS, 2007). Women are often abandoned and left with children, while the spouse is likely to be excused for the behaviour which led to the infection in the first place (Avert, 2007; Ogden & Nyblade, 2005). The in-laws blame the woman for infecting their son and sadly this prejudice is exercised by other women, like the mother-in-law (Avert, 2007; Fleshman, 2004). Furthermore, testing is the only way to know your HIV status. Since women will negotiate access to voluntary testing and counselling or be forced by antenatal testing, this increases their chances of being identified as HIV positive and thus perceived as the main transmitters of HIV (Avert, 2007; Department of Health, 2003; UNAIDS, 2007). This further contributes to the stigmatisation of women within the context of HIV. In

the case of expectant women, if a child is born HIV positive this leads to the label as 'mother-to-child' which also stigmatises women without considering the root of the infection.

In a study in Zambia, Tanzania, and Ethopia, participants' views of HIV and stigma as related to gender were different. The findings showed that both women and men are stigmatised for breaking the sexual norms of their gender (Nyblade et al., 2003). Participants also acknowledged that females are at higher risk of infection because they are unable to negotiate safer sex. Moreover, participants concur that women have more controllable sexual urges and that they are too busy with house chores to be engaged in extra-marital affairs. While many differences emerged from the views of the participants, women still remain more stigmatised than men. This is so because of power relations which allow the man to shift the blame to the woman. Other forms of stigma are reserved for women, like sex workers, who are thought to be responsible for their infections (Campbell, 2003; Rintamaki &Weaver, 2008; Singhal & Rogers, 2003). The personal characteristics of people with HIV (people who are already negatively perceived) create and strengthen the stigma of HIV and AIDS. Notably, sex-workers are not only worried about stigma but also the loss of clients who might know their serostatus (Campbell, 2003). The element of fear of rejection, loss of clients, and the loss of love they get from their regular partners, always prevails. I conclude that women are highly stigmatised and I therefore agree with Fleshman (2004) that women are the face of AIDS in Africa.

### 2.2.7 Efforts in addressing HIV and AIDS-related stigma

It is necessary to highlight the policies designed to combat the pandemic. In South Africa the White Paper 6 is explicit that no learner must be discriminated against for his HIV status (DoE, 2002). The Department of Education (2002) also proposed the integration of HIV and AIDS with life skills education to mitigate the effects of stigma surrounding people living with HIV and AIDS. Asmal recommends that life skills programmes need to include values, the context of the community within which schools operate, and the broader community, to mitigate the effects of stigmatisation on people living with HIV and AIDS (Ministry of Education, 2002).

There is a growing 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 sure of their serostatus. Francis and Francis (2006) conducted research on how HIV-related stigma and its associated prejudice and discrimination can be addressed in the classroom. Francis and Hemson (2006) explored a participatory visual arts method to challenge HIV-related stigma. The key argument is that progress in fighting the epidemic can only be made if shame is replaced with solidarity, and fear with hope. Moletsane, et al. (2007), through the use of photo-voice as tool for analysis and activism, in response to HIV and AIDS stigmatisation, argue that stigmatisation can be eliminated when we successfully develop new understandings about HIV-related stigma and also when we have in place new ways of taking action by both individuals and groups.

Researchers conclude that education has a significant role to play in the struggle against HIV and AIDS (Griessel-Roux, Ebersöhn, Smit, & Eloff, 2005; Stuart, 2006). They recommend that a holistic approach to HIV and AIDS education continues to be a critical component in any strategy to reduce stigma (Francis & Francis, 2006; Francis & Hemson, 2006; Moletsane et al., 2007). The Education Labour Relations Council (2005) emphasises that adequate strategies to address the complexity of the HIV and AIDS pandemic must be in place in educational institutions. In rural communities, stigmatisation amongst other things, continue to be a stumbling block.

Deacon (2005) observes that few anti-stigma programmes have been successful. However, recent studies show that success has been achieved in using visual participatory methodologies such as photo-voice, visual arts, and collage, to study the social determinants of HIV and AIDS particularly when working with youth (Francis 2004; Mitchell, De Lange, Moletsane, Stuart, & Buthelezi 2005; Stuart, 2006; Moletsane et al., 2007). Francis and Francis (2006) agree that the issue of HIV and AIDS-related stigma can be addressed in the classroom which confirms Griessel-Roux, Ebersöhn, Smit and Eloff's (2005) findings that learners desire a more practical way of delivering HIV and AIDS education. However, society still stigmatises those who have AIDS and those affected by it, including children who have been orphaned. Even those

who are neither affected nor infected are not spared from the stigma (Singhal & Rogers, 2003). This is an indication that urgent attention to the HIV 'scourge' must be given.

Campbell et al. (2005) argue that the fight against HIV and AIDS and the fight against stigma have to go hand-in-hand as it is not possible to get rid of one without the other. 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/AIDS epidemic." According to Deacon (2005) most research on HIV and AIDS-related stigma has been done in the United States. In Africa the focus has been on HIV and AIDS in general and the politics around HIV and AIDS. Campbell et al. (2005) confirm that stigma emanates from the level of the individual, families, and even the whole community, which causes unsuccessful HIV management.

Parker and Aggleton (2003) suggest that anti-stigma intervention needs to go together with educational programmes. Although Holden (2004) argues for the adoption of core programmes and internal systems to address the impact of AIDS, UNAIDS (2008) concur with Campbell et al. (2005) and Deacon (2005) that intervention strategies must deal both with HIV and AIDS, and that stigma as stigma has been identified as an illness on its own. Having argued that stigma is key in addressing HIV and AIDS, I will highlight the theoretical framework I draw on to explore how teachers can use a digital archive to address HIV-related stigma.

## 2.3    THEORETICAL FRAMEWORK

Current literature on stigma shows that the theoretical framework for understanding stigma draws on research conducted before HIV was known, and the studies refer mostly to the definition of stigma, discrimination, and the causes and effects thereof (Deacon, 2005; Nyblade et al., 2003).

Vithal and Jansen (2004) posit that a theory is a perspective on events and exists in the context of competing theories, while a conceptual framework is a less developed explanation for the events to which the key concepts or principles are linked. I draw on Hitchcock and Hughes' (1995) definition of theory, as I will be employing more than one theory in my study:

> Theory is seen as being concerned with the development of systematic construction of knowledge of the social world. In doing this theory employs the use of concepts, systems, models, structures, beliefs and ideas, hypothesis (theories) in order to make statements about particular actions or activities so as to make analyses of their causes, consequences and process (Hitchcock & Hughes, 1995, pp. 20-21).

This is in line with Visser (2007, p. 20) who views a theoretical framework as "not absolute laws." The complexity of HIV-related stigma and the use of digital archives in this study calls for more than one theoretical framework, that is, stigma from a psycho-social approach within an ecosystem perspective; and research as social change and the values of community psychology.

I frame the study in a *psycho-social* approach within the ecosystem, emphasising the effects of the immediate social and situational context on the stigmatiser, on the stigmatised, on their interaction; and ultimately on the personal, social, affective, cognitive, and behavioural consequences of these transactions (Dovidio et al., 2000). Stigma as it has been described is a social construct, and conceptualisation of stigma could provide an entry point to reduce stigma at all levels of the ecosystem (Dovidio et al., 2000), that is, the individual, the family and the school in a rural community.

Psycho-social theory focuses on the ongoing interaction of the person and the social environment throughout his or her development (Newman & Newman, 2006). Also, De Lange et al., (2005) point out that HIV and AIDS finds its cause in the whole ecosystem, and therefore the solution should be located in the whole *ecosystem.* Moletsane et al. (2007) concur that if there is no new way of seeing HIV-related stigma, the impact will continue to affect schools, communities, and individuals. It is for these reasons I argue that in order to understand the complexity of stigma we need to explore stigma within the ecosystemic layers, allowing people who construct HIV as stigma to better understand hence employing visual data (within digital archives) in a participatory way as a tool for social change.

Individuals cannot be understood without considering the community in which they live, as 'humans are community seeking animals' (Dalton et al., 2001, p. xix). An individual lives within many social structures that form communities at multiple levels.

These include networks of friends or extended family, workplace, school, voluntary association, religious congregation or spiritual community, neighbourhood and wider locality, society, and culture (Donald *et al.,* 2002). *Community psychology* is about the relationships of the individual to community and society. Through collaborative research and action, community psychology seeks to understand and enhance the quality of life for individuals, communities, and society.

Seedat et al. (2001) emphasise the role played by community psychology in social change, seeking to understand how to move beyond the individual and promote the well-being of a larger community. Values of community have been used in other psycho-social problems such as mental health programmes, gun violence, gender and violence. HIV and AIDS-related stigma is another psycho-social issue, requiring focusing on and analysing social structures to bring about change in a people-centred paradigm. Therefore the values of community psychology can be drawn on to address local concerns where change is needed, namely the issues of HIV-related stigma that obstructs HIV and AIDS intervention and prevention programmes.

Donald et al. (2002 p. 32) define *ecosystemic perspective* as "a blend of ecological and systems views of interaction between different levels of social context and the individuals with them." An ecological perspective, which Seedat et al. (2001) define as a person-environment fit, emphasises 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. I found it fit to consider the ecological perspective as I framed the study around the psycho-social within the ecosystem. I have already indicated that the psycho-social theory focuses on the ongoing interaction of the person and the social environment throughout his development (Newman & Newman 2006). Ecosystemic theory views the person as developing within a complex system of relationships affected by multiple levels of the surrounding environment (Berk, 2001). This approach moves away from linearity and focuses on the wholeness, interdependence, and complementarity of living organisms. Individuals, families, small groups, organisations, communities, societies, and cultures can be viewed as systems, all of them interdependent (Donald et al., 2002).

A systems approach focuses on multiple levels of the phenomenon simultaneously, for

example, individuals, families, and workplace. Emphasis has been placed on the multi-level approach of HIV prevention (Campbell, 2003). To analyse problems, people, and situations, to plan a remedial intervention and to implement appropriate techniques, requires an adequate grasp of practical theory and knowledge about human behaviour in social environments (Hepworth, Rooney, & Larsen, 2002). An ecosystemic perspective places emphasis on the person in the environment, claiming that a human is a bio-psychosocial being whose behaviour is influenced by the environment the person lives in (Donald et al., 2002).

Bronfenbrenner (1979) illustrates the ecological levels (which has evolved over time) by using a metaphor of a nesting doll which contains a succession of smaller dolls each inside the other with the smallest one which appears in the centre. As a metaphor, the nesting doll calls for attention on how the smallest doll exists within layers of larger dolls, just as each individual exists within layer of social relationships.

The *individual* is at the centre and considered the smallest doll, nested within a set of interdependent layers of relationships (Dalton et al., 2001). The person chooses his/her relationship with the layers/levels to some extent, and influences them in ways just like they influence his/her choice.

The *micro systems* level refers to systems in which individuals are closely involved in proximal to other familiar people such as family, social support networks, care giving relationships, classrooms, and adolescent peers (Donald et al., 2002).

*Meso systems* are also known as the environment and include organisations and localities/communities. Organisations consist of sets of micro systems such as schools, health care settings, workplaces, religious organisations, and human service organisations (Dalton et al., 2001). Community in this ecological level of analysis refers to geographical localities, including rural districts, small towns, and entire cities.

The *macro system* includes national values, legislation, policies, prevailing ideologies, and funding patterns. It also refers to the broader environment, with which the individual members of family do not have direct interaction but which does have an influence on individuals (Naidoo, 2004). I outline (See Figure 2.1) a psycho-social

approach within an ecosystemic framework and show how they complement each other. I also show how they are underpinned by the values of community psychology and research as social change.
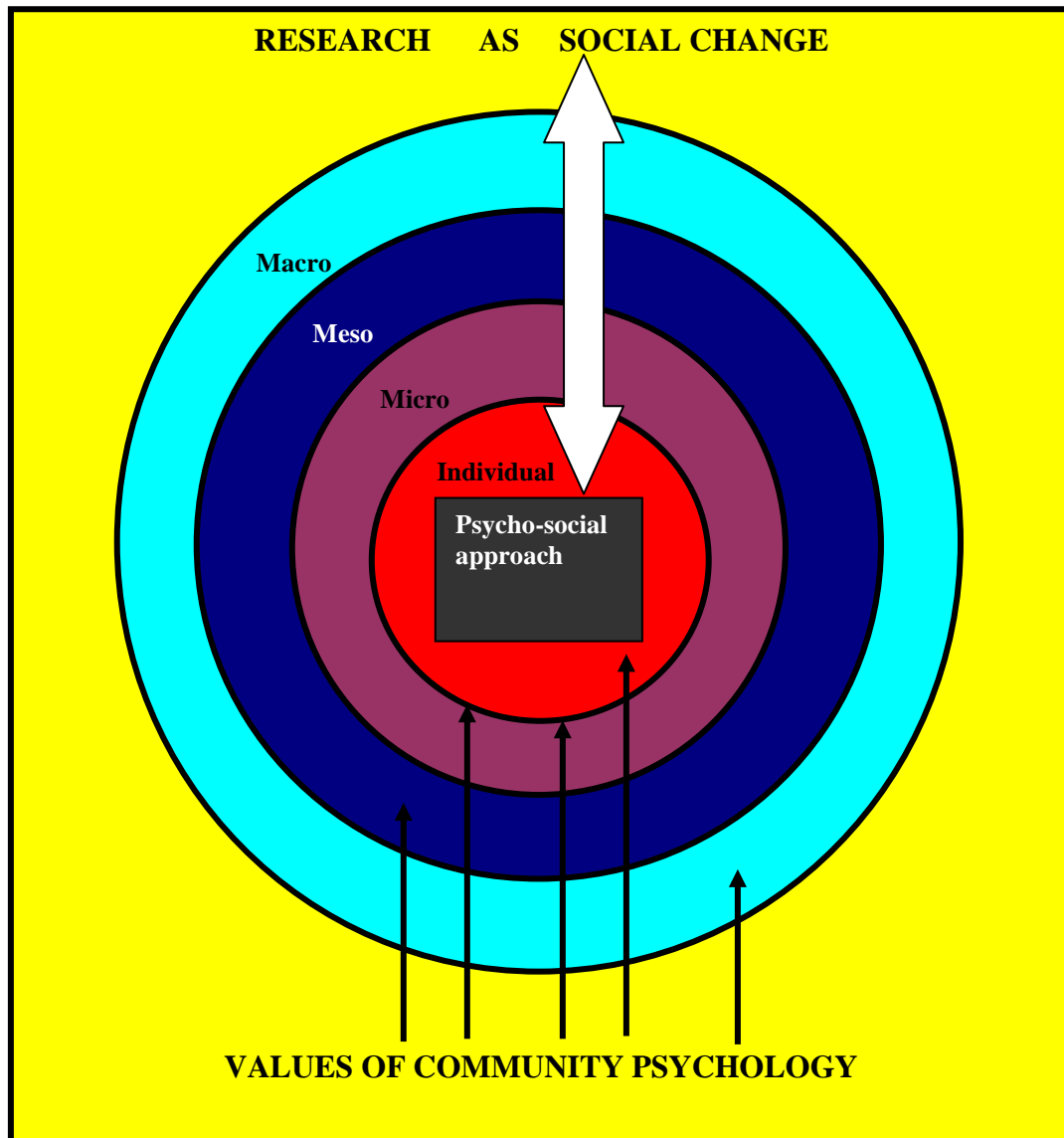


**Figure 2.1: Theoretical frameworks used in this study**

In this research the values of community psychology are drawn in a CBPR methodology. Community psychology seeks to explore psychosocial problems and empower people through community development (Duffy &Wong, 2000). Since stigma

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[3] The theoretical frameworks have been adapted from various scholars (c.f. 2.3) but I designed the diagram showing how the theoretical frameworks inform each other. The colours used have no specific significance, they were just chosen.

has to do with discrimination of a person by members of mainstream society, I adopt the *values underpinning community psychology*, since one of its goals is to "induce social change" (Duffy & Wong, 2000, p.16). Community psychology (as a discipline) is about understanding people within their social worlds and using this understanding in improving their wellbeing. It is about understanding and helping; focusing on social issues and settings that influence groups and organisations (Visser, 2007). The goal is to optimise the wellbeing of communities and individuals to innovate alternative interventions designed in collaboration with affected community members (Duffy & Wong, 2000). A community psychology approach is embedded in an ecosystemic approach, (Donald et al., 2002) which includes wider social context, in this case, to understand HIV-related stigma which is not merely individuals' problems but which has its origins in a broader social context (Eloff & Ebersöhn, 2004). The success of addressing HIV-related stigma is most likely to be maximised when located within the broader community and social contexts that support health and enhance behaviour change (Campbell, 2004).

The goals of community psychology are the promotion of health and wellbeing, caring and compassion, self-determination and participation, respect for diversity and human dignity, and social justice (Dalton et al., 2001; Visser, 2007). The values include focusing on preventing problem behaviour and promoting social competence, citizen participation, and organising for community and social change (Dalton et al., 2001; Visser, 2007). Employing the values of community psychology is motivated by the fact that stigmatised topics, such as mental health problems, use a community psychology approach (Cowie et al., 2004) to encourage both citizen participation in problem behaviour and also social change. Stigma, as has been described, is a social construct, and targeting communities could provide entry points to reduce stigma at all levels of the ecosystem (Dovidio et al., 2000).

Informed by Dovidio et al. (2000), as explained above, I adopt values of community as it seems to be an ideal approach concerned with transforming the way in which psychological problems are conceptualised and how they are understood. The goal is then to optimise the wellbeing of communities and individuals with *innovative* and alternative ways of addressing HIV-related stigma, for example, by the use of a digital archive in the classroom.

The theoretical unity for the study is found in the ecosystemic theory, combining all levels and seeing the individual as a bio-psychosocial being.

## 2.4    HIV-RELATED STIGMA AND THE USE OF VISUAL METHODOLOGIES

The study is most importantly focused on how educators can use a digital archive, with a visual data focused on stigma, to address issues around HIV-related stigma. Visual arts-based methodologies are recommended for involving the community and young people in HIV interventions (Mitchell & Smith, 2003). The use of photography, reflection, and dialogue with decision makers can result in social change (Wang, 1999). The methodology has shown the potential in bringing about social change and democratic community-based participation while enabling the community to 'give voice' and be heard (Mitchell et al., 2005).

Emmison and Smith (2000) argue that there are many forms of visual data, including photographs, drawings, television, and video documentaries. They also posit that objects and buildings carry meanings just like images. Gombrich (2000) argues that the study of the visual should not be common-sensibly equitable to the study of image and representation of a kind of two-dimensional visual data. Emmison and Smith (2000) dispute that it includes issues of visibility, mutual interaction, and semiotics as they relate to objects, buildings, and people, as well as to the study of images. Visual data can be used to explore abstract theoretical ideas (Emmison & Smith, 2000). In addition, Karlsson (2004) suggests a need for exploration of documentation of research and also draws attention to the possibilities of digital archives.

The use of digital archives can bridge the digital divide by establishing pockets of experiences among the "have not" educators to access and use the digital archives for teaching and learning, hence spreading the "gospel" of 'Digital Hope' in an age of AIDS as part of social change, to borrow from Mitchell, Barnes and Stuart (2005).

Why have digital archives been not used in the social sciences? Vitalis (2006) suggests that although archiving is associated with the historical approach, it can be useful to all social scientists. The organisation of an archive makes it easier for oneself and others to

identify sources to use, particularly in research.  It is for this reason that this study will also be informed by the work of Schratz and Walker (1995), Martin (2004), Troer (1995), Wang (1999) and Ewald (2001) who use visual and participatory approaches to address social problems in communities (c.f. 1.6).

## 2.5  SYNTHESIS

It goes without saying that when locating a study within a theoretical framework, the researcher draws on relevant literature and is given a chance to lead the readers to the origins of his or her study; that is, what other theorists are saying on the same topic, and how similar and dissimilar is his or her study is to others done before.  In so doing, comparable and contrasting intellectual voices in previous studies are highlighted.  In this chapter, international and local research shows evidence that foundational work has been done on HIV-related stigma, and sound strategies have been tried using various methodologies.  The phenomenon, HIV-related stigma, has been looked at through many lenses and theoretical analysis has been done.  It is evident that even the modest computer-based interventions can influence several theoretically important variables, and even short-term behaviour.  The method, in this case a digital archive, could be best used to complement rather than replace more traditional school-based HIV and AIDS prevention curricula.  It enables activities to be completed outside classroom-based interventions.  Knowledge, attitude and self-efficacy are prime targets for computer- and internet-based interventions.  The main focus is on using the research and pedagogical tools/methodologies for bringing about change around HIV-related stigma and increasing wellness in schools and communities.  In the next chapter which deals with digitisation and the digital archive, I will explain how I have drawn on the "Learning Together" project to conduct this study.

# CHAPTER THREE

# THE DIGITAL ARCHIVE AND ITS SOCIAL USES

*"Repurposing" investments in data to avoid what is, in turn, termed "data tombs in mono-disciplinary silos" and enabling larger sets of data to be available for further analysis across related disciplines* (Carlson & Anderson, 2008, p.1).

## 3.1  INTRODUCTION

In the previous chapter I focus mainly on the issue of HIV-related stigma which of course, cannot be dealt with in isolation from HIV. Some of the important foundational work done by researchers has been discussed, investigating the cause of stigma, the prevalence, the types of stigma, the trajectory, and how it has been addressed in the levels where it emanates from. Of particular importance are the theoretical frameworks which are employed in this research.

This chapter explores the use of the digital archive as a research tool. It comes in recognition of the successes of creative and participatory visual approaches such as photo-voice and collaborative video which have been used in an attempt to address HIV and AIDS-related stigma (c.f. 1.1). Firstly, I outline how the combination of visual arts-based methodologies and ICTs has been used by other scholars in addressing HIV and AIDS. Secondly, I describe the process of compiling a digital archive using secondary data from a previous photo-voice project which addressed HIV-related stigma. The understanding is that visual data is not only limited to drawings, pictures, and videos, but also representation on computers which are ICT-based. While my work draws on visual data, the overarching area is best described by the technology in use with the visual data. The chapter also intends to answer the question which I have often been asked by my colleagues, "why am I not using photographs instead of a digitised version in a digital archive?" Returning to the quotation of Carlson and Anderson (2008, p. 1) above, I link it to my difficulty in locating hard copies of hundreds of photographs inside envelopes kept in drawers, digitising them for wider use, and being allowed to use the archive for my research project hence relevant to the process of "digging data tombs" in mono-disciplinary silos and "repurposing" them. I illustrate the overall

approach of digitising the data and report on first experiences using a sample collection from the "Learning Together" project (2004-2006) which is hosted on a restricted website of Digital Innovations South Africa (DISA) available on www.disa@ukzn.ac.za.

In this chapter I also discuss the social uses of a digital archive in social sciences and its implications. Towards the end of the chapter, I discuss the issues of ownership, ethics, copyright, and its implications in the age of HIV and AIDS.

## 3.2  VISUAL AND ARTS-BASED METHODS IN THE CONTEXT OF HIV AND AIDS

Visual arts-based methodologies are recommended for involving the community and young people in HIV interventions (c.f. 2.4). The use of photography, reflection, and dialogue with the participants can result in social change as Wang (1999) describes in her work with rural Chinese women. A methodology such as photo-voice has the potential to bring about social change and democratic community-based participation while enabling the community to 'give voice' (Mitchell et al., 2005) and be heard (c.f. 2.4). In this case a digital archive was compiled through the use of Information Communication Technologies, which is computer-based and cannot be disassociated from the visual and arts-based methods which yielded success in the "Learning Together" project (De Lange, et al., 2003). Various successful projects by the University of KwaZulu-Natal researchers, such as the Every Voice Counts project (De Lange, et al., 2006) and the Youth as Knowledge Producers project (Stuart, et al., 2006) have drawn on photo-voice and participatory video techniques (Mitchell et al., 2005) for giving voice to communities of educators, learners, health care workers, and parents identifying key issues and challenges affecting their lives.

To explore the critical question which guides the study, I drew on an archive designed by the project team and built by me. I used secondary data; the stigma photos staged by Grade 8 and 9 learners in a Senior Secondary School in the Vulindlela District. The data set of photographs shows the nature of HIV and AIDS-related stigma and discrimination and awareness of its impact on participants (Moletsane et al., 2007). This is evident in that the learners' photographs and captions are about people who have

been shunned and isolated by friends leading to silence because people fear to be discriminated against. Another photograph depicts a young man hanging himself, an example of the result of internalised stigma (Leickness et al., 2007).

A digital archive was created as a means of storing and managing data for re-use by the group of researchers and the participants. Digitisation in its essence is the transformation of analogue material into binary digital code of 0s to be readable by a computer for storage and use (Hughes, 2004). Therefore, for the purpose of digitising the "Learning Together" project's visual data (staged HIV-related stigma photographs) each photo was scanned into surrogate images of digital formats.

## 3.3 BUILDING THE ARCHIVE

The steps taken by me to compile the digital archive, after I received training by DISA, are described in detail in the next section.

### 3.3.1 Scanning process

The first steps involved scanning the hard copies of the photographs using a scanning protocol for the whole collection to safeguard the digital formats. The protocol involved the following:

- Identifying a scanner and suitable software: e.g. Coral Paint Version 9, for the scanning and image manipulation process as this programme has the potential for image manipulation, for instance, resizing of photographs.
- Opening a new folder which saves photographs once the digitisation process is complete i.e. in my name and the project's name, that is, "Learning Together" project.
- Naming each photograph, i.e. before each hard copy is scanned I wrote its name and number on the back of the photograph using a lead pencil, for example, ltph001 (Learning Together Photo number 1).
- Scanning the photographs, converting them to jpeg (joint photographic expert group), and setting resolutions at 300 and the output type as 'millions of colours'.

- Using a cropping tool used to remove all unwanted bits once the scanned photograph is visible on the computer screen.

- Resizing the photographs to the same size e.g. 10 cm x15cm or 15cm by 10cm, depending on the width and length.

- Saving the file in a folder created in my name and the project's name after the digitising process. This in essence means the folder containing the collection of digital images is ready to be uploaded into the Green Stone Digital Software Library.

## 3.3.2  Metadata elements

The second stage of building the archive involved identifying metadata elements using Greenstone Software. Metadata is data about data and describe and documents the subject matter like, when, where, and by whom, the data was generated; the format, access and copy right, and so on. For the purposes of this project, additional elements to Greenstone were added, i.e. captions and a facilitator prompt. It therefore is index-type information pertaining to the entire visual data set and described with detailed information under a standard metadata scheme, such as the Dublin Core (2008). Using the Greenstone Librarian Interface Version v2.72, the "Learning Together" collection was uploaded. The **description** which follows attempts to show each step that was taken to design the digital archive.

## 3.3.3  Adding the metadata

Browsing through a large database can be impractical because of its massive volume (Flewelling & Egenhofer, 1999) which can result in loss of data because the scope of the base is too big. This is even worse in situations where you have to browse through hard copies in what Karlsson (2007, p.191) describes as "envelopes stuffed with photographs" with no information about the data. However, new methodologies are available to support a user's desire to find an online dataset, and then a specific piece of data. Building a database is ongoing and tested for its effectiveness in relation to the requirements of various projects. To facilitate searches, metadata is added. The coding in this case was kept very simple, keeping to the description of what one can see in the

image.

The Dublin Core contains the following *15 elements* for resource description:

An *element* refers to properties, attributes, or characteristics of resources, e.g. title, publisher, or subject, while *qualifiers* (element refinements) are narrower and more specific (refined) information about the element. The elements include the Title, Creator, Subject, Description, Publisher, Contributor, Date, Type, Format, Identifier, Source, Language, Relation, Coverage, and Rights.

**Title:** The title of the photograph, as assigned by the photographer and because in this project no titles were assigned "No title" was entered.

**Creator:** The person primarily responsible for the creation of the photograph, e.g., the photographer.

**Subject:** These are keywords reflecting the content of the photo. The keywords are predefined and selected from a *controlled list* e.g. male/female, youth/adult, student/teacher/healthcare worker/community member, urban school/rural school).

**Description:** A free text/paragraph description of the visual content and subject matter of the resource. An example taken from this project is: "A staged photograph of two male students harassing a young female student in a senior secondary school ground in a rural district".

**Date:** Date of creation of the photograph (note: not the date for the creation of the digital archive). If there is no date, we simply put 0000-00-00 for the yyyy-mm-dy, for the project, otherwise, a specific date e.g.2005-04-16.

**Type**: This denotes the genre of the item being described. It is normally drawn from a controlled list for example, photograph, drawing, poster narrative, video documentary. For this research project photographs were used.

**Format (size)**: The size of the photograph. This will be drawn from a controlled list of

dimensions, for example, 15 x 10 cm which is width by length or 15x10 cm, depending on whether it is portrait or landscape.

**Format (colour)**: The colour of the photograph, drawn from a controlled list, e.g. black and white, sepia, colour.

**Identifier:** A unique identifier i.e. a digital file number is allocated.  In this instance the abbreviation for "Learning Together" and the number of the photograph was used as the identifier, e.g. ltph025, (c.f. Figure 3.1)

**Source:** This is the catalogue or archive number of the physical photograph e.g. Centre for Visual Methodologies and Social Change, Learning Together Project, Stigma.

**Language:** The language of the visual data.  For the photo data set, this will refer to the language of the captions which was isiZulu and/or English.

**Coverage**: The geographical area where the photo was taken. The area names will be drawn from a controlled list, e.g. South Africa, UKZN; the Vulindlela district was the area covered in this project.

**Rights Management**: Information about rights held in and over the resource, e.g. Centre for Visual Methodologies and Social Change. The "Digitising Data" project researchers decided to add two elements which were the *Caption (Photographer narrative)* and *Facilitator prompt.*

**Caption** relates to the photographer's narrative for example, "I took this photograph because I wanted to show how people with HIV are treated by the community;"

**Facilitator prompt** refers to the prompt or instruction that was given to participants, e.g., "Take photographs of situations showing stigma and discrimination."

*"Akakwamukeli ukuthi une HIV ukhetha ukumshaya futhi ubona sengathi uyena omthelelile ubona sengathi ukumshaya kuzomenza athule ngoba akafuni abantu bazi. Intombazane izimisele ngokuthi basamukele lesi simo bese bet shela abanye".*
*He could not accept that he is HIV positive he decided to beat the female to silence her because the girl is willing to reveal their HIV status.*

**Figure 3.1: Ltph025 from the Learning Together digital archive**

The above figure 3.1 shows a scanned photograph with its caption.

### 3.3.4   Software for building a digital archive

Greenstone is Open-Source software used to build and distribute digital library collections. The origins of the software are said to be the New Zealand Digital Library Project at the University of Waikato, and it was developed and distributed in cooperation with UNESCO and the Human Info NGO. This is a multi-lingual software packager which allows users to build their own digital library collections. It has been used by universities, libraries, and other public service institutions. To enable easy access it has two interfaces: the *Reader* interface and the *Librarian* interface. The librarian interface "is a Java-based graphical user interface (also available as an applet) that makes it easy to *gather* material for collection (downloading it from the web where necessary), *enriching* it by adding metadata, *designing* the searching and browsing facilities that the collection will offer the user, and *building* and *serving* the collection" (Greenstone Fact Sheet, 2008).
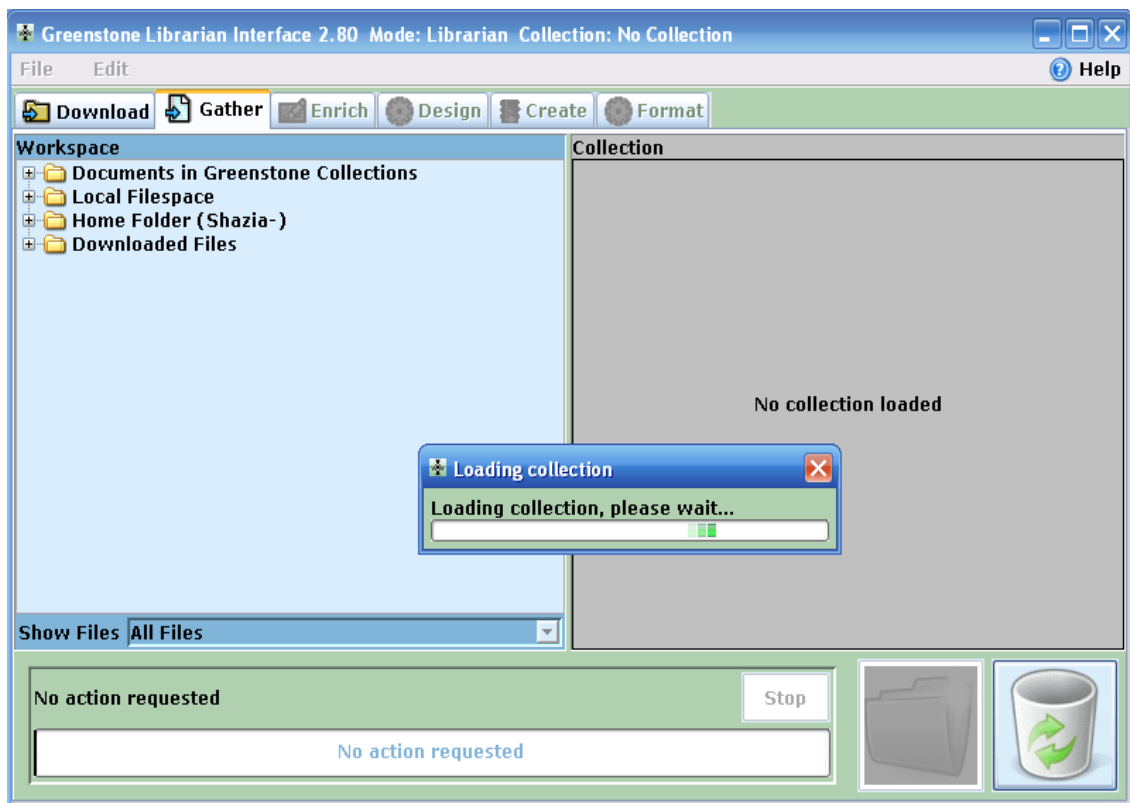
**Figure 3.2: Greenstone Digital Software Library**

Once the elements have been added, one can start adding the metadata for the specified elements Title, Creator, Identifier, Language, Description, Coverage, Source, Format (size), Format (colour), Date, Subject, Type, Rights Management, Caption and/or Prompt. The user-friendly software allows for easy upload of scanned photographs of the data set through the 'gather' function (as shown in figure 3.2). Once the information is added to the specified elements (See Figure 3.3 and 3.4) the programme is ready to combine the metadata and the photograph with the click of a 'create' button. The final stage of building the archive is shown in Figure 3.5 and in the website design in Figure 3.6.
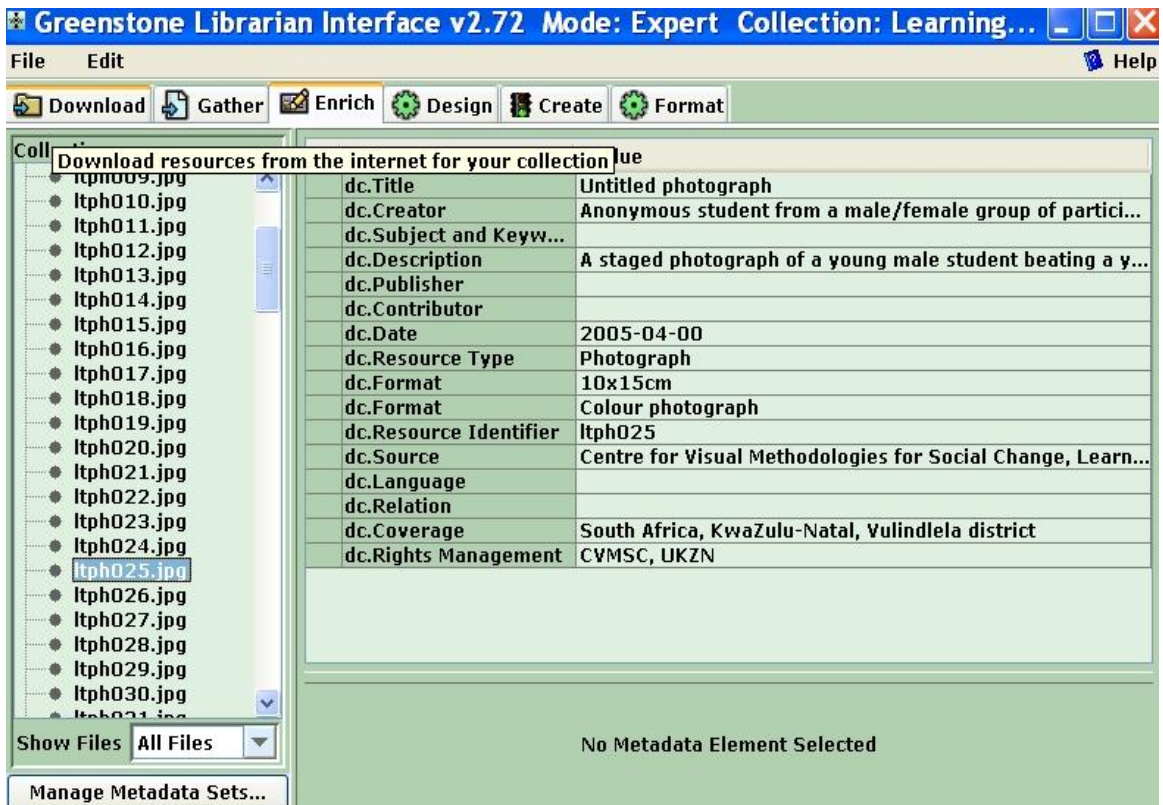
**Figure 3.3 Scanned images 'gathered'**
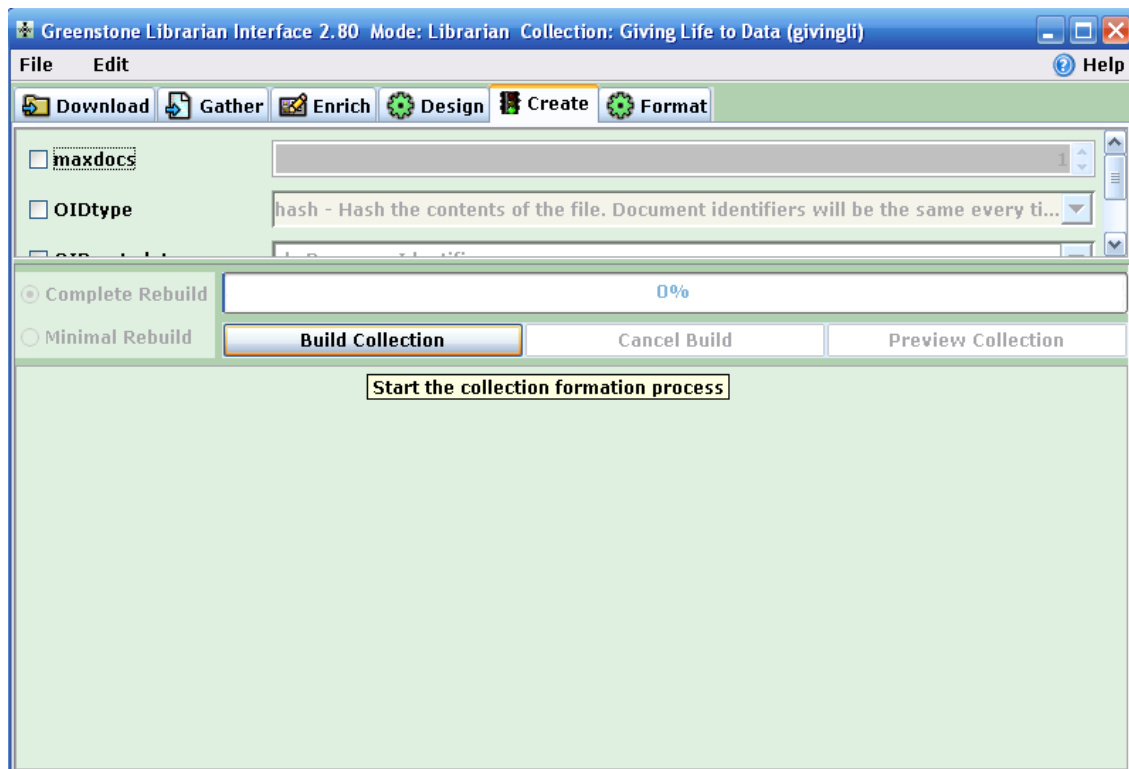


**Figure3.4 Uploaded images 'enriched'**
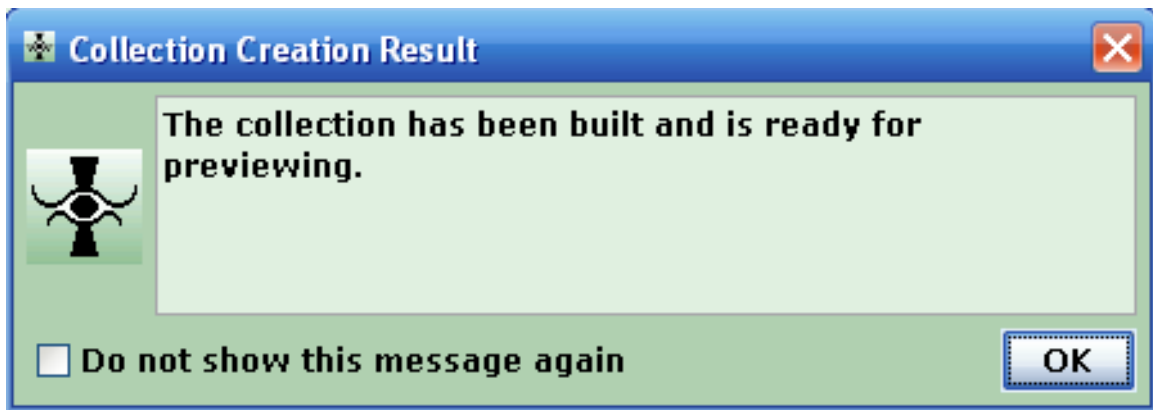
**Figure 3.5 Final stage of building up the digital archive**
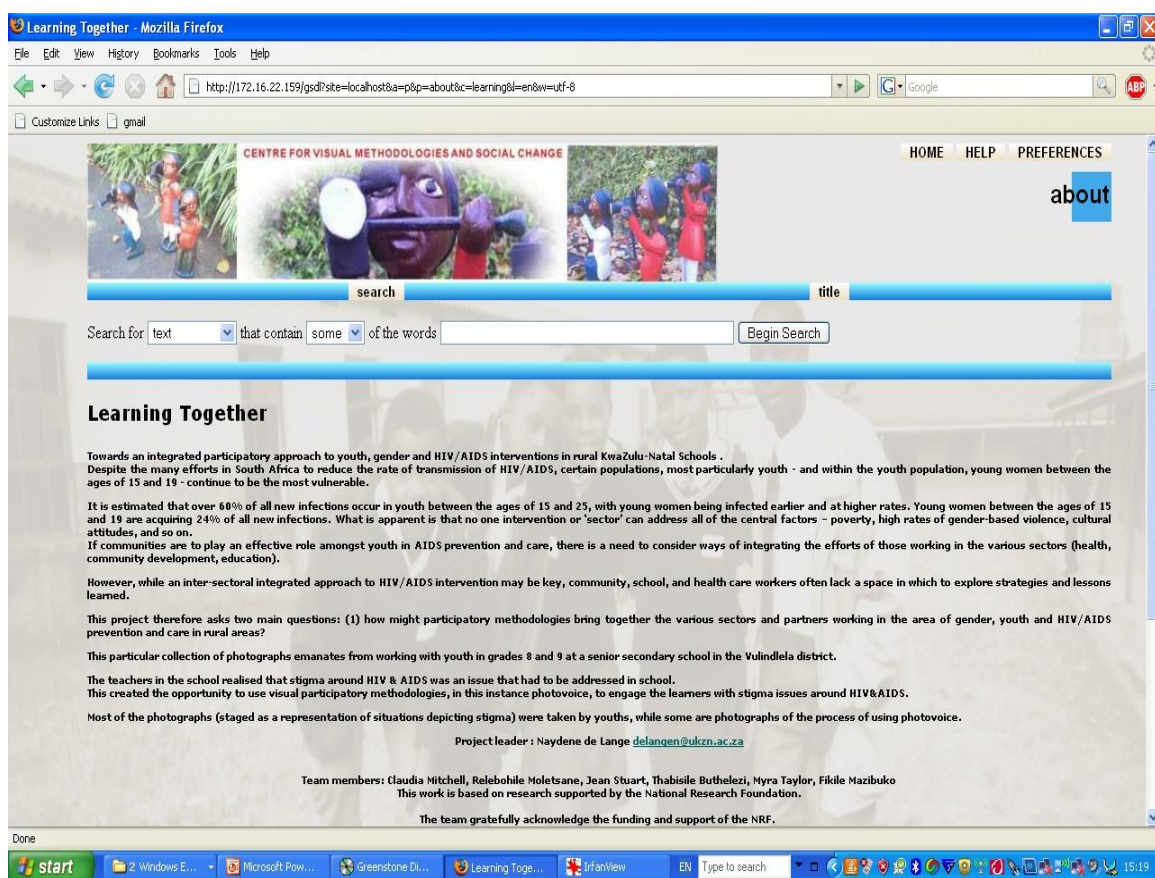


**Figure 3.6: The Learning Together digital archive**

Once the digital archive was built it was taken to the community to pilot its effectiveness in addressing HIV-related stigma.

## 3.4   THE DIGITAL ARCHIVE AND ITS SOCIAL USES

Digital archives provide long-term preservation of electronic information and have the

command to enable constant access despite rapid technology changes. A digital archive is a collection of records in digital format designed to store data in such a way that it is accessible by software applications, and support restoration of part or all of a system (Pearcer, 2005 as cited by Park et al*.,* 2008).  Still and moving images can be saved and described using metadata protocol (Hodge, 2000). The digital images are saved in a data base for retrieval, access, and preservation (Park et al., 2008).

Roberto and Carlyle (2008) argue that the use of computers and the Internet (which the digital archive embraces) has important strengths in HIV interventions.  Their argument is that such technologies are becoming more popular, providing cost effective means of access to a large number of users, allowing individually tailored messages to be regularly updated and providing researchers and practitioners with high levels of control over implementation and monitoring.  Similarly, in this study the main focus is to explore working with sets of visual data including storing, managing, and accessing, and ultimately using the data to save lives through a better understanding of HIV-related stigma.

The preservation of digital information for long periods of time is becoming feasible through the integration of archival storage technology with computer technology (Moore et al., 2000; Carlson & Anderson, 2008).  Information models from the digital library community and preservation models from the archivist's community enable huge amounts of data to be stored and made available when needed. Moore et al. (2000) state that computer-based technology provides the technology needed to store immense amounts of digital data that are being created, in this case stigma photographs.  I therefore concur with Forman (2004) who argues that PLWHA organisations and AIDS NGOs should train their members to use such technology.  This would enable documentation of their experiences and make the latter electronically available for researchers, policy makers, and PLWHA elsewhere.  However, due to ethical, ownership and authorship concerns, such data is not freely and openly available.

Building digital archives has become prevalent in the field of information management in various organisations in recent years.  A prolific science writer, Jon Cohen, has compiled comprehensive archives of HIV and AIDS literature and recently received a grant from the John D Evans Foundation for digitisation (University of Michigan News

Service, 2008). In conjunction with World AIDS Day, December 1, 2008 the University of Michigan launched a searchable online trove of AIDS-related literature which was gathered by Cohen (Moore, 2008). The archive (available on http://quod.lib.umich.edu/c/cohenaids) contains various categories of data which include speeches and proceedings of AIDS conferences, abstracts, new articles, and books, and the materials are in full text. Such a resource is useful for everyone interested in HIV and AIDS, such as those infected with HIV, policy makers, journalists, policy makers, non-governmental organisations, and researchers (Moore, 2008). Digital archives are valuable for present and future generations of researchers and the public at large (Park et al., 2008). The fact that this particular study was carried out with educators (who volunteered their time) in a rural school setting using a sophisticated digital archive, demonstrates the success of participatory research. However, the full potential of such material can be realized only if the resulting digital objects are easily accessible, have a suitable search function, can be manipulated, and are accompanied by sufficient metadata to support the use of the data (Linden & Green, 2006). The context being rural, presented challenges of limited or no access to the Internet. There was success in spite of the challenges, showing that schools in rural contexts can do well despite local conditions, and questions the strategies to be put in place to bridge the digital divide.

Archives are not really new, as historians use archives (Featherman, 2006). Vitalis (2006) suggests that although archiving is associated with the historical approach it can be useful to all social scientists (c.f. 2.4). The reality is that those exploring social life as it is unfolding, might also need to explore archives for information. Similarly, with HIV there is a strong case for the need of archives to capture how the pandemic is unfolding. In this regard I wonder why digital archives are not frequently used.

## 3.6 INFORMATION AND COMMUNICATION TECHNOLOGIES IN THE CONTEXT OF HIV AND AIDS

The AIDS epidemic continues to pose public health and developmental problems for many African nations. Forman (2004) asserts that a primary impediment in the fight against AIDS is lack of information and communication about the disease. Information and Communication Technologies (ICT) hold vast potential to combat the spread of the disease, as key elements of all aspects of HIV and AIDS strategies, including

prevention, treatment and care, and protection of human rights. They offer potential solutions to misinformation and myths, silence and denial, and stigma and discrimination against people living with HIV. They are also key to a civil society response to the epidemic, enabling advocacy, mobilisation, empowerment, and participation.

Formal institutions such as health care institutions and schools need to increase the knowledge of workers in the field through access to the Internet and other easily accessed technologies. Even without the more expensive connections, CD ROMS, radio, and other communication tools can provide access to information, education and training, and need to be used.

Internationally, HIV-related stigma deters people from getting tested, and accessing care and support services (Srivastava & Noznesky, 2005). As a result of stigma, HIV and AIDS is underreported and an issue not freely discussed even among family members (Campbell et al., 2005). The key role of ICT in the prevention and mitigation of efforts against HIV and AIDS, is generating awareness and providing practical information to people (Forman, 2004). Availability of information and communication technologies including (although not limited to) CD-ROMs, the Internet, film, mobile phones, and media, have altered the landscape of what counts as data and the approaches of working with the latter (Park et al., 2008). ICT has the potential to deal with problems through audio-visual and electronic media and is helping in capacity building of health functionaries towards counselling, getting tested, and treatment for HIV (Srivastava & Noznesky, 2005). Some countries are more advanced in ICT, for example, Asia-Pacific countries have an e-portal set by the UNDP for users to foster community connectivity and to disseminate information on HIV and development. It provides online counselling, treatment guidance, databases on resources, and published and other information from stakeholders for prevention programmes (Srivastava & Noznesky, 2005). Not only does it foster connectivity, it also strengthens the basis for decision-making and promotes information exchange among researchers and students (Peltzer, 2008). This was another reason I intended to conduct the study on how educators in a rural school could use ICT and a computer-based digital archive. In making the case for the adoption of digital archives in two rural schools, I believe it holds potential to save lives in the same way as ARVs do.

One wonders how digitisation can be adopted for social contexts across all disciplinary boundaries looking at all the advantages it possesses. Carlson and Anderson (2008) argue that archiving must be encouraged and data must be available (in digitally processable forms) and released for re-use from the point of collection. They also highlight the urgency to manage increasing quantities of complex data (textual, still visual data, and moving visual data). Lastly, the fact which I have highlighted is the concern of funding bodies to "repurpose" their investments in data to avoid what is, in turn, termed "data tombs in mono silos" (c.f.3.1). Although there are controversies surrounding the ethics of sharing data, and methodological reasons for not doing so (Borgman, 2005), I consider that in this age of HIV, data must be freely available for further use. I concur and also argue that data produced when using a community based participatory research approach, should allow for further research, reflection, and action.

## 3.7 COMPLEXITIES OF WORKING WITH THE DATA

I have already mentioned in the preceding sections that a digital archive has the potential for storing and managing visual data. It provides opportunities for librarians, archivists, and field-based researchers to work together to develop archives and ultimately 'give life to visual data' through digitisation (Park et al., 2008, p.2). The processes of building the digital archive of staged HIV-related stigma photographs focused on the processes of scanning, resizing and working with metadata schemes. However, the coding of photographs and working with metadata is one of the challenging tasks in developing a digital archive. Park et al. (2008) describe it as social tagging, a challenge embedded in the fact that images can mean different things to different people and can have further layers of meaning. However, Park et al. (2008) argue that social tagging is a way for people to express their own perspectives.

An interesting and important addition is that this method engages participants with their collections to better understand what participants consider meaningful in each photo and worthy sharing with the general public. Rather than employing the professional terms of librarians, the captions provide the actual words of the participants (Trant, 2006). In this case, each subject term is related to a theme in HIV-related stigma research. Photograph coding can provide a deeper understanding of the interpretive stage of working with photographs within the context of the digital archive (Park et al., 2008).

The process of adding metadata elements and coding is what I term 'an analysis in itself' in that several researchers within one team may have different interpretations of the social meaning of the narratives. I also concur with Park et al. (2008) who argue that the different types of representations may offer another lens through which researchers or other users may read and study the photographs. This triggers viewers' imaginations and opens up new interpretations. The viewer becomes part of a living historical artwork in the present day; this in spite of the argument provided by Prosser (2000) that interpretations can be fixed through captioning and accompanying text.

### 3.7.1 Copyright licences

As libraries move into the digital age, they increasingly face copyright issues (Bessek, 2003). Creating digital surrogates and using technologies to make works available to the public, raise many issues. The collection and long-term preservation of digital content pose challenges to the intellectual property regime within which libraries and archives are accustomed to working. The law distinguishes between ownership of the copy of a work (even the original copy, if there is only one) and ownership of the copyright rights (Bessek, 2003). Therefore, the issue of copyright has to be dealt with at a different level than the issue of ownership of a copy.

### 3.7.2 Ethics of the visual

"Issues of ownership are embedded in ethics" (Mitchell et al., 2005 p.266). A number of ethical dilemmas are highlighted by Karlsson (2007) with regard to the use of visual data. This includes issues such as informed consent, anonymity, confidentiality, and ownership. She suggests the use of existing data from archives should minimise some of the challenges of the visual researcher. In the case of this study, for ethical reasons, I had to ask permission to use the secondary data from the project leader. The CVMSC is the holder of the rights and only the research team can access it using passwords. Considering the stigma around HIV and AIDS, one has to consider the differences between photographs taken as part of the research process and used only by the participants and the research team, and those used for public display as argued by Mitchell et al. (2005). The photographs were staged by learners in their school in a previous project they were involved in. While the "blanking out and anonymising of

participants' features" (Karlsson, 2007, p.194) was not used in this research, this is not meant to cause harm but to do good by making the youth's voices and messages heard, and also used in the community. Karlsson (2007) cites Nespor (2000) who contends that anonymity of places and people through the use of fictitious names does not always serve the purpose and interests of researchers who seek social change. In social sciences, the issue of informed consent is discussed at the very beginning. However, one acknowledges that some concepts may not be understood by all the participants, and that they may actually not know what they are consenting to.

In social sciences data is derived from people, not from material phenomena (Carlson & Anderson, 2008). These authors further question how one achieves an appropriate balance between copyright owners and users; a topic of ongoing debate. In this case there is a need to use the data to stem the tide of AIDS. Also, working with the sensitive issue of HIV, issues of ethics have to be carefully observed.

It is a dilemma for those who copy publicly from websites as Bessek (2003) states, that the law is silent about his type of copying. The author further suggests studies which suggest constructive ways to achieve the goal of creating and operating an archive to ensure long-term preservation of work in digital form to benefit society. I concur with the author, more especially when dealing with issues of HIV and AIDS as the online digital archive has the potential to provide information to groups of researchers, funders, and the affected community. Although it may be argued that ownership of data is an ethically complex question for the visual researcher (Karlsson, 2007; Prosser, 2000) other authors argue that in the biomedical field different practitioners would refer to the previously generated data when treating a patient and forge a way forward, as I have already mentioned (Carlson & Anderson, 2008). Ethical issues cannot be exhausted in this space, however, Karlsson (2007) suggests that the visual researcher ought to incorporate reflexivity from the early stages of the research and highlight the importance of metadata about the photographs. She further suggests that novice researchers can avoid the issues of ensuring anonymity, informed consent, and accusation of contrived re-enactment, by using pre-existing photographs in archives.

## 3.8  SYNTHESIS

The intention of this chapter was that those reading it will have been persuaded that qualitative research and the adoption of the use of a digital archive (with visual data) have much to offer above and beyond the researcher's own analyses.  I argued that data must be digitised and be online so that it may be analysed by other researchers because issues of HIV are sensitive and obtaining data has many complications.  The responsibility of archiving (providing infrastructure) to enable this process, should fall on the shoulders of those who sponsor the research.  It may be an uphill struggle for some time to come, to prove that preserving data is worthwhile.  My hope is that I can look back in twenty years' time and see that it was worth all the hard work.  Because this research is most importantly focused on exploring the use of a digital archive with educators in rural schools in addressing issues around HIV-related stigma, I have found it important to include this chapter on digitisation.  I concur with Park, Mitchell, and De Lange (2007) that the main goal of developing a conceptual framework and technical framework for working with digital archive is to expand possibilities of HIV and AIDS awareness and dissemination of information.

# CHAPTER FOUR

# RESEARCH DESIGN AND METHODOLOGY

*…You know I remember this project since 2005, when we were involved in this project. I could think when a person comes to me and tell me about his status because you see I couldn't imagine a person doing that. I don't know what I could have done during those years but now I sit with them and talk about it without any problem. I think this project has made some difference…* (Male participant)

## 4.1  INTRODUCTION

This chapter outlines all the actions in the research setting, with the participants and the researcher. Therefore, a full description of the research setting, the participants and their roles, the researcher's role, and details of each data generation session will be given. I have also included a section where I have positioned myself as the researcher, in an attempt to explain where I come from and to uncover other factors that might influence the research. Issues of ethics run throughout the research process, following Creswell (2009) who argues that ethics have to be observed in formulating the research problem, question, data generation, data analysis, and also in writing and disseminating the research. Therefore, this chapter will also explain the ethical issues involved.

It is more than twenty years after the Director of the World Health Assembly predicted that stigma will be an illness on its own, that is, the main barrier to HIV prevention (Nyblade et al., 2003; UNAIDS, 2008). Abdool Karim and Abdool Karim (2005) say that even if the youth themselves are not infected they would still be affected if their parents had died of AIDS. Children from HIV affected families are exposed to psychological risk factors which include stigma, secrecy, exposure to acute and chronic illness, and the death of parents (Gilbert, 2001). Thus the effect is twofold in that the parents have passed away, and there is also the stigma of having had parents who died of AIDS. This raises the need for addressing HIV-related stigma, especially in schools. In the absence of a cure for HIV, education remains the key to HIV and AIDS prevention including HIV-related stigma. The Education and Labour Relations Council

(2005) suggests a need for adequate strategies to address the complexity of HIV and AIDS-related stigma (c.f. 2.4). Not only is there a need for adequate strategies but most importantly, prevention and awareness education, as we live in an age where there is still no cure for HIV. Education, therefore, remains a key intervention strategy and the need to employ visual arts-based approaches which engage young people in playing an active role in addressing HIV and AIDS (Mitchell et al., 2005), is crucial. The significant role played by education in the classroom has been noted (DoE, 2002; Francis & Francis 2006; Francis & Hemson, 2006; Griessel-Roux, Ebersöhn, Smit, & Eloff, 2005; Stuart, 2006).

## 4.2  RESEARCH QUESTION

How could educators in rural schools access and use a digital archive (the visual data and its metadata) to address HIV and AIDS-related stigma?

## 4.3  RESEARCH AIM

The research aim is therefore to 'give life' to the visual data with which I worked and to 'save lives' through a better understanding of HIV and AIDS-related stigma, by exploring how educators in rural schools could access and use a digital archive to address issues around HIV and AIDS-related stigma.

## 4.4  RESEARCH DESIGN

### 4.4.1 Qualitative approach

I adopted a qualitative, interpretive, exploratory and contextual design which was determined by the research objective; in this case exploring the use of a digital archive with educators in rural schools to address issues around HIV-related stigma. The research design must suit the research problem (Creswell, 1994; Maree & Van der Westhuizen, 2007). One of the reasons for restating the research aim was to crystallise coherence between the research aim and the research design. The research question informed the choice of a qualitative approach because qualitative research is inductive and exploratory (Fouche, 2005; Hatch, 1998). It is mostly used in social sciences (Ely,

Anzul, Fiedman, Gardner, & Steinmetz, 1997; Guba & Lincoln, 1981) to understand and explain social reality through the eyes of different participants, who define their reality (Cohen et al., 2007). In this research there was a need for an approach which allows participants to draw on their own experiences.

Qualitative and interpretive approaches allow for creativity of participants in their actions, they "make meaning in and through their activities" (Cohen et al., 2007, p. 20). This was required for the exploration of different ways of using a digital archive in addressing HIV-related stigma. For instance, flexibility enabled the number of visits to be determined by the saturation of data and interpretation of participants' responses and needs. I also ensured that no data was missed hence generated data using different methods to capture the data which included field notes, audio and video recordings. Participants modified the approaches to using the digital archive in relation to HIV-related stigma, coming up with a number of activities which they finally tried with their learners.

Qualitative researchers stress that reality is "socially constructed" as asserted by Denzin and Lincoln (2003, p.271). People actively construct their social world rather than being made objects of research. They understand their context and are able to construct their worlds in an attempt to address the needs which are best known by them. I drew from the participants' understanding and explored how they interpreted their worlds and gave meaning to their actions. Description and understanding are the ultimate intent of qualitative research and that is why the data generation methods engaged had to allow and create rapport, mutual trust, and honesty between the researcher and the participants. Similarly, in this research the data generation methods and the methodologies tie up with the qualitative research as there was a great need for rapport and flexibility. Tedlock (2003) cautions that the kind of rapport should not cultivate friendship, identification and love, but there must be respect and understanding. This attitude guards the researcher from not losing site of purpose in the field (Denzil & Lincoln, 2003) which I was careful about. My intention was not to explore the use of this digital archive with learners but the participants insisted on trying it with learners and coming back to the focus group to reflect on what they did.

## 4.4.2 Interpretive paradigm

De Vos (2005) believes that it is not only an understanding of the nature of the paradigm selected that the researcher needs to have, but there is also a need to spell this out in the research report to keep communication with the reading public clear and unambiguous. A paradigm is a set of assumptions or beliefs about essential aspects of reality (Nieuwenhuis, 2007). Paradigms serve as "the lens or organising principles" by which reality is constructed (Nieuwenhuis, 2007, p.48). It is actually a model for observing and understanding, which shapes what we see and how we understand it, (Babbie & Mouton, 2004) before we can tell a coherent 'story' which in this case is the research report.

The interpretive paradigm suits CBPR and the data generation methods used in this research. The interpretive approach views the world as changeable and people as defining the meaning of a particular situation. I explored, through the eyes of the participants, how they interpreted the events, their contexts, and situations (Cohen et al., 2007) and I only set out to understand their interpretations of their understanding of HIV-related stigma and how they could use the digital archive in their rural context. The person's context is seen as very important insofar as the way in which a person behaves in a certain situation depends on previous experiences and circumstances (Bloor, 2004). The kind of data produced in the interpretive approach cannot be objective as the researcher is also a person and cannot maintain a fully objective distance (Maree & Van der Westhuizen, 2007).

## 4.5   RESEARCH METHODOLOGY

### 4.5.1   Introduction

For this research study a community-based participatory research methodology (CBPR) was adopted and this was informed by the theoretical framework (c.f. 2.3).

### 4.5.2   Community-based participatory research

Community-based participatory research aims to bridge the gap between knowledge

produced and practices used in communities, to improve health (Clinical Information, 2004). CBPR is an interactive process, incorporating research, reflection, and action in a cyclical process (Wikipedia, 2008). In this study I took previously produced visual data back to the community who participated in the research, so that they could have access to and work with the data. This being an interactive process, allowed for reflection and action, including/involving the intended beneficiaries in addressing HIV-related stigma (Parker & Aggleton, 2003).

CBPR recognises the unique strengths that each participant brings, in a way similar to how Kretzmann and McKnight (1993) and Eloff and Ebersöhn (2004) do in their asset-based approach. A community-based participatory approach has also been used in interventions for stigmatised mental health illnesses (Cowie et al., 2004). In the process of exploring what educators can do with the visual data, the community-based participatory methodology enabled me to collaborate with the community of educators to facilitate community change (Marsden, 2002). Such participatory research is based on a partnership between the researcher and those affected by the issue being studied with the aim of promoting the voice of those being researched (Agency for Healthcare Research and Quality, 2004). This research study sees research as intervention because the participants' voices can bring about social change. This methodology promotes collaborative research and links research and practice. It benefits the community and develops knowledge applicable to their settings and the knowledge can be inferred to other settings (Macaulay, 2007). In this study, the objective was to find out how the participants can use the digital archive containing visual data which originated from them, and re-use it to address the HIV-related stigma they previously identified as a problem in their community. It is important to note that CBPR starts with research of importance to the community, and seeks to combine the knowledge with action with the intention of achieving social change (Agency for Healthcare Research and Quality, 2004).

Another reason for the choice of CBPR is that HIV is related to sex and sex is conceptualised differently in different cultures. More often than not the culture becomes a barrier to HIV prevention strategies (Stuart, 2006), and CBPR could help overcome cultural challenges to conducting research in culturally diverse or unique communities. I intended to use a more participatory and culturally sensitive

approach.  The adoption of the values underpinning community psychology (c.f. 2.3) was also complementary to the process and choices of methodology as one of its goals is to "induce social change" (Duffy & Wong, 2000, p.16).

## 4.6  RESEARCH SETTING

In this section I give a picture of the research settings as this project was undertaken in more than one setting.  The research drew on a secondary data set of HIV-related stigma staged photographs which were taken by Grade 8 and 9 learners from a rural school in the Vulindlela district.  Vulindlela is approximately 120 km from Durban.  Photographs were taken in an attempt to address stigma which was pointed out by the participants in a photo-voice project.  Interest in studying HIV-related stigma developed as I was (as an intern for the project [4]"*Digitization and Data Management with visual Data in Social Research: Giving life (to data) to save lives*") digitising visual data which was accumulated by UKZN researchers in an earlier project "Learning Together".

### 4.6.1  Setting for digitisation

Digitisation of data took place in the Centre for Visual Methodologies for Social Change (CVMSC).  It is housed in the School of Language, Literacy and Media Development (SLLMD) of the University of KwaZulu-Natal.  The CVMSC has two computers with the necessary software for scanning and software for compiling the digital archive.  I worked one day per week as an intern to digitise the visual data.  For this specific project 125 photographs were digitised, metadata added, and a digital archive compiled.  The actual procedure was described in detail in the chapter 3.  After compiling the digital archive I started working with the participants whom I visited in their schools on five different occasions.  I describe each school setting to create a picture of the schools.  Both schools are in the same district but are approximately ten kilometres apart.

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[4] De Lange, N., Mitchell, C., Moletsane, R., Stuart, J., Buthelezi, T. and Taylor, M. *Digitization and Data Management with Visual Data in Social Research: Giving life (to data) to save lives* (2008-2011).  This project is often referred to as 'Digitising Data' project in this research report.

### 4.6.2    Setting for School A

What follows is a description of the setting of the first school I worked with and for ethical reasons I refer to it as school A.  A male guard protects the gate of the fenced school and the 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.  The school has thirty educators of which fourteen are males and sixteen females, and most of the educators do not live in the community around the school.  There are 892 students.  There are two blocks of classrooms opposite each other and in the middle there is a lawn.  Most of the classrooms are swept and clean but the lawn is strewn with sweet papers.  The school has electricity, a well equipped computer laboratory with more than twenty computers and connectivity to internet, a tribute to the principal's dedication and fundraising.  The computer laboratory was used for the sessions with the educators.

### 4.6.3    Setting for School B

School B is also fenced but the fence and the buildings are in need of repair.  The lawn is bushy and the windows are broken.  One wall has art on it showing Zulu warriors.  This was done by learners and UKZN student teachers as part of the Rural Education project.  There is an administration block with three offices housing an administrator, the principal and deputy.  There is only one computer available in the school that of the administrator and electricity is only supplied to the administration block.  The school has a principal, a deputy, and a head of department.  The deputy and the HOD share office space.  The school has sixteen educators, seven males and nine females, mostly from the local community.  There are 443 students enrolled at the school.

### 4.7  SAMPLE

I used purposive sampling which was vital to the success of the ICT-based focus group interviews about using the digital archive (Nieuwenhuis, 2007).  The intention was to work with educators, as Mitchell et al. (2005) believe that the voices of educators must be heard in debates about curriculum and care in addressing HIV and

AIDS, as well as HIV-related stigma. I was working with educators who are directly responsible for raising awareness, prevention of HIV, assisting the infected and the affected, and dealing with the trauma of illness and death of others (Bhana et al., 2006), as well as trying to address the issue of stigma. Baxen and Breidlid (2004) note that new research needs to pay close attention to providing opportunities and support for teachers to engage their views and experiences in the teaching of sexuality, HIV and AIDS education. Moreover, the specific selection of participants matches the methodology (CBPR) of working with a community with a common problem, interest, or goal. A sample of fourteen educators from the two schools in the Vulindlela District where the data was previously collected, participated. I deliberately selected these particular people because they were seen as more likely to produce rich data (Denscombe, 2005), having been involved in the previous research project (Rallies & Rossman, 2003), that is, the "Learning Together" project to address HIV and AIDS, HIV-related stigma and gender violence (as the quote from the beginning of the chapter confirms). The choice of the participants was therefore driven by the knowledge they had, their context, and also their willingness to participate.

The biographic information of the participants is presented in the tables below:

| Gender | Age | Teaching Experience in years | Previous Training in HIV |
|--------|-----|------------------------------|--------------------------|
| Female | 48 | 11 | Yes |
| Female | 34 | 08 | Yes |
| Female | 29 | 05 | Yes |
| Female | 38 | 08 | Yes |
| Male | 34 | 02 | Yes |
| Male | 34 | 07 | Yes |
| Female | 37 | 08 | No |
| Female | 35 | 07 | No |

**Table 4.1: Biographic information of participants at school A**

| Gender | Age | Teaching Experience in years) | Previous Training in HIV |
|--------|-----|-------------------------------|--------------------------|
| Male | 41 | 20 | Yes |
| Male | 40 | 9 | Yes |
| Male | 24 | 3 | Yes |
| Female | 38 | 9 | Yes |
| Female | 24 | 1 | Yes |
| Female | 34 | 8 | Yes |

**Table 4.2: Biographic information of participants at school B**

The sample in school A consisted of six females and two male participants. Their teaching experience ranged from two years to eleven years. For ethical reasons their real names are not used. Their ages ranged from twenty nine to forty eight. Most of the participants have had previous HIV training as can be seen in Table 4.1. In school B three males and three females volunteered to participate in the project and their teaching experience ranged from one year to twenty years. Their ages ranged from twenty four to forty one. All participants in school B have had previous training on HIV.

## 4.8   DATA GENERATION

To explore the critical question which guided the study, I used secondary data, namely stigma photographs staged by grade 8 and 9 learners in a Senior Secondary School in the Vulindlela District. The set of photographs shows the nature of HIV and AIDS-related stigma and discrimination in a rural school. The steps taken to compile the digital archive are described in detail in the chapter on digitisation (See Chapter three). This digital archive was then used to explore the critical question of how teachers can use it to understand and address issues around HIV-related stigma in a rural school context.

### 4.8.1   ICT-based focus group interviews

Focus group interviews have the potential to encourage debate among participants about a particular topic and participants are able to build on each other's ideas which generate an in-depth view (Harrington, 2003; Morgan, 1997; Nieuwenhuis, 2007). A focus

group interview is designed to obtain perceptions in a specific area of interest in a non-intimidating environment (Kreuger, 1994; Nieuwenhuis, 2007). It is a tool for studying ideas in a group on a topic determined by the researcher (Morgan, 1997). The study drew on the aforementioned potential of focus group interviews. Short (2006) explains the term 'focus' or 'focused' as connected to the intervention of the interviewer who guides the discussion.

Focus group interviews are also seen as a suitable vehicle for participatory research (Short, 2006) as is the case in this study. If focus group interviews are successfully conducted the ideas which emerge from the discussions are developed by the participants (Smithson, 2008). In this way the participants are regarded as collaborators in the research procedure. My role was to encourage discussion and maintain focus, observing and collecting oral data by taking notes, voice recording, and video recording. This data production method therefore helped include the participants in a participatory way.

The ICT-based focus group interviews also allowed observation of the participants and access to contextual factors in their setting (Johnson & Turner, 2003). Working with ICT and the archive allowed me the advantage of observing what the participants do. All my observations were recorded as field notes.

For the purpose of this research, that is, to explore how educators could use the digital archive and the metadata as a tool to address issues around HIV-related stigma, a focus group was suitable for getting their collective views. In this study the digital archive and its metadata was the focus for the discussion and the open-ended questions I asked appear in the appendices (See Appendix D).

### 4.8.2 Preparing the field

Working with the digital archive in the two rural schools required access to computers. School A has fully equipped computer laboratory and Internet connectivity. School B does not have a computer laboratory. Both school A and B were presented with a laptop, data projector, and digital camera as part of the process of "Digitising data" project (funded by the Social Sciences and Humanities Research Council of Canada and

the National Research Foundation).

### 4.8.3   Working in the field

Four data generation sessions were conducted and Table 4.3 shows a summary of the sessions and what was aimed at and achieved in each session.

| PURPOSE | PROCESS | PRODUCT |
|---|---|---|
| **Session 1.** To explore the content of the digital archive with educators | <ul><li>Informal discussion</li><li>ICT-based focus group interview</li></ul> | <ul><li>Field notes</li><li>Recordings</li><li>Transcription of recordings</li></ul> |
| **Session 2**. To explore how the educators understand and can use the digital archive in addressing HIV and AIDS-related stigma | <ul><li>Working with the archive</li><li>Discussing how the digital archive can be used in facilitating understanding of HIV-related stigma with learners at school</li><li>Designing classroom activities and participants 'presenting' their designed activity</li></ul> | <ul><li>Designed activities</li><li>Field notes</li><li>Recordings</li><li>Transcription of recordings</li></ul> |
| **Session 3.** Implementing the designed activities with the learners | <ul><li>LO educators from each school tried out the designed exercise with learners</li></ul> | <ul><li>Recorded video</li><li>Field notes</li><li>Transcription of recordings</li></ul> |
| **Session 4**. To reflect on the use if the digital archive in the classroom | <ul><li>Showing video recording of using the digital archive to the participants</li><li>Focus group interviews reflecting on the use of the digital archive</li></ul> | <ul><li>Field notes</li><li>Recordings</li><li>Transcription of recordings</li></ul> |

**Table 4.3 Data generation in the field**

The following narrative description of the unfolding of the data generation in the field is given to support the summary of the process (Table 4.3) which shows how the purpose, process, and the data produced, are linked.

**4.8.3.1 Session one: Exploring the content of the digital archive with educators**

**School A and B**

Both schools were visited on the same day as I was working under pressure and within time constraints. The first meeting with the participants was to introduce my work and also to invite volunteers to be part of the study. I was introduced to the principal who agreed that the school could participate and then to a life orientation educator who was to be the liaison person. She organised for the participants to go to the computer laboratory where we introduced ourselves. I gave the participants the background to the study by giving a summary of the earlier "Learning Together" project. I also emphasised that the photographs in the digital archive were staged by learners in an attempt to address HIV-related stigma which had been identified in the community. I explained the consent forms to the participants, before they signed them (See Appendix B).

Generating data through ICT-based focus group interviews in a rural area posed challenges such as unreliable Internet connectivity. The interactive CD with the digital archive was therefore loaded on computers and the session covered what a digital archive is, what it contains, how to access it, use it, and improve it. I briefly demonstrated how to get into the collection, how to read the metadata, how to search for a photograph, and how to see the full image. We discussed some of the terminology involved, like the drop down bar, clicking, scrolling and so on. Three teachers then shared one computer and I demonstrated while they followed on their computer. They were able to search and try it out without my help, until I stopped them and posed a question to be discussed by the focus group.

A similar introductory exercise was done with school B. Upon arrival at the school, the administrator directed us to the deputy's office. The deputy tried to organise a bigger venue but a constraint in this school is that electricity is only supplied to the administration block. She was not able to get a bigger venue and we finally settled in her office working from three laptops. The same process of introducing the study and the digital archive was followed, after which the ICT-based focus group interview question was asked:

*"Having looked at the whole collection, suggest how you can make use of the digital archive with the dataset of staged HIV stigma photographs in an attempt to address stigma".*

The sessions were video taped, audio taped and transcribed. The participants were allowed to respond in English and isiZulu.



**Figure 4.1: Educators from school B watching a demonstration of the digital archive**
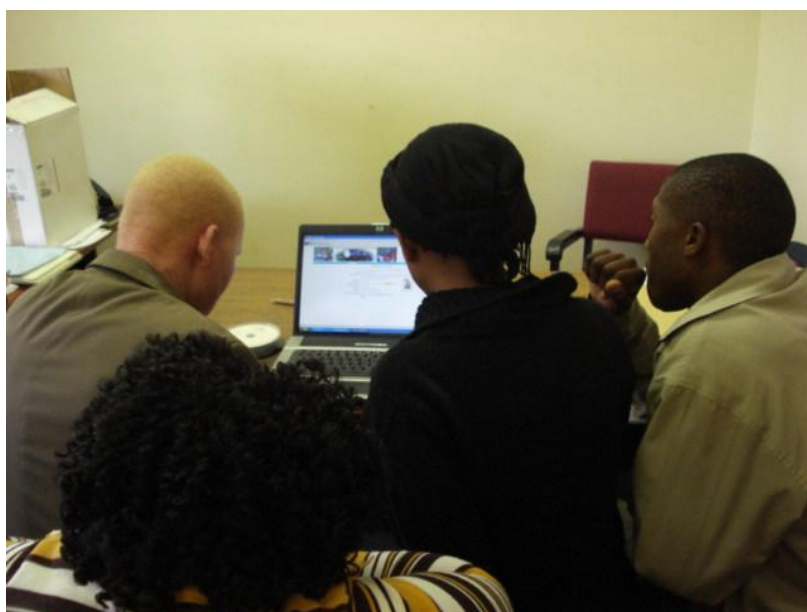


**Figure 4.2: Educators from school A exploring the digital archive**

**4.8.3.2 Session two: Exploring how educators understand and can use the digital archive in addressing HIV and AIDS-related stigma.**

**School A and B**

The second session with school A and B was set up to explore the use of a digital archive to address HIV and AIDS-related stigma by designing classroom activities. The same venues for this session were used. I found participants ready to start in the computer laboratory in school A, each one sitting in front of a computer. Four educators were available to work with me on this session. The university student acting as independent observer took field notes as I was working with the participants. In school B three participants were available and we used the deputy's office. The plan for the session was clearly explained and the participants were to look through the digital archive collection and identify two photographs which they were to use to design two activities for use with their learners in addressing HIV-related stigma. The aim of the exercise was to engage the learners to deepen their understanding of the issues of stigma. The ICT-based focus group prompt was formulated as follows:

> *"Design activities which would engage your learners in discussing issues around HIV stigma."*

The educators from school A took their time before they finally selected one photograph. They used the same photograph to design four different activities. When asked about the choice of one photograph they said they chose independently of each other, but asserted that the photograph could be used to design different activities. In school B educators chose six different photographs and came up with six different activities.

Participants then talked about their designed activities (presented), saying why they chose the photograph(s), explaining the activities and how they were going to implement the latter with their learners in class. Educators designed their activities on paper although they were supposed to design them using a computer since most of them had challenges of computer literacy. Their 'presentations' of their choice photographs and designed activities and purpose were recorded and a reflection on the whole

exercise was also recorded.

At both schools a reflective exercise was done towards the end of the session aimed at assessing how participants' felt about the whole exercise. They felt that the exercise was not an easy one but that it was interesting to do. They felt it was not easy to settle on one photograph, the problem being that all the photographs were relevant and that one could come up with many different exercises from each. They would have preferred to look at the digital archive at their own pace enabling them to give it more thought, but in general appreciated the possibility the archive has.

One educator at each school volunteered to try out an activity using the data projector, laptop, and CD. Although not all the participants were there (in both schools) I was able to work with those who were available. I made an appointment for a third visit with the aim of seeing their designed activities in use in the classroom.

**4.8.3.3 Session three: Implementing the designed activities**
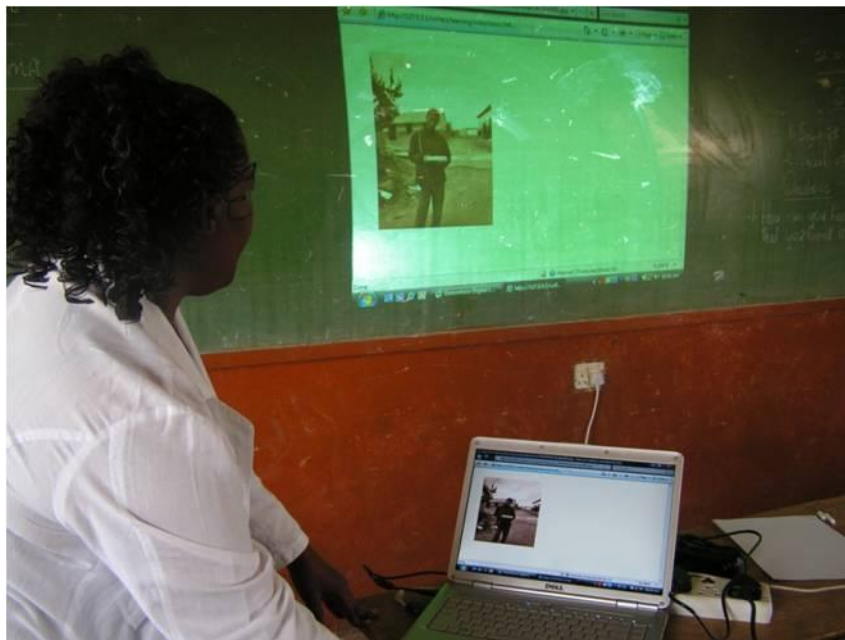


**Figure 4.3 Educator using a data projector and a laptop**

**School A and B**

This session was primarily aimed at allowing one educator from each school to try out

the activities which were designed in the previous session. I arrived before the school started to set up the venue for the lesson planned. Some students entered the classroom and settled down before their teacher came in. They were clearly excited and they made comments like "We will be appearing on TV." The educator in school A started her lesson and emphasised that the photographs in the digital archive were staged by other learners as one way of addressing HIV-related stigma. The educator continued to introduce her interactive lesson about stigma, with learners giving different responses to what stigma is. She then proceeded to ask them about how they would react if they heard one of their classmates was HIV positive. The teacher wrote all the answers on the board. The next step for the educator was to use the laptop and data projector to select one photograph to project on the board. She then asked the learners what they could say about the boy in photograph with regard to HIV-related stigma. The learners discussed the question in groups and responses were discussed by the whole class. In the next step the educator asked the learners to design a drama and discuss characters to show the extent of HIV-related stigma and show in their play how the stigma associated with the illness can be eliminated. The learners discussed it and went out to change clothes and came back to class to role-play. All the proceedings were video recorded and some pictures were taken.

The purpose of the session in school B was similar to school A except that the educators had designed different activities for their learners. The class was already seated and ready for the lesson when a learner realised that the extension cord was too short and volunteered to get an extension cord from home near the school. (This is a typical challenge in rural schools where electricity is not available in all the classrooms). The educator then started his lesson by projecting a picture and opened the dialogue with the learners guided by five questions written on the board. The educator encouraged learners to look at the photograph and go beyond what they see to say what they thought about the boy and his life (See Figure 4.3). Three groups were formed to answer the questions and that was followed by presentations which were made by one member per group. The lessons were video recorded and transcribed.

**4.8.3.4 Session four: Reflecting on the use of the digital archive in the classroom**

**School A and B**

This session was designated to be a reflective exercise after watching the video recording of an educator trying out the digital archive with the learners in class. A laptop, data projector and a DVD was used for the session. The video recordings were projected on the classroom wall. After watching the video where life orientation educators were using the digital archive (with a dataset of staged HIV-related stigma photographs), the question which guided the reflection was, *"What would you have done differently?"* The focus group discussion was video recorded and transcribed.

**4.9   DATA ANALYSIS**

Qualitative data analysis is primarily an inductive process of organising data into categories and identifying patterns among the categories (McMillan & Schumacher, 1993). This process of interpreting data is done for the purpose of drawing conclusions that reflect the interest, ideas, and theories of the study (Babbie & Mouton, 2004). After the process of building the digital archive using visual data (carefully described in chapter 3), as well as the metadata, the digital archive was used with the participants. The data from the ICT-based focus group interviews, in answer to the research question about how digital archives can be used optimally to address issues around HIV-related stigma, was analysed using Tesch's descriptive analysis technique to identify units of meaning and to look for emerging themes as described by Cresswell (1994). The raw data was transcribed from audio-tape and video recordings to text, including non-verbal cues. It is from the transcribed interviews that thorough analyses were done in order to come up with themes. Kvale (1996) states that transcribed interviews make analysis more amenable. 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. Thoughts were written down in the margin and units of meaning then identified and categorised in order to come up with emerging themes. 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 was grouped together under a code (Strauss & Corbin, 2004). This was where I was able to identify emerging patterns and code the data, trying to understand what the data means.

## 4.10  POSITIONING MY SELF

At the beginning of the research process my fear was around the technicalities involved in using the digital archive: wondering whether the participants would master the skills in such a short time and whether my knowledge in ICT would be adequate as I have an educational psychology background. However, when the actual process started my fears were not realised. I had to multitask: as researcher I had to plan and facilitate each session and sometimes do the video recording as well. Performing the researcher-participant task was quite a challenge, not because I could not handle it but I needed to ensure that data was not lost.

As a researcher working around a sensitive issue such as HIV and AIDS, I had to be vigilant as to what the discussion of such a topic can raise, not only with the educators but also with the learners. One learner came to me and narrated her experience of looking after a younger sister whose HIV serostatus was confirmed positive. Both parents had passed away and the sister was already taking ARVs. The concern she had was what she should tell her sister because she uses gloves to bathe her. This resonated with me as I had to handle a similar situation in my own family and it was not easy for me to work around HIV either. Studies show that in south sub-Saharan countries which include South Africa and Swaziland where my extended families reside, the HIV prevalence rate is high (UNAIDS 2008). I too am therefore not spared and this experience allowed a deeper understanding.

I have a background of educational psychology which equipped me with school guidance and counselling skills but on this day I was emotional and felt like I needed some time with the learner. I however, applied Rager's (2005) self care, took her name down in my journal and noted how I felt that day. Rager (2005) suggests self care tips for researchers dealing with sensitive topics which include keeping a journal, debriefing, counselling, and also taking a necessary break from the research field.

When I arrived back at the university and CVMSC to return the equipment I spoke briefly to the Director because I felt I needed to talk which is what Rager (2005) encourages (debriefing). I suggested to her that students who do research on HIV must participate in a module on HIV education and counselling. It is also my opinion that the issue of HIV needs a different approach even in research. At some point I was afraid that my emotions could jeopardise my research as I can remember how I would initially 'freeze' whenever I had to write the word HIV. I would stop and reflect on whether my practices and experiences as an HIV researcher were different from other people's who do not research the disease. HIV impacts on most people's lives directly and I am equally affected. However, having support from my supervisor who provided timeous guidance, counselling and care during the social upheavals I went through, I kept myself focused. I quote the words she would pronounce frequently: "The door is open not only for the research, but for other issues too."

As a researcher, who is the research tool as well, I am aware of my own position in researching HIV and AIDS, which contributes to my sensitivity towards the participants and the issue of this disease.

## 4.11   ETHICAL ISSUES

I will define ethics before I discuss the necessary ethical considerations taken into account in this study. I use literature to contextualise it in the field of research. Ethics as defined by Babbie and Mouton, (2004), Glatton and Joyner, (1998) and Neuman (2006), refers to the acceptable moral principles which guide a researcher's conduct and activities during the research process. Issues of ethics were considered according to the principles of equity, honesty, and human consideration (Glatthorn & Joyner, 1998).

The study reflects no discrimination based on age, ethnicity, gender, social class, or disability and was characterised by honesty and openness of the researcher and participants taking part of the process. I exercised voluntary participation (Neuman, 2006) and it was stated in the consent forms participants could withdraw from the research process without any disadvantage. The study also ensured that the research process did not result in emotional or physical pain for participants. Before each session I had to re-emphasise that the photographs were staged although the participants

were quite aware of it, as it was part of their own earlier photo-voice production. The digital archive, consisting of the staged photographs on stigma and metadata, was placed on a website and CDs which only the group of researchers has access to, that is, restricted access.

Where informed consent had to be obtained the correct procedure was followed. This includes obtaining consent and undertaking to protect the data (Maree & Van der Westhuizen, 2007) (See Appendix B). Therefore, permission to use the digital archive was requested from the project leader and ethical clearance (See Appendix C) for the use of the photographs was obtained. Permission from principals from both schools was obtained (See Appendix A) and all participants who volunteered signed informed consent forms (See Appendix B). All recorded sessions were permitted by the focus group participants who were informed about the use of the audio-tapes and video camera. These recordings were to accurately document what the participants said. To cultivate a culture of openness and honesty, the activities designed by the educators to be tried with their learners (See Appendix E and F) were scanned and saved in a special folder at the CVMSC and the video recording was viewed by the participants as a reflective exercise. The issue of ethics runs through the entire research process (Creswell, 2009; De Vos, 2005) which implies being open and honest must be maintained throughout the process of the study.

Anonymity and confidentiality was ensured through the use of letters A and B for the schools. Celia and Anushko (2008) emphasise the issue that is always raised in social research ethics namely that it should not be possible for any participant to be identified by anyone afterwards. Even though this is a CBPR I am aware of the ethics which apply including privacy and confidentiality, human dignity, and human rights (UNESCO, 2005). Article 9 of the Universal Declaration on Bioethics and Human Rights (on privacy and confidentiality) states that personal information must be respected and only be used for the purposes consented to (UNESCO, 2005). In this research where faces are shown, consent was obtained from participants and the use of the images is limited to study purposes (Karlsson, 2003; Karlsson, 2007). The images are not shown to cause harm but good for the community and also make the voices of the participants heard.

## 4.12  TRUSTWORTHINESS

In this study, an interpretivist, qualitative approach was used, and this suggests that reality is based on the participants' views (Henning, 2004) and that generalisation therefore will not be relevant to my study.  However, Guba's model (Krefting, 1991) for trustworthiness of qualitative research was used, i.e. issues of credibility (truth value), transferability (applicability); dependability (consistency) and confirmability (neutrality) (Krefting, 1991) were adhered to.

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.  An observer was invited to record his/her own observations and in addition member checking of the transcribed interviews was done with participants as well as providing a chain of evidence, as a means of increasing trustworthiness (Strydom, 2005).  Different forms of data capturing which included taking field notes during focus group interviews, voice recording, and video recording were done to increase credibility.  Using different methods of data generation facilitates crystallisation thereby increasing trustworthiness of the study (Maree & Van de Westhuizen, 2007).   The video recording was watched by participants as a reflective exercise and as a means to avoid misinterpretation.

Transferability is the degree to which findings can be applied to other contexts and settings and still yield similar results (Poggenpoel, 1998).  For example, the findings from this study can be transferable to another rural school setting, although generalisation is often not possible.  Poggenpoel (1998, p.349) refers to applicability as "the degree to which findings can be applied to other contexts and settings within groups."  In essence, a thick description, so that others can replicate the research, was provided.

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 report findings as the product of the inquiry and not of the biases of the researcher.  In this instance the supervisor endorsed the research findings.  Vockell and Asher (1995) suggest that 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, therefore the distance between the researcher and participants is decreased.

The issue of dependability, which is consistency, was addressed by the use of audio-tapes and video recordings. 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). The idea was to "learn from participants [rather] than to control them" (Bisschoff & Koebe, 2005, p.5) and the techniques used to enhance consistency were the use of video and voice recording in addition to field notes.

## 4.13  METHODOLOGICAL LIMITATIONS OF THE STUDY

I acknowledge that the ICT-based focus group interviews have shortcomings like any other data collection method and that minority opinions may be silenced by those who have more power as some people dominate discussions (Hollander, 2004). I introduced myself to the participants as an educator in the process of data production for my Masters in Education. I wanted to ensure that they viewed me as 'one of them'.

In school B one of the participants was the principal, and I noted that he contributed a lot in the focus group discussion and that most of the participants were silenced, until he received a telephone call and excused himself. It was only then that all the others started to contribute their views. Short (2006) concurs that power relations may lead to the silencing of other voices within group interviews. However, some researchers have published useful studies primarily based on focus group interviews (Morgan, 1997).

Another limitation was relying on the rapport created by previous researchers from UKZN. It took a while for me to establish rapport, but once established the discussions became richer.

Although a researcher may like to confer anonymity and confidentiality, members of the focus group would from time to time call each other by their real names and they also

wrote their real names in the transcripts used to design the exercises to be tried with their learners, and there seemed to be no technique for avoiding such incidence. Their names however, are not referred to in this dissertation. The visual data poses its own ethical dilemmas, requiring a thorough explanation of consent for using photographs in the dissertation.

It was not easy to fully disassociate myself from the learners and concentrate only on the educators. This is the kind of subjectivity which De Vos (2005) talks about with regard to social science researchers.

Also, there were some technological challenges typical to a rural school. I have explained in the section on school setting that the computers have to be kept in a 'safe'. Similarly, the laptop is safeguarded by the principal and when he is absent it means the school is without a laptop. Other minor technical hitches were resolved.

I also observed that some female participants were apprehensive about exploring the archive but once they mastered the skill, they could do it independently. The participating educators were also interrupted by others colleagues who from time-to-time would come in and request their attention.

## 4.14  SYNTHESIS

In this chapter I have mapped out my methodological approach and I also outlined all sessions conducted with the participants. I have described the methods used and the reasons for their choice and described how ethical issues were addressed. The process of data analysis was described and how the themes emerged. In the next chapter I present the findings on how HIV and AIDS-related stigma can be addressed using a digital archive in a rural community.

# CHAPTER FIVE

# FINDINGS AND DISCUSSION

*"…You can say different things about the picture… There are many answers, there are many ways you can interpret the picture…because these pictures talk, and they talk anything you want them to talk…"* (Participant)

## 5.1  INTRODUCTION

In the previous chapter I outlined the methodology employed in order to answer the research question. I explained how the data was produced from four constructed sessions: exploring the digital archive; using the archive in designing lesson plans; implementing the lesson plans; and reflecting on the process. I further described the sample, the research setting, the data production tools, the data sources, the data analysis, and limitations of the study.

This chapter describes and discusses the responses of the educators who participated in exploring a digital archive to address HIV and AIDS-related stigma in their schools. Analysis of data from the four sessions of ICT-based focused group was done. Most emerging themes and categories cut across all the sessions. This chapter is divided into four themes: working with the content of the archive; using the archive for learning and teaching; using the archive for engaging with stigma in the classroom; and using the archive to effect change in the community. The themes and related categories (See Table 5.1) that emerged from the data are presented and supported by direct quotes from the participants. These findings are re-contextualised by using relevant literature to support or refute the themes and categories (Poggenpoel, 1998). Maree & Van de Westhuizen, 2007) describes this as moving between existing theory and literature in order to deliver insights from the data in the context of an established knowledge base.

## 5.2   FINDINGS AND DISCUSSION

## TABLE 5.1: THEMES AND CATEGORIES REGARDING THE USE OF A
##                    DIGITAL ARCHIVE

| THEME ONE | THEME TWO | THEME THREE | THEME FOUR |
|---|---|---|---|
| **WORKING WITH THE CONTENT OF THE ARCHIVE** | **USING THE ARCHIVE FOR LEARNING AND TEACHING** | **USING THE ARCHIVE FOR ENGAGING WITH STIGMA IN THE SCHOOL** | **USING THE ARCHIVE FOR CHANGE IN THE COMMUNITY** |
| **Interpreting visual data** | **Pedagogic strategy** | **Breaking the silence** | **Regenerating 'Ubuntu'** |
| **Engaging with captions** | **Interesting ways of learning** <br> *-Independent/individual learning* <br> *-Opening space for debates* <br> *-Opportunities to role play* | **Projection of feelings** | **Revisiting cultural norms** <br> *-Stigma* <br> *-Gender* |
| **Coding the data** | **Developing skills** <br> *-Problem solving skills* <br> *-Computer skills* | **Contributing to policy development** | **Bridging gender digital divide** |
| | | **Sense of agency** <br> *-In the school* <br> *-Reaching out to the community* | |
| | | **Raising awareness** <br> *-HIV prevention* <br> *-HIV stigma and pregnancy* <br> *-HIV stigma and rape* <br> *-Sensitising towards solutions* | |

## 5.2.1   THEME ONE: WORKING WITH THE CONTENT OF THE ARCHIVE

This theme highlights how the participating educators engaged with the archive in terms of interpreting the photographs and the captions, and the potential to extend the existing coding.

### 5.2.1.1 Interpreting visual data

The participants believed that the learners could interpret the visual data in the digital archive and that this could deepen their understanding of HIV.

> *…The teacher will ask the learners about what they see in his picture, like if this boy look like a happy people or and thereafter, after presentation as a teacher I need to say, to make a conclusion about this picture, what I see, or I see a boy crying or this boy maybe he is crying because he is lonely, he is hungry, that's all……you can say different things about the picture…*
>
> *…There are many answers, there are many ways you can interpret the picture…*

The above points to the versatility of the digital archive as images increase awareness and stimulate further dialogue, even among people who did not create the images (Francis & Hemson, 2006). Reading and interpreting a photograph, either individually or in groups, is likely to provide the necessary space for participants to initiate and sustain a dialogue around issues which are not easily discussed like sexuality and HIV issues (Moletsane & Mitchell 2007). In exploring what the photograph means in terms of HIV-related stigma, the learners could possibly extend their own understanding.

### 5.2.1.2 Engaging with captions

The metadata of the archive includes captions in isiZulu or/and English (c.f. 3.3.2). The participants suggested making use of the captions (that is, what was said or written by the photographer about the photograph taken) for deepening the understanding of stigma in the rural school community. Captions like the one which appears in Figure 5.1 could be used for further dialogue to address the issue, as one educators said:

> *…Yes captions, I like that because it has something that can open, open up some discussions, let them say what do they.. Like the one the learner wrote that, "I took this picture because this girl is HIV positive and the friends are running away." I can project it; let them read the captions make them critique it, that is, is that the way people who are HIV positive should be treated?*

"Ngikhethe lesisithombe ngoba lentombazane ibukeka ikhathazekile ngoba inalesi
sifo iHIV/AIDS. Manje isixalaza abangane bayo
ukuthi bazoyisiza lentombazana. Kodwa abangane bayo bathi bona abathandi
ukushotha ngoba bathi bona abanayo
iHIV/AIDS. Abangane bayo bayayibalekela ngoba ine HIV/AIDS".

I have chosen this picture because this girl looks depressed because
she is HIV positive. She is looking for her friends to help her
but her friends do not want her near because they are not HIV positive,
they now discriminate against her.

**Figure 5.1: Ltph058 from the Learning Together digital archive**

Similarly, when a caption tries to make more than one point, (See Figure 5.2) it opens
up discussions, for example,

> *...here we are having a boy whose parents have died of HIV, the community is
> not supporting the boy, and HIV is there and it is killing people and we have to
> support the people.*
>
> *...I think I can also use this as an exercise to know from them why our
> communities are doing this, ask them on what is written why this happens in
> communities. I would use this picture to hear why that, why their communities
> are treating these people like this...And how must the people treat people, and
> why people should provide care and support...*

*"1. The community hate this person because he has got HIV and AIDS so they do not wants him in their community they are discriminating him about her HIV status.*
*2.People hates this man because they don't wants him in the community they think that if they let this person live in the community he will spread this dieses all over the community so they tell him to live.*
*3. The people in the picture hate this man because of his HIV status so they dont want to welcome her in the community".*

**Figure 5.2: Ltph048 from the Learning Together digital archive**

It is interesting to note that the first two quotations refer to exploring the reason for the behaviour of the community, while the last moves towards a solution, towards exploring ways of addressing the issue. Mitchell and Weber (1999) argue that captions and inscriptions (data about what was said by the photographer of a photograph) are important aspects of the social uses of photography (c.f. 2.4). Factual information about photographs enhances the reliability of the records and is associated with academic integrity (Karlsson, 2007). In this study the captions, or an analysis of the photograph by the photographer, are viewed as elements of the visual data that can be used to trigger further dialogue.

**5.2.1.3 Coding the data**

Working through the archive stimulated the participants to offer suggestions about extending the digital archive in terms of coding. They suggested adding their own interpretations of what they see in the photographs.

> *…What if you do have got more information based on the picture, assuming that that there is a background of the picture which you… just highlighting… certain*

84

*information you need to amend or to put more…*

*…Because you also have you own explanation, you can explore more and you can say quite a lot of information with one picture…*

*…They [learners] can add or put their opinions…*

This refers to the coding and recoding by the community of participants, adding to the richness of the analysis. Others went to the extent of suggesting that music and colour should be included in the digital archive. This idea is similar to the views of other researchers that digital archives can be made more interesting if the archives are made more graphic and comprehensible by incorporating diagrams, pictures, and videos available on the web, or by enabling educators to give lessons on-line (Education Technologies, 2008).

The digital archive should include knowledge generated across all stake holders and be made available to wider audiences to promote society's well-being. It could provide the community with easy-to-use, credible, interactive, relevant, private, and secure information that could theoretically be used to improve health in schools and ultimately in the entire community (Neuhauser & Kreps, 2003).

## 5.2.2 THEME TWO: USING THE ARCHIVE FOR LEARNING AND TEACHING

In relation to using the digital archive in the school community, educators focused on using it in class as a pedagogical strategy, as an interesting way of learning about HIV-related stigma, and also for developing problem solving skills and simultaneously improving computer skills.

### 5.2.2.1 Pedagogic strategy

There was generally a concurrence among viewpoints on the use of the digital archive in the classroom gathered from the participating educators. Keeping in mind that each school received a laptop, data projector, and digital camera, the participants entertained the idea of introducing technology in the rural classroom. The participants suggested using a data projector to project the photograph(s) and allow learners to read the

captions, deliver critique, and suggest appropriate ways of treating HIV positive people. The collection of photographs is therefore seen as a concrete prompt to open up the discussion around HIV-related stigma:

> *...I can use it for my Life Orientation class. When I want to teach about HIV, I can allow them to talk about the collection, take one picture and talk and just talk about this issue of HIV and anything you can say... ...Then they [can] come up with some ideas on the HIV stigma. Because even in [other] subjects you can use those pictures, because those pictures talk, they talk anything you want them talk...and objective - help learners understand stigma using the picture in the classroom and that how all learners should help each other in eliminating the stigma...*

Education and life skills training in schools are fundamental to effecting appropriate behavioural changes among youth. Educators are a crucial link in providing information about HIV and AIDS and therefore need to acquire good teaching strategies (Kelly, 2002). UNAIDS (2002) suggests that national AIDS programmes should aim to provide school children with AIDS education addressing effective prevention, non-discrimination, and care and support for people with HIV and AIDS. However, issues of sexuality and AIDS education are often not discussed with children and young people in schools due to religious, social, or cultural sensitivities to sexuality, HIV and AIDS. Moreover, the availability of information does not guarantee its application in some places, and schools may teach information on AIDS but not the behavioural skills needed for prevention and support. Kelly (2002) suggests methods that are interactive and participative to be considered because they allow for discussion, reflection and some of form of action. This idea is conveyed by a participant:

> *…I can give them a task, take any picture, any picture without the captions and let them say anything about the picture and relate it with HIV stigma. What can they say about the picture?*

The importance of varied pedagogic strategies, including electronic tools is also mentioned:

*...there are issues the teacher cannot tackle but if the learners by using the digital archives, it is easy for them to see because I, I must be honest there are some learners who [do] not want to see a teacher in front of them but they enjoy watching something so that is why I'm saying its very important...*

The archive can also be used to stimulate critical thinking:

*...I can project it; let them read the captions make them critique it, that is, is that the way people who are HIV positive should be treated?*

It is clear that educators realise that they have to keep up with the electronic era we live in by introducing computer technology into their classrooms. In this way individuals are encouraged to engage in classroom work.

*...the department has introduced the learner-centred, that is, the teacher will just facilitate and the learners, and the learners are hands on. So the teachers have to facilitate and the students do their work. Because most of the time you find the teachers talking, talking, talking, talking (giggles) and you don't know whether they are understanding... Now those learners who cannot memorise [recall] I think it will... they can just write, and in the computer there is a lot they can do to respond.*

Curriculum 2005 promotes learner participation, activity-based education, flexibility, and critical thinking (DoE, 2002). The participants regarded the archive in use as relevant to the expectations of Curriculum 2005 which emphasises learner-centred participation.

They also envisaged using the digital archive to facilitate group work:

*...Yes, when they came into groups I would have placed say a copy of questions for them...*
*...I think differently, I would put a picture for every group with the intention of further opening them up that group...*

The participants also referred to an inductive process of learning, that is, the notion of drawing information from learners and engaging with it, particularly around a sensitive topic such as HIV and AIDS.

> *...About picture 21 where a young girl is sitting lonely at the doorstep, asking herself why the others are ignoring her. Is it HIV/AIDS that has brought her to poverty or is it because she is clumsy or not. I can give learners a chance to brainstorm before asking them a question that: Why do they think other learners stay alone at their homes? Where are the parents? I can even arrange one of the learners to come to school in a funny dirty look, especially during my period to demonstrate the picture. The demonstrator should be taken from learners who are not disadvantaged in real life. So that learners don't get intimidated.*



"This person is not HIV/AIDS she is think by asking her self. In a classroom they were laughing at him because her parents are total died with HIV/AIDS. She ask "What did they laughin at? Did I wear rong uniform?" she doesn't came with an answer".

**Figure 5.3: Ltph021 from the Learning Together digital archive**

A study conducted by Mdunge (2005) also concludes that introducing technology into the learning environment can encourage cooperative learning and student collaboration. Similarly, in this study, participants alluded to the fact that the use of technology can

lead to possibilities of authentic engagement.

## 5.2.2.2   Interesting ways of learning

Although the research question is aimed at finding out how they can use a digital archive to address issues of HIV-related stigma, participants suggested that the digital archive is an interesting tool for learning.  They suggested that the visual data being interesting to them, it would be equally interesting to their learners.  An equally important issue of integrating HIV into other learning areas such as mathematics was raised.  They also thought it would be interesting because their learners like to use computers.

> *…Interesting because they like using computers…but I think now as we have this digital archive we can also use this to… to teach the other class…*

A female participant stated that the digital archive can be used for any learning area:

> *…Yes, yes...even when we are having maths, I think it's useful...Because even the learners if they can see this, even if you've got this [computer with online digital archive] (pointing) they can be excited...*

Another concurred that it was interesting and highlighted the value of visual materials:

> *…It was interesting, it is just that it was a short notice.  As I have said that if you can leave it we can generate more ideas at our own time. But it's nice because you use visual methods to send the message…Ya it was nice.*

When asked how they found the whole exercise of exploring the digital archive and designing activities (as a reflection activity) educators came up with two key benefits for themselves: improving their own computer literacy and providing access to visual data around HIV and AIDS particularly in a rural area.  They were confident that the digital archive is a tool that can support their teaching and provide ways of addressing HIV-related stigma.

*...I think it was useful and the information can be helpful to the learners to challenge HIV...It was difficult but it was quite interesting...*

*...I even go [went home] and talk about my family so it was a very good lesson and I saw the learners who was enthusiastic they were really looking and you could see that they were expressing themselves they come, they come to even understand this disease now so it was good. When I started I thought it was difficult to give the lesson, it was... it was simple and enjoyable...*

Information and communication technologies have been praised for promoting new forms of learning (Strydom, 2009). The use of an online digital archive is possible in school A with Internet connectivity. Waller (2006) further suggests that such technologies and activities have the potential to extend learning in new and exciting ways; in this study to learn about and address HIV-related stigma. Mitchell and Smith (2003) identify the 'sick of AIDS' phenomenon and propose improved strategies to address the issue of HIV. It is clear from the above quotes that the use of the digital archive with its visual data is part of such an improved strategy.

### *Independent/individual learning*

The possibilities of allocating a computer to individual students (one-to-one) and allowing the students to browse through the collection individually and make their own suggestions on addressing the issue of stigma was suggested:

*...They would be reading on their own...*

*...I think the activities which we [usually] give to the learners sometimes, only the capable students will do the talking and if it is one-to-one everyone will be learning and thinking what am I going to say, and how am I going to write.*

*...Everyone is working and the individuality... individuality... it will also help stop the laughing at each other...*

*...He will have time to thinking alone and saying what he wants to say alone, there is no limitation...Everyone is now supposed to stand for himself and do that is what he is supposed to be doing. Other learners are shy you find that, and now he does not want to say things where everyone has to say but if you have an activity where everyone has to do her or his own things no one will hide you can see those who are struggling in English or whatever...*

90

> *...Let's say every learner has digital archive so, let's say maybe I've seen that picture then I want to see more, if I've got mine I can just continue looking at them not like looking... watching that [the photos] as a class.*

The above highlights an important issue when working around HIV and AIDS in a classroom context. The nature of the topic might prevent all learners from engaging in the discussion, but individual access to a computer opens up the opportunity for all to engage with the stigma at individual levels, and in their own way. Learners can therefore repeat the exercise in their own time and at their own pace (Education Technology Services, 2008).

Today's computer assisted programmes are 'descendants' - of Skinner - the behaviourist's programmed instruction (Sdorow, 2003, p.303). Computer programmes can take a learner through a graded series of items at his/her own pace. Though the computers cannot replace teachers, they add another dimension to the classroom (Education Technology Services, 2008; Sdorow, 2003). Similarly, a digital archive which is computer-based can enable learners to learn better and more in the same amount of time (Skinner, 1979). Individual decision making is likely to differ from the decision made by a group, therefore individual learning on issues of HIV-related stigma can allow an individual to reflect on and learn in a different way, suited to his or her needs.

### *Opening space for debate*
Although technology can result in losing the dynamic, interesting, face-face discussion with learners in the classroom, it does have the advantage of allowing thinking and reflection on sensitive issues which are not easily discussed with other learners (Education Technology Services, 2008). Participants also suggested using the digital archive to open up space for learner discussion. When using ICT, learner participation improves because there is often more depth and thoughtfulness (Education Technology Services, 2008).

Participants suggested that the use of a digital archive allows each learner to share ideas and then further discuss it:

*...The first thing I would do , I would divide the learners into groups, then I give each of them [learners], group the picture of this boy...each member of a group make a presentation ehm... about what they are discussing in their groups...*

They also referred to how it can open up talking about gender-based violence and Voluntary Counselling and Testing (VCT).

*...They can do a debate whether it is correct for male learner to beat the female learners.  Another debate question in group would be whether it is good to be tested for HIV or not...*

After watching the lesson tried out by a colleague they had this to say:

*…I liked the fact that they are opening up, they discuss things around this stigma…*

It is clear from the above that a concrete and visual piece creates space to discuss otherwise silenced issues.  Interaction and communication is more effective than one-way communication from the educator.  While learners want knowledge and ideas to enhance their lives, at times receiving it in a perceived authoritarian form from educators may be disempowering (Smedley & Symie, 2000).  The digital archive allows for tailoring or customising information to the needs of the recipients, in this case, the learners (Neuhauser & Kreps, 2003).  The fact that the photographs were created by the learners' peers gives them a sense of being relevant and appropriate, and can be used to produce competent future citizens with reliable and adequate information to facilitate informed choices (Feasey & Still, 2006).

However, issues of ethics must be emphasised and observed by the educators as they attempt to engage learners.  One participant suggested:

*…I will just get them into groups and ask them to discuss the picture.  They should explain if they have seen these incidents in their homes.  They will discuss about different sick people around their home they have seen around their area.*

Expecting learners to draw from their own real life experiences such as HIV is quite sensitive, and therefore an educator needs to know about ethics and care (Rager, 2005). Questioning learners at such a personal level is not encouraged, unless psychological care is in place (Mitchell et al., 2005; Stuart, 2006). This clearly points to the need for sensitive engagement with learners around issues of HIV and AIDS.

### *Opportunities to role play*

Educator participants also suggested role playing by drawing on the digital archive, as participatory learning. The quotes below point at role play touching on three issues, namely, empathy, problem solving, and agency. Merril (2007) applauds role play for this potential and also for learning by doing:

> *...let them say how they are going to role-play something which they see in the picture...*
>
> *...Learners will role-play whereby two boys will find out that they are HIV positive* [Figure 5.4]. *They can involve people like counselors, also involve people like reverend. They can also involve these two boys. They will have to role-play a sick person because of HIV suffering and how that person is helped. So I will want them to feel for this sick person. I know that this lesson can help them to understand that, although HIV is dangerous, but it is not good to run away from the sick people. It's better to help them and get them around...*
>
> *...Learners will discuss the issue of the boy and come up with different ideas and then the learners will discuss the characters while they are planning their role play. They, they will discuss the characters and then how to help each other to eliminate the stigma within the school or within a classroom situation...*

*"Ngikhethe lesisithombe ngoba bahamba bayoshekha bazithola bene
HIV and AIDS batshela izintombi zabo zase zibala ingakho bebebukeka
bekhathazekile.
Izintombi zabo zabalela ngesimo sokuthi besaba ukuthi nazo
zizothola lesi sifo".*



*I have chosen this picture because the two went for an HIV test and
they found they were  HIV positive.
They informed their girlfriends about the results and their girlfriends
decided to end their relationship.
They feared their partners were going to infect them with HIV.*

**Figure 5.4: Ltph063 from the digital archive**

From the participants' suggestions it was clear that role play provides exploration and discovery learning which promotes engaging with content.  Genat, Naidu and Fong (2008) in their paper *"Shifting perspective about aboriginal health and history: Using digital archives in an online role play",* argue that role play provides learners with educational activities that are situated in meaningful and relevant contexts.  The above quotations points to the learners having to study the character, and write a role which means, 'putting oneself in the character's shoes'.  Acting out characters relevant to their context provides learning opportunities.  Similar outcomes can be achieved through performed ethnography (Thomas & Mulvey, 2008), and forum and image theatre (De Lange & Stewart, 2008; Raht, Smith, McEntee, 2009).  Such vehicles for story telling are often used in the African context, where oral tradition is important.

### 5.2.2.3 Developing skills

*Problem solving skills*

The participants also viewed the digital archive as facilitating creative ways of addressing the 'scourge'. Learners can identify the problem from looking at the photograph and because of its open-endedness they can offer solutions.

> *...this exercise is for Grade 8 and the aim was to make learners identify the problem using the picture and express their views about the picture...*
> *...then they can come up with some ideas on the HIV stigma...umh help the learners to come with different ideas...*

Although problem solving skills can be mediated without ICT, these quotations confirm that a technology-enriched environment can contribute to mediating the preparation of learners for critical and high order thinking skills (Mdunge, 2005) which are necessary in informed decision making, an element is needed in dealing with HIV. In a rural area where resources are few, a digital archive can become a rich resource for learners who can not only learn from using it, but can contribute their own views on health issues, including the issue of stigma.

*Computer skills*

Learners may also benefit from computer-assisted instruction because it permits them to work at their own pace, prompting and guiding them in areas of weakness (Sdorow, 1993). Participants thought the use of a digital archive could not only address the issue of HIV-related stigma but also encourage the development of computer skills among learners.

> *...I think they can start developing their skills of computers...We need to use the computers because nowadays we need technology...*
> *...And I think it helps her or him to acquire some skills that he or she did not have. And now he is having his own computer he can write than talking to the teacher...*

The above points to a pertinent issue, that is, learners need to be computer literate;

something which is difficult to achieve in under-resourced areas. Feasy and Still (2006) are of the opinion that computers enable children to make mistakes in a safe environment and further suggest that experience gained in a safe problem-solving environment can help to develop future citizens. The use of a digital archive can therefore improve computer skills and at the same time address HIV-related stigma.

## 5.2.3 THEME THREE: USING THE ARCHIVE FOR ENGAGING WITH STIGMA IN THE SCHOOL

Although much of the discussion focused on the pedagogy of teaching and learning, the participants were quite clear on how the archive can address the issue of HIV-related stigma, by breaking silence, allowing for projection of feelings, reaching the community, and contributing to policy change.

### 5.2.3.1 Breaking silence

Participants applauded the use of visual data in the digital archive and viewed any effort towards HIV prevention and intervention, including the digital archive for breaking silence among individuals, as useful.

> *…You know I remember this project since 2005, when we were involved in this project. I could think when a person comes to me and tell me about his status because you see I couldn't imagine a person doing that. I don't know what I could have done during those years but now I sit with them and talk about it without any problem. I think this project has made some difference…*

Among suggested uses of the digital archive were using it in education to encourage talking about the disease and creating acceptance as opposed to denial. They cited instances which show that people are still silent about the disease:

> *…Right now we are living in a stage where people would say I am going to Songonzima clinic because I have stomach ache. We should reach a stage where people talk freely about this illness…*
> *…It is difficult to tell your partner about your status. Even at home it is difficult*

> *to tell them because other parents can chase you away…*
>
> *…Ya, it is difficult because even at home they can say you can't touch the spoon, you can't touch the dish because you are this filthy…*
>
> *….if they speak about it people will run away from you and be isolated…*
>
> *…I would canvass for support for this one [picture showing a brave girl who revealed her HIV status] and develop a whole lesson of "UKWAMUKELWA" (ACCEPTING).*

Forman (2004, p. 1) writes that during the eighties, American AIDS advocates used the phrase "silence equals death" from the environmental movement to describe the danger of lack of information and communication around HIV and AIDS. In South Africa we are living in an age where people still do not communicate about issues of HIV (Deacon, 2005) and lack of information still persists, even more so in rural areas. This is evident through the increase in the statistics of new infections and the number of people who are infected versus those who go for treatment (Steinberg, 2008). Here, a lack of information and a lack of voice continue to be primary causes of infection among the worst affected groups, namely women and youth (Campbell, et al., 2005) in rural areas.

### 5.2.3.2  Projection of feelings

Participants viewed captions and the metadata as triggers for further dialogue and expression of new views, or using photographs without captions to allow for projection of feelings:

> *…which means one will take one picture and describe…which says something to him or her…*
>
> *…if they [learners] write the journals they will write about their happy days, their sad days…*

After watching the video of the implemented lesson, the educator was asked if the learners opened up, to which he responded:

> *…initially I did not explain to them I just gave them the freedom and said please*

*just look at the picture and say what the picture is all about so you say because I wanted to say, I mean to speak, I mean to activate opinions...*

HIV and AIDS being a sensitive issue creates difficulty in accessing feelings and emotions of those infected and affected, yet in terms of care, it is important to express what is felt and experienced. The digital archive therefore, creates space for the projection of feelings and lived experiences. The learners can safely talk about the feelings of the people in the photographs of the archive. Globally adolescents are active Internet users (Halpern, Mitchell, Farhat, & Bardsley, 2008) and web-based education for youth may be especially useful in certain cultural contexts or for sensitive health contexts because computers may be perceived as more confidential sources of sensitive information (Berger, Wagner, & Berker, 2005) and can be accessed anytime.

### 5.2.3.3  Contribution to policy development

Various viewpoints on the use of the digital archive were expressed by the participants, including using it as a resource to draw on learners' ideas when developing school policies. One participant suggested:

*…I am just thinking… although I do not know how… but I am thinking of a possibility of using the whole collection especially because it concerns their [learners] school. They can give their views in trying to come out with an HIV and AIDS policy. As we develop such a policy we try to project the photos allow them to talk about. Let them to talk so that you can get some ideas or topic that they would like to include in the policy, get it from them…*

Another participant suggested sensitising learners to human rights:

*…the activity can be centred around the violation of human rights…That every child has the right to education…Learners can be corrected that it is wrong to discriminate other learners in school situation.*
*…I have been thinking about the picture where the community is ill-treating the boy that learners can be reminded of human rights. That even if a person is HIV negative or positive he has right to life…*

Carolyn Wang (1999) initiated photo voice with the particular aim of giving 'voice' to a group of marginalised Chinese women and thereby informed policy making. This underscores the importance of including every voice and the notion that maximum effectiveness for intervention requires a partnerships between policy-makers, religious and community leaders, parents, educators, and learners to formulate sound policies on AIDS education; using curricula adapted to local culture and circumstances; focusing on life skills rather than biomedical information; teaching students to analyse and respond to social norms and to understand which norms are potentially harmful and which protect their health and well-being; and training teachers and peer educators (UNAIDS, 2002).

Information and communication (and the technologies that facilitate them) are therefore seen as elements of a society's response to the epidemic, enabling advocacy, mobilisation, and empowerment of PLWHA, women, and other vulnerable groups. ICT also increases democratic participation (Dralega, 2007; Forman, 2004). Teen Web, for example, aims to better understand the educational and sexual health needs of secondary school learners but also to share this knowledge to improve policy and services for adolescents (Halpern et al., 2008). The use of the digital archive in a rural school community therefore not only holds potential to address HIV-related stigma issues but also to inform policy making.

### 5.2.3.4 Sense of agency

*In the classroom*
The responses of the participants indicate that a digital archive containing photographs can act as a vehicle for behavioural change. One photograph showing a deserted classroom, according to a participant, can evoke discussion about where the learners had gone and compels educators to prepare lessons or interventions.

"*Lesisithombe sisho ukuthi izingane seziphelile ingculaza azisakwazi nokuthi ziye esikoleni ngenxa yengculaza isizicedile izingane zesikole amaclass asesele dengwane ingane azisakwazi ukuthi ziphumelele esikoleni nekhambi lalesifo alitholakalikuze izingane zithole ukuphila zifunde*".

*This picture shows an empty classroom because children are suffering from AIDS they are unable to attend school.*
*There is still no cure for HIV and there is no way the children can get help.*

**Figure 5.5: Ltph090 a photograph from the Learning Together digital archive**

*...the fear that this photograph leaves, could make them start talking ....and start developing lessons on the prevention of the disease because it makes you feel obligated to do something before this gets worse. You can use it to develop a whole chapter on prevention...*

While another participant elaborated that:

*...As a learner is using this kind of learning which interest I think they can develop a positive attitude...*
*...By having that computer there will be having access to getting more*

*information...and it will help them with their attitude...*

E-health communication can improve behavioural outcomes (Nuehauser & Kreps, 2003) however, we have much to learn about whether the technical promise of e-health communication in this study, that is, a digital archive will be effective in the social reality of a rural landscape. It does however hint at the possibility of engendering agency in educators and learners.

### Reaching out to the community

The agency of addressing HIV-related stigma and its consequences, in the classroom, is extended to the community. The participants suggested ways of reaching the entire community as they felt addressing HIV and stigma issues at the level of the school might not have enough impact. If individuals do not change their behaviour and intervention strategies fail to address the seriousness of the pandemic, classrooms will remain empty as in the message contained in Figure 5.5.

> *...Can I add on that picture? I think I can bring to their attention that there are anti-retroviral now available so there is no need to wait until the classes are empty while there are ARVs. I can inform the learners that there is the treatment that prolongs [living with] HIV because many people are dying because they lack the knowledge. Then they can even spread the news at their homes that people must come out and get tested so that they get the treatment sat the right time before we see empty classes. People should not be afraid to go and get the treatment...*

The participants suggested that the transfer of information on HIV prevention strategies, testing, and availability of ARV treatment, begins with the learners, who could sensitise their families at home. Anti-retroviral drugs prevent the HIV from reproducing inside the body, allowing the immune system to recover, and has brought hope to HIV infected and affected individuals (UNAIDS, 2008). Taking ARVs is a life-long commitment and therefore requires psychological readiness as well as support from families to adhere to the treatment (Miller, 2002). The importance of knowing that HIV is medically manageable, can only contribute to the eradication of HIV and AIDS, if stigma is addressed.

It is also interesting that educators thought fear of the virus can impact on behavioural change. One educator felt the photograph can instill fear and curb the spread of the virus.

> *...Ah, umh, I am thinking of two things here, first one is prevention and second one is cure. The second one would be difficult maybe one would use the first one, the fear that this photograph leaves,* [Figure 5.1] *could make them start talking...*

The educators upheld the notion that 'fear' can have an impact on behaviour. Similar sentiments are echoed by Gyarmathy, Thomas and Mikl (2002) and Griessel-Roux et al. (2005) who suggest that effective communication based on fear result in effective behavioural changes especially in learners. This is contrary to the perception that anxiety and fear does not make people change because sex is pleasurable (Khau, 2006). While I agree that photographs should not use 'fear' to scare people into behavioural change, but photographs help bring to the surface the existing 'fear', making it possible to move beyond fear to a more thoughtful response.

Educators also suggested:

> *...Another debate question in group would be whether it is good to be tested for HIV or not. My lesson is based on picture 63* [Figure 5.] *where the two boys went for an HIV test and they found they were HIV positive. They came and show their results to their girlfriends...*

Treating HIV and AIDS as a medical condition, and making ARVs more readily available, may reduce the stigma ascribed to people with HIV and AIDS. Treatment is one of the greatest possible incentives for people to be tested, however Steinberg (2008) noted that people prefer to die rather than to face the stigma of AIDS and go for the ARVs. These deficiencies in a comprehensive response are only partially explained by a lack of resources. Educators suggested using a digital archive for disseminating information to the community on the availability of ARVs. The digital archive could also be used as a tool for transferring messages about availability of treatment which the VCT often does not emphasise (Charles et al., 2009; Hammil, Copas, & Murphy, 2006).

Another way of reaching the community, the participants suggested, is through informal meetings:

> *...contribution to reaching out we can start with parents because we can invite them to school, we could start small or start by big parents meeting because it is quite a big group... we've got grade meetings in this school and we can call grade8 or 9 and their own children presenting...*
> *....we can try something like parents meetings, eh... we usually have occasions here at school like there are things like 'matric' dance and in the items we could include presentations from learners...*
> *...Because other diseases can be cured then we can teach the community to understand this issue better in their level of understanding so we have to make plans to reach out...*
> *...I think we can start small create, create parents' meetings...from the digital archive, pictures, videos that are there we will make them critique together with the learners...*

Getting learners to present at such meetings, making use of the digital archive, could lure parents to the school. Hayes (2006) suggests the learners should be in control of the technology they will use.

> *...I was looking at the video we shot on 30 August, women's day I noticed that parents are very proud of presentations made by their own children that can also be used in reaching out...*

One participant reflected on how educating the community about HIV does make a change, by referring to the example of her mother:

> *...When my mother was still alive, I liked her idea, they were called to the community hall and there were these people, the 'Siyanqoba'. What year was that Mr YYY was it 2006 or what? ...When she came back from that meeting, she started to tell us about gloves, razor blades (laughing) things she has never talked about [before] and do you see that this [education] can be a driving force...*

*…Nokuthi uma ekhaya bebona lezithombe ezinombhalo kungashintja nendlela abaphatha ngayo abantu kwicommunity.* (And also that if the parents can see these pictures and the captions that can reflect the way they treat other people who are infected and affected) [Translated from isiZulu].

The educator's reflections on his mother's source of information highlights the importance of informal channels of communication such as local meetings, which could be exploited to reach men, women, and children with vital information (Duvuury et al., 2006). There is a need for understanding how specific personal actions can improve population health. The challenge is to use the body of knowledge to create interventions that will succeed in changing people's behaviour as Neuhauser and Kreps (2003) propose. Health communication is a process that seeks to change a person's physical, psychological and social world. An effort to transfer and to share information using the digital archive in this research could allow educators and learners to address the issues of HIV and AIDS stigmatisation not only in their personal lives but also in their schools and in the community; in this way exercising a sense of agency.

### 5.2.3.5 Raising awareness

The participants referred to how the digital archive can raise awareness about HIV prevention, HIV-related stigma and rape, and sensitising towards stigma**.**

### *HIV prevention*
The educators felt that the digital archive could contribute in a participatory way to HIV prevention messages.

> *…lesson should be around the topic ABC, Abstain, Be faithful, and Condomise. Learners can be shown the picture and told that anyone who practices sex can be in a risk of HIV. The best thing is to abstain using the ABC approach to life. That females can choose to enter into relationships sexually at their own risk and be able to bear the consequences thereafter…*

Knowledge is a necessary pre-requisite for a positive attitude and behavioural change although it does not necessarily mean this is sufficient (Phaswana-Mafuya & Peltzer,

2006). HIV knowledge should be associated with consistent protection and preventative behaviour (Peltzer et al., 2004).

### HIV-related stigma and pregnancy

The educators felt that they could make the link between teenage pregnancy and HIV clearer, using the digital archive.

> *…If the young ones are still getting pregnant it shows clearly that they still don't play it safe. So HIV can spread very quickly…*
>
> *…I will come with a magazine with an adult pregnant female, but also projecting the picture on the wall, showing them the difference between the young pregnant female and the old one…*
>
> *…Learners will come forward and each one would tell about the advices they get from their home about their safety. What the parents tell them about engaging into sex while they are still young.*

The rate of teenage pregnancy is still high despite the risk of contracting HIV and it is increasing in South Africa. In addition, most teenage pregnancies are the consequence of sex without consent or rape; many girls' first sexual experience is forced and one in every five women is a rape victim (Amnesty International, 2004). There is a need to address the issue of pregnancy especially among the youth as there is a high risk of contracting the virus (UNAIDS, 2008).

### HIV-related stigma and rape

Some of the photographs showed a link between rape and HIV. One participant suggested that the visual data and the captions can be used to raise awareness of HIV infection through rape. She suggested raising awareness in learners that rape cases should be reported so that victims can get treatment (ARV) before it is too late to prevention contraction of the virus, as explained in the caption. The photograph and the caption (Figure 5.6) could be used:

> *…The girl was raped and the girl told Aphiwe but Aphiwe didn't help the girl instead she was gossiping about her. When the aunt of the girl heard that the girl was raped but it was too late. When they took the girl for a check up, she*

*was already infected…*



*"And I took this one because they don't want her to be their friend anymore because she has AIDS".*

**Figure 5.6: Ltph043 from the Learning Together digital archive**

The participant also felt that it is necessary to find out how much information the learners have about the link between rape and HIV:

> *…Questions like, umh, what is the first thing that you need to do when you find out, or what is the first thing to do if you are raped by someone? And further encourage them that they should report such instances*
>
> *…You are not supposed to keep quiet but you need to tell someone who is closer…*

Rape is condemned but victims are stigmatised and some rape victims prefer to be silent. Low perceived personal vulnerability is a risk factor because it reduces the necessary precautions (Phaswana-Mafuya & Peltzer, 2006). Most children often do not tell anybody if they had been raped because of the way sex is culturally constructed. Without knowing the risk involved in silence, they eventually contract the virus. It has been documented that young women in South Africa face a greater risk of becoming infected than elsewhere in the world, and that girls between 15-24 years account for

about 90% of new infections.  This could be linked to the fact that South Africa has one of the highest rates of gender-based violence (UNAIDS, 2008).

*Sensitising towards solutions*

The participants also suggested that the archive could be used to elicit solutions from the learners regarding stigmatisation in their rural context.

> *… The picture of the learner who lost his parents, I think I can use this picture like to ask what can be done to help a learner who lost a parent. Like to put emphasis on the…They can also say how do they treat learners who do not have clean, (tidy uniform) or those who have complete uniform…*
> *…Learners will start answering questions using the pictures/ the picture and how they would help and HIV positive boy…*
> *…teacher will let the learners role-play, how to treat an HIV learner in your school or within the school…*

The concept 'teaching for tomorrow' which Hayes (2006) uses in her book *ICT in the early years,* is intended to convey the dual purpose of teaching tomorrow's lesson and also tomorrow's citizens.  We cannot second-guess the future of the learners we teach, but we can try to keep ourselves informed about how the present is changing.  The learners we teach today are future adults who will be determining the future and it is the educators' responsibility to enable them to make informed decisions and choices (Hayes, 2006).  Feasy and Still (2006) assert that ICT develops learners' thinking and problem solving skills by experimenting with world roles in models of real life problems using a range of contexts**.**  The learners, using a digital archive, could generate solutions regarding stigmatisation.

## 5.2.4   THEME FOUR: USING THE ARCHIVE FOR CHANGE IN THE COMMUNITY

In this theme the emphasis is on broader issues than teaching, learning, and information; highlighting issues such as ubuntu, support, trust, compassion, caring, cultural norms, gender, and the digital divide.

**5.2.4.1  Regenerating 'ubuntu'**

Mkhize (2004) asserts that possession of the qualities of personhood is reflected in people's relationship with others and their milieu.  In African societies the concept of a person is that of "a person-in-relation, a 'being-with-and-for-others' and not an isolated, atomistic individual" (Mkhize, 2004, p.24).

More than one participant raised the issue of lack of 'ubuntu' as a cause of the stigmatisation of those affected by HIV and AIDS.

> *…Learners may be taught that aspect of 'ubuntu' should be practiced in a classroom situation by sharing a piece of bread one has with the other who have nothing.*
> *…My main aim is to encourage learners to help each other and also, umh, don't laugh about other people's problem.  And I am also trying to emphasize on ubuntu, trying to help. (Take other people's problem as your problem).*

These quotations above suggest that if a person can be a 'being-with-and for-others' there could be a sense of empathy in the time of HIV and AIDS.  Failure to attain such personhood is often blamed on the individual, the family, and the entire community because the person is viewed as not being-with-and for-others (Mkhize, 2004).  Participants also view the regeneration of 'ubuntu' as having the potential of reviving empathy which would reduce HIV-related stigma.  They assume that using the photographs in the digital archive for reviving personhood could help to discuss and remedy the situation.

Participants showed awareness that stigmatisation leads to discrimination, isolation and lack of support, and they suggested using the digital archive to design lessons which can encourage support and caring.

> *…I know that this lesson can help them to understand that, although HIV is dangerous, but it is not good to run away from the sick people.  It's better to help them…*
> *…HIV and AIDS is affecting all learners such that they lose their parents as a*

*result of poverty but they need care and support…*

*…My main aim is to encourage learners to help each other…*

Unlike other chronic diseases like cancer or diabetes, HIV and AIDS is a highly stigmatised condition and associated with "immorality, preventability, disenfranchisement, and lack of social support" (Moletsane, 2003, p.56). Cancer is one of the life threatening diseases and patients suffer from psychological stresses such as fear of death, perceived helplessness and also financial worries (Lego, 1994). People with HIV experience a greater level of psychological stress because they are also subjected to isolation, shame, and guilt (Francis & Hemson, 2006; Govender, 2006). Social support from family is necessary because social isolation and hopelessness are major factors which contribute to depression caused by HIV and the stigma attached to it (Brouard, 2005).

### 5.2.4.2  Revisiting cultural norms

Participants felt it was important to use the visual data in the digital archive as it had potential to remind them of other issues some of which are culturally embedded and obstruct HIV prevention. Culture, the development of HIV prevention, and treatment programmes should go hand in hand to address HIV-related stigma (Resnicow, Dilorio, & Davis, 2008). The idea of wearing gloves when working with your family could be constructed as negative unless hygiene and infection is clearly understood as below:

> *…Mr XXX told me that they were talking about an experience where a member of the family (caregiver) used gloves [when caring for an HIV positive family member]… it was interpreted as a negative thing [by the sick person]… so that further tells, that it depends on the way people are socialised…*

The participant further elaborated that hygiene is relative depending on context:

> *…we can talk about simple things like go wash your hands before you eat, it's a hygiene thing like wash your hands after you have used the toilet …*
>
> *…I think it will rest upon the socialisation and upbringing...the challenge therefore to us perhaps…is that we start talking about these hygienic things…*

These findings concur with Pekarsky's (2009) suggestion that individuals and groups are represented in each culture structures and shape the attitudes of its members. However, Vygotsky (1978) argues that culture can be challenged and can adapt to new things. Similarly, participants saw that the digital archive has the potential to challenge behaviours which impact on the understanding of HIV-related stigma. Therefore, the digital archive can be used as a tool to challenge cultural norms which exacerbate stigma.

### Stigma

Participants noted the importance of understanding stigma, as educators, before they can design lessons using the archive to address the problem. One participant said:

> *Firstly I [educator] have to understand what is stigma and then show them the picture...then would make them look at the picture in their discussion they have to think of the people with HIV how did the community treat the people and then using the pictures they have to make their own opinions their ideas how they should treat people with HIV.*

While others concurred that:

> *...we still have that challenge that we need to address but we need some deep means of how to address such questions of stigma to learners...*
> *...As an educator do we have a challenge of making them [learners], or of making their families comforting maybe we should do a lot or do quite a lot of things...*

Other studies aimed at addressing HIV-related stigma reveal that education influences stigma and discrimination. A study carried out by Phaswana-Mafuya and Peltzer (2006), shows that those who had at least grade 12 were less stigmatising. In rural areas where education levels are lower, educators will have to be creative in addressing the issue.

### Gender

The participants suggested using the digital archive in educational campaigns to

encourage both females and males to talk about the disease. A photograph [Figure 5.7] from the digital archive which shows a male 'hanging' himself could be used to lead discussions about the gendered nature of the disease.

> *...On rare occasions it would be men and they would say I should not tell their wives...Everyone is still afraid to confide their status to many people but I can use it to show that female can go for testing and they are always willing to come out but men do not easily accept... That is why you see the rate of suicide in men is very high in men. Once a man finds out he is positive goes straight with a rope and hangs himself in a tree...*
>
> *...May be to look at the picture and say why females are usually beaten by their boyfriends...I was just thinking of a campaign, educational campaign directed to males so that they are as accepting as females then the gospel spreads...*



*"Akakwamukeli ukuthi une HIV/AIDS. Ubona ukuthi azibulalae ngoba akathandi ukutshela abantu ukuthi une HIV".*
*He could not accept that he is HIV positive he decided to commit suicide because he does not want reveal to other people that is HIV positive.*

**Figure 5.7: Ltph014 from the Learning Together digital archive**

The participants also considered the possibility of using the digital archive to address the plight of females who are victimised when they reveal their status. Some participants thought of using photographs which show the extent of gender-based violence.



"*Akakwamukeli ukuthi une HIV ukhetha ukumshaya futhi ubona sengathi uyena omthelelile ubona sengathi ukumshaya kuzomenza athule ngoba akafuni abantu bazi. Intombazane izimisele ngokuthi basamukele lesi simo bese bet shela abanye*".
He could not accept that he is HIV positive he decided to beat the female to silence her because the girl is willing to reveal their HIV status.

**Figure 5.8: Ltph025 from the Learning Together digital archive**

> *…About picture number 25 where by a girl is beaten by male student because of her HIV positive status. The male is claiming that it is the female student that has brought the disease…*
>
> *…The second one, umh, is a pregnant, young pregnant female learner with the boy who is refusing paternity…*

And another participant thought:

> *…it's a question of just disclosing your status to someone you trust. In this situation, you find this guy in picture number 14 where you just hang himself or committing suicide because there was no one to talk to…*

A female participant suggested:

> *...I can advise [learners] that anyone can be HIV positive and transmit to other sexual partners. It does not have to be a male or a female...*

Often, females are the ones who bring HIV issues to the attention of their partners; they are the ones who get information about their HIV status, for example, in pre-natal cases (c.f. 2.2.3). They are also often blamed for bringing the disease into the relationship, or protect their partners (by carrying the blame) because they are dependent on them (Nyblade et al., 2003). Moreover, behaviour change strategies that are likely to be most effective in reducing the spread of HIV and AIDS, namely condom use and faithfulness to a single partner, are strategies which women do not have control over. This further exacerbates the stigma attached to women in that even if they would have condoms for protection they are labeled as sex seekers (Campbell, 2003). This highlights the importance, even more so in rural communities, of addressing gender issues which hinder effective prevention and treatment.

### 5.2.4.3 Bridging gender digital divide

The use of the digital archive enabled female participants who were apprehensive at the beginning about using technological tools, to address HIV-related stigma. Participants from school A initiated the idea of trying it out with their learners in the classroom while in school B, I suggested the idea of trying it out with learners, and asked who was willing to try it. A female participant said:

> *...Choose Me! Choose Me! I will do it!*
> *...I want to try it with my L.O learners, my Grade 10...*

The male participants were fascinated by the use of computers in the study:

> *…We did not know it [computers] pertained to us…we thought it was this 'women's stories' about HIV and AIDS…"*

This suggests that although men believe that a computer (technology) is 'their' (the

men's) tool, African women and girls are at particular risk of exclusion from information and communication technologies (Palitza, 2007) yet most HIV and AIDS programmes are initiated and run by women. Where HIV is concerned women will 'stand up first' irrespective of the strategy in use (UNAIDS, 2006). It is quite encouraging, however that this tool was able to draw males into participating and suggesting ways of addressing HIV and AIDS-related stigma using the digital archive. This also suggests that the digital archive has the potential to contribute to achieving the Millennium Development Goals (MDGs) 3 and 6, which focus on the empowerment of women on promotion of gender equality and combating HIV and AIDS (United Nations, 2006).

In spite of the challenges encountered and articulated by participants, the research has demonstrated that educators can use digital archives as a learning tool to address HIV-related stigma. Although the study shows the possibility of narrowing down the digital divide, there still exist some restrictions to accessing the interactive features of on-line information. This was encountered by the participants at first:

> *...In fact to select the picture we had difficult problem because we did not know what to use when we want to go back to check other picture/another picture...*
> *...and remember we were supposed to write our activities on the computer, but we ended up writing on the paper [with free hand]...*
> *...Maybe the problem is that we do not know how to write it on the computer?*

When they were reflecting on the whole research project and the possibility of future use, some cited the challenges of technological skills to access computers which are required to access the digital archive.

> *...is highly impossible to take all the learners and ask them to sit down and [use the computer] as some of them don't have a clue what the mouse is and how so you use the computer and as even other teachers can no...as teachers we don't have this...For future we should learn how to use a computer, that's important. It is hectic (laughing)...*

They also all agreed that access to the Internet and computers was not possible because

they have to ask for permission whenever they want to use it.

> *...And even in this computer room we are not allowed [by administration] to come here anytime...*

However, the administration cited problems like the need to restrict Internet access lest staff members use it for private purposes. The challenge faced by the school reminded me of a study by Sheena Bull on the incorporation of computer-based technology and the Internet in health promotion, especially HIV prevention. She concluded that the challenge is not only the acquisition of skills, but also the need to reduce the risk incurred by individuals actively seeking sex partners on-line, exacerbating the risk of STDs (Bull, 2008).

## 5.3 SYNTHESIS

While resource limitations and infrastructural gaps hamper both extensive ICT connectivity and significant scaling up of a comprehensive response to HIV and AIDS, South Africa has the human resources and initiatives necessary to enable an effective response to HIV and AIDS. South Africa has a growing base of personal computers, and mobile telephones and also incorporates ICT to educate, prevent, and treat the HIV and AIDS (Forman, 2003; Theron, 2002). ICT, which enabled the building of the digital archive, can play a substantial role in improving access to health services and primary health care in rural areas in public education campaigns to promote healthy behaviour in areas such as HIV and AIDS; to transfer diagnostic information to specialised centres; to strengthen the basis for decision making; to promote information exchange among researchers and students; and to enhance the effectiveness of health institutions (Peltzer, 2008). The Ministry of Education is trying to increase ICT access in schools, for instance, in 2002 16.6% of the schools in KwaZulu-Natal had computers although not all these schools had access to the Internet (DoE, 2003). President Jacob Zuma, in his response to questions following his State of the Nation Address stated that by 2012 each educator should have access to computers, laptops, and the Internet (Department of Education, 2009; SABC, 9 June 2009). Additionally, the Department of Health has initiated a Telemedicine pilot project aimed at developing a cost-effective e-health system in the country (Baskaran & Muchie, 2006). Such developments can

challenge the deficient framework many educators have in rural contexts, and develop a more positive orientation to the possibility of working in such contexts (Moletsane, 2009; Pennefather, 2008).

# CHAPTER SIX

## CONCLUSIONS, IMPLICATIONS AND RECOMMENDATIONS

*"We did not know it [computers] pertained to us… we thought it was this 'women's stories' about HIV and AIDS…"*
(Male participant)

## 6.1  INTRODUCTION

This study explored the use of a digital archive - consisting of photos of HIV and AIDS-related stigma taken by grade 8 and 9 learners - with educators in order to see in what ways they might be able to use the archive to address issues around HIV and AIDS-related stigma in two rural schools.  This chapter presents conclusions drawn from the main findings, implications, and recommendations.  In addition, limitations of the study are put forward and suggestions for further research provided.

When I first thought of using the digital archive with the stigma photographs I was touched that the photographs were taken by Grade 8 and 9 learners, expressing problems they saw in their community.  I was also struck by the fact that they had "done" the research as opposed to the "being done to"; they were what Mitchell and Smith (2003) refer to, as knowledge producers, rather than passive recipients of messages.  The study was based on taking back an electronic version of the stigma data, stigma being an issue identified by the school community who produced the photos, to the community. (i.e. a feature of a community-based participatory approach).  This study has adopted the *values of community psychology* in that HIV and AIDS and HIV and AIDS-related stigma find its cause in the whole ecosystem, and therefore the solution should be located in the whole *ecosystem,* hence beginning with educators.  A *psycho-social approach* highlights the central position of the individual within the immediate social and situational context and the influence the stigma ultimately has on the personal, social, affective, cognitive, and behavioural transactions.  Participants, while working with the digital archive, were 'hands-on' in this study and identified stigma as still being a problem, but which could be addressed by using a digital archive.  It must be noted that some of the values and

117

goals of community psychology are the promotion of health and wellbeing, caring and compassion, self-determination and participation, respect for diversity and human dignity, and social justice (Dalton *et al*., 2001; Visser, 2007). As such, addressing HIV-related stigma through the digital archive in a participatory way has the potential to influence the individual, the school, and the community.

## 6.2  CONCLUSIONS

The study has highlighted the use of the digital archive for not only storing, managing, retrieving, preserving, and analysing visual data, but also of extending its use to bring about social change. Themes that emerged from educators' discussions were: working with the content of the archive; using the archive for learning and teaching; using the archive for engaging with stigma in the school; and using the archive for change in the community.

Looking at the above findings through the lenses of psycho-social and ecosystemic approaches, it is seen that they emphasise addressing HIV-related stigma in an integrated manner (Donald et al., 2002). Interventions should also encompass bio-psychosocial understanding at all levels of the ecosystem. Lamming (2006) concurs that HIV is a biomedical issue which impacts on all spheres, that is, psychological functioning of the individual as well as the social environment, as is the case of HIV-related stigma. I reiterate that stigma should not be treated in isolation of HIV and AIDS. Education remains an effective strategy in the absence of a cure for the virus. A re-conceptualisation of both research and education as a process whereby participants become knowledge producers (Mitchell & Smith, 2003; Stuart, 2006), is required.

### 6.2.1 Working with the content of the archive

Regarding the first theme, working with the content of the digital archive, highlighted the archive as a useful tool in interpreting the visual data in the archive in new ways to increase awareness and stimulate dialogue among participants. The captions which accompanied the photographs were of importance as they could be used to further explore and deepen the understanding of HIV-related stigma. The participants suggested further coding and recoding by the school community to add more

information and richness to the metadata of the photographs. This emphasises the possibility of re-use of such an archive which contains local and relevant knowledge. Haour-Knipe's study (as cited in Moletsane et al., 2007) concurs and concludes that stigmatisation can be eliminated only when new understanding about HIV and AIDS-related stigma and new ways of taking action by individuals and groups, are in place. Of key importance here is the participant input, which makes the new knowledge, i.e. new metadata, relevant and appropriate.

## 6.2.2 Using the archive for learning and teaching

In relation to using the digital archive in the school community, it is natural that educators' discussions of using the digital archive revolved around it as a pedagogical tool. While the focus of transferring information on HIV-related stigma was not lost, educators suggested that using the digital archive was an interesting way of learning, possibly referring to the archive's ability to eliminate what Mitchell and Smith (2003) identified as a 'sick of AIDS' syndrome. The use of computer technology brings with it a sense of innovation and excitement, particularly so in a rural school community. The possibility of each learner engaging with the photos and captions either individually or in groups is important in providing spaces to initiate and sustain a dialogue for issues which are not easily discussed, that is, sexuality, HIV and AIDS and stigma (Pithouse & Mitchell, 2007). The principle of individualisation while working on a computer, opens up the possibility of each learner having the opportunity to make his or her voice heard.

What also became clear is that the digital archive was talking to their curriculum, that it could be integrated across the curriculum in an interactive and participatory way (DoE, 2002). Drawing on performance as a way of raising the issue of empathy, problem solving, and agency (Merril, 2007) is especially important in the African context. Furthermore, the digital archive can be a tool to facilitate skills development, firstly computer skills, but also problem solving skills, which are needed in modern South African society.

## 6.2.3 Using the archive for engaging with stigma in the school community

Stigma still prevails in the community to the extent that some people were not

comfortable about disclosing their HIV status, even within their immediate families. Participants showed awareness of the stigma that still exists in their community as well as its impact on individuals and groups. Therefore, the digital archive in use was seen as an important tool to break the silence among individuals, to project feelings and to encourage disclosure.

Furthermore, the educators considered it a resource to elicit learners' ideas for school policy development and as a reminder of existing policies, for example, the human rights policy. A sense of agency was promoted as educators themselves, through engagement with the archive, were moved to discuss the need for taking action. The need to thoroughly understand stigma before it can be dealt with constructively was highlighted, recognising the possibility of extending the 'message' in the archive to the wider community. Additionally, they suggested using the digital archive for transferring information about the availability of ARVs and the benefits of voluntary counselling and testing (VCT), which is not often emphasised (Hammil et al., 2006). Treating HIV as a medical condition that can be managed like all chronic diseases must be taught in the schools, and filtered through to the community. The educators also proposed raising awareness of HIV prevention, and how the stigma related to rape and pregnancy could increase the risk of contracting HIV. They saw the possibility of providing HIV-related stigma solutions which are relevant to their own community's problems.

### 6.2.4 Using the archive for change in the community

While the digital archive was explored with educators, it was apparent that the school is part of the wider community. They suggested the use of the archive for social change in the whole community. This included regenerating 'ubuntu', that is, personhood amongst individuals in the community. The need to eradicate stigma through support, trust, compassion and caring, was highlighted. The idea of addressing cultural norms and gender issues become important when considering stigma in a rural community. What was also clear was that the digital archive could help bridge the gender digital divide, since both males and females were attracted to the use of computers and the data projector to access the digital archive.

## 6.3 IMPLICATIONS OF THE STUDY

It is clear that HIV-related stigma lies at the intersection of individual, family, school, community, and society. Therefore, one cannot sufficiently emphasise the potential that the digital archive has for challenging stigma at the level of individuals, families, schools wider communities, and also society. The fact that the digital archive gives individuals the opportunity to engage with the issue of HIV-related stigma, and interact with other people in trying to challenge existing policy and cultural norms, should be recognised. The findings also suggest that there are several opportunities to learn from the content of the digital archive and that it forms part of education in as far as HIV prevention is concerned. The archive does not only provide a pedagogic strategy but also opportunities to unearth what the learners want, and what they know, by contributing knowledge on HIV-related stigma. This implies that it provides creative ways of learning, from the school level to the wider community.

From the research findings the study implies that:

There are possibilities of interpreting the visual data in the archive in new ways, by engaging with captions and further re-using it. The combination of image, sound, and text can bridge the literacy divide (Waller, 2006) and provide access to the visual information. Literacy in its essence means more than to read and write and can be enhanced by the use of ICT, as in the case of this study, by a digital archive. People have the potential to interpret visual data in their own way (Emmison, 2004; Pithouse & Mitchell, 2007) which also bridges the literacy divide, by using their own language to interpret data and to discuss the issue of stigma. The findings also imply that visual and arts-based approaches through the use of ICT which are participatory provide opportunities to learn more about participants' experiences and viewpoints. In a rural area, such ICT, if it is available, can open up the possibility to access global information.

The use of the digital archive with visual data can promote fundamental improvements in teaching and learning. Creative, interactive and contextually appropriate messages can enhance the teaching and learning process. Also, the digital archive can serve as a focal point for shared discussions and assist learners to develop their ideas in a socially

mediated context. Messages and materials developed together with the learners can be used to address HIV-related stigma in the school and stored for ready access on demand. This implies that there may be more work to do like photography, drawings, and moving images to address HIV-related stigma individually and with small groups. These could include opportunities to debate, role play, skills development, and independent learning in the school. ICTs also provides the opportunity for one-to-one interactions between the digital archive on the computer and the individual, which could enable an individual to think differently about HIV and AIDS-related stigma and change his/her behaviour on a deep and meaningful level. Of importance is that the learner has to respond to the archive, and therefore has to think for him or herself. Therefore, using the digital archive as an educational tool can improve coping skills and facilitate a psychological and social shift in responding to the issues of stigma.

The digital archive shows potential for enabling communication which can facilitate engaging with stigma in the school. It can address the issue of HIV-related stigma by breaking the silence, allowing for the projection of feelings, providing a sense of agency, and also contributing to policy change. There is also a possibility of deepening the understanding of stigma and reaching the community through the use of the digital archive. Creation and transferring of relevant messages to deal with stigma could be effected using the archive. This implies that stigmatised issues related to HIV such as rape and pregnancy which increases the risk of contracting HIV, could be discussed.

This study is neither intervention nor critical research but the interpretation of the participants' views implies that using a digital archive could bring about social change in the community. The research raises the issue of the regeneration of 'ubuntu', to eradicate stigma through support, trust, compassion, and caring (Mkhize, 2004). Opportunities exist for the consideration of cultural norms, gender issues, and also using the digital archive to bridge the gender digital divide, and in doing so, contributing to social change.

## 6.4 RECOMMENDATIONS

The HIV and AIDS issues make one obligated to do things in a different way, as it affects everyone. All the layers of the ecosystem consist of individuals and individuals

exist as a collective, therefore individuals must be targeted. Considering that the individual is at the centre of stigmatisation, strategies must begin at the individual level within the community. The idea of recognising the ongoing interaction between an individual in his/her context and recognising the potential the individual possesses in identifying problems and providing solutions in his own context, is necessary.

There is no doubt that the school is an organisation within a wider context. In this regard educators are protagonists addressing social, health and welfare issues, not only of their learners but of the wider community as observed by Olivier et al. (2007). Therefore educators need to find creative, innovative, and participatory approaches to address such issues, including HIV and AIDS and the problems associated with the disease (Wood, 2008). This shows the relevance of a community-based participatory research approach which has been described as research which benefits a community with the intention of social change. It recognises the unique strengths which each participant brings.

The educators themselves had a number of suggestions about using the digital archive, additionally, the following recommendations are made to address and improve the use of digital archives in addressing HIV-related stigma (See Table 5.1).

## 6.4.1 Working with content of the archive

It emerged from the study that the content of the archive was useful for interpreting the visual data in new and different ways, and engaging with the captions. Therefore, the archive and visual data could be made available to both individuals and groups in schools to use and interpret in their own way to challenge their knowledge, beliefs and attitudes. There could be a relationship between avoidance of talking about HIV and AIDS and literacy (Peltzer et al., 2004), which means a person can look at the visual data in the archive, apply it to his own real life situation, weigh up the evidence, and choose a path to follow in terms of matters of health, including HIV-related stigma. Accessing the visual data and talking about it in your own language, can help in acquiring information to generate HIV-related stigma solutions.

Educators should therefore have access to educational materials, in this case, the digital

archive with the visual data set, and it should be at their disposal to use anytime when needed. School libraries should keep relevant resource material to address HIV and AIDS-related stigma to deepen understanding and the effect it can have on an individual, a school and the entire community.

## 6.4.2 Using the archive for learning and teaching

The following recommendations are based on pedagogic strategy, interesting ways of learning and developing skills as it emerged from the findings.

### *Pedagogic strategy*

Educators focused on using the tool in the classroom as a pedagogic strategy, and therefore the following recommendations can be useful to educators who are doing 'something' about HIV. There is value in broadening the palette of approaches for educators to address HIV and the repercussions thereof. In this connection, the study advocates that educators explore different ways of addressing HIV-related stigma, including technology-enhanced ways.

What emerged is that there is a need for educators who are skilled, well-informed, and sensitive towards HIV and AIDS and its links to social and cultural influences. Most of the educators themselves have not received training to contribute to the understanding their own perspectives and positions to address HIV and AIDS (De Lange & Stuart, 2008). Initiatives to prepare educators more adequately must be put in place (Higher Education in South Africa, 2006) by the Department of Education and also draw on ICT activities which can be helpful in this regard. Educators in schools in the same area can cluster together and invite skilled people in the use of visual and art-based participatory methods to workshop them on the use, firstly exploring their own positions as well as using innovative teaching strategies for HIV and AIDS prevention and education with their learners.

There is also a need for all educators as professionals working in the field of HIV and AIDS to draw on an interdisciplinary approach. HIV is a health issue taking place in social context, hence the need for all educators to have insight into ethics and sensitivity towards topics related to HIV to avoid further stigmatising. An example could be that

an educator who draws from the values of community psychology would be able to deal with issues of HIV with care, respect for diversity, human dignity, and social justice. Educators need an ongoing in-service training as far as the HIV pandemic is concerned.

There should be a reconceptualisation of both the education and research process acknowledging participants' inputs, rights and responsibilities. A participatory model is recommended as it shows the potential for engaging the participants more deeply (Banks, 2001). Just as the participating educators were involved, learners in the classroom should be encouraged to engage in dialogue, something which the digital archive makes possible.

The idea of using the digital archive containing HIV-related stigma photographs across all learning areas (other than life orientation) as suggested by the educators, should be encouraged. Such examples are found in mathematics education with scholars like Van Laren (2007), as outlined in her paper "*Using metaphors for integrating HIV/AIDS education*". Similarly, in history education the importance of the social issues that shape history (Eley, 2008), can be dealt with, including innovations on medicine and developments in curing of diseases. Historians being pioneers in archiving could assist in storing history on how the pandemic unfolded, hence making relevant content available in schools. HIV and AIDS is constantly changing and evolving; the disease never stops mutating, the social factors that affect HIV and AIDS are always transforming, and the stigma that people living with HIV face is continuously taking on new shapes and forms (Raht et al., 2009). It is therefore crucial that responses to HIV and AIDS are relevant to the needs of those affected.

### *Interesting ways of learning*
The findings revealed that the educators regarded the archive as a tool which holds potential for interesting ways of learning.

#### *Independent/individual learning*
The digital archive shows the potential for allowing an individual to gain problem-solving skills, learn to make informed choices, and acquire reliable and adequate information which would facilitate discussion (Hayes, 2006), but in a safe space. This supports the argument that it should be made available by the school. Educators could

offer more opportunities for individual learning by designing activities which require independent learning.

*Opening space for debates*

There is opportunity for the digital archive to open debate; a method of learning which is participatory and interactive. Educators could encourage debates on the issues of HIV-related stigma raised by the content in the archive. Debating societies/clubs in the school could be a space for such discussion.

*Opportunities for role play*

Drawing on the use of the digital archive educators could encourage participatory learning, like role-playing, with learners drawing on the content of the archive to write and play [role play] about issues and solutions to the problems presented by the content. Merril (2007) asserts that role playing has the potential of learning by doing.

### Developing skills

Educators could facilitate the process of access and providing skills for developing solutions. Learners could also be encouraged to develop computer skills. This means educators themselves should be computer literate. I also concur with Peltzer (2008) who suggest that HIV prevention projects have to increase technology in schools throughout the developing world. He highlights the high rate of HIV infection among the youth in sub-Saharan Africa. He further argues that technology gives opportunity to build children's coping capacities and self confidence, foster sound decision making, as help them deal with negative attitudes towards those who are infected.

### 6.4.3 Using the archive for engaging with stigma in the school

Under this theme several categories emerged including breaking silence, projection of feelings, contributing to policy development, and also sense of agency in the classroom and reaching out to community. As alluded to before, the archive offers not only the potential for innovative teaching and skills development, but through it, the opportunity to address the stigma.

*Breaking silence*

On the basis of the findings the school is fundamental in addressing HIV-related stigma. The digital archive could be available and the content shared by the whole school. Supporting and encouraging creative arts-based approaches which are ICT-based for education and HIV and AIDS prevention are viewed as key by global organisations such as UNESCO (Centre Pompidou, 2007), in breaking the silence around HIV and AIDS and thereby reducing stigma.

*Projection of feelings*

The use of the digital archive also has the potential to stimulate learning and reflection rather than continuing simple didactic transmission of information, creating space for the projection of feelings. Therefore a school should set up an HIV and AIDS support committee, foregrounding the need for learners to learn and change their beliefs about HIV and AIDS. The committee should be responsible for providing access to the archive, and assess and ensure that the needs of the learners are met, whether individually or as small groups.

*Contributing to policy development*

At structural level strategies may include legislative lobbying, civil lobbying, and human rights activism as it transpires that policies need to be reviewed and be in place in all structures, including the school as an organisation. The school should engage in relevant, contextualized, forward-looking policies to provide a safe environment and structured support to all learners (Buthelezi, 2008). Collaborative work amongst the department of health, social welfare, and education is encouraged and can be done at grassroots level as experienced in the "Learning Together" project (De Lange, et al., 2003), where educators work together with community health workers. I agree and suggest however, that focused applications of ICTs could help inform (Wang, 1999) appropriate policies that empower intermediary groups such as community institutions, health care providers, and those working with the poor and vulnerable groups. Formal institutions such as schools need to increase knowledge of workers in the field through access to the Internet and other easy access technologies. Knowledge dissemination must be from broad structures and it is important that the work done at community levels reaches the policy makers.

*Sense of agency in the classroom and reaching out to the community*

Information contained in the archive should not be restricted to classroom context only but could be extended to the entire community in an effort to address HIV-related stigma. The context-based content should be shared by the school and ultimately reach the community. In this regard, partnerships with social and health services, and community organisations could be explored (Phaswana-Mafuywa & Peltzer, 2006). In Rwanda TRACnet (TRACNET, 2008) was established and implemented by TRAC (Treatment and Research AIDS Centre); an institution working under the aegis of the Ministry of Health of Rwanda in 2005. It is a dynamic information technology system designed to collect, store, retrieve, display, and disseminate critical programme information, as well as manage drug distribution and patient information related to the care and treatment of HIV and AIDS (Pambazuka, 2007; TRACNET, 2008). Similarly, a wide range of visual technologies is used to provide health information to communities in South Africa (Baskaran, Muchie, & Maharajh, 2006; Peltzer, 2008). A digital archive with visual data shows potential for transferring information on HIV, addressing HIV-related stigma, testing, availability of ARVs, and also other relevant issues to rural communities. Therefore using health centres, the content in the digital archive could reach the community, and be showed as slides while people are waiting for service. This could be educative and trigger dialogue on HIV-related stigma.

*Raising awareness*

Educators are expected to provide education towards HIV prevention, HIV and pregnancy, HIV-related stigma and rape, and also sensitise learners to solutions. There is a need for stigma reduction programmes, strategies and policies which are generated towards increasing knowledge on HIV transmission, promoting safety awareness, stressing risk sensitisation, anti-discriminatory behaviour and a sense of individual responsibility towards HIV infected and affected people (Buthelezi, 2008; De Lange & Stuart, 2008). Strategies must address real context issues which may include illiteracy and cultural norms which often result in stigmatisation due to myths about the spread of the virus, gender-based violence, and must involve the whole community.

### 6.4.4 Using archive for change in the community

The following inferences are made with regard to regenerating 'ubuntu', revisiting

cultural norms, and bridging gender digital divide.

## *Regenerating 'Ubuntu'*

Photo collections, collages and drawings trigger memory by simultaneously engaging the senses, emotions, and intellect (Weber & Mitchell, 2004). Working with the data set in the digital archive exemplifies this. Empathy can be developed with the existing data- set to influence other people. The attitudes of educators and parents towards HIV-related stigma ought to reflect compassion and empathy so that learners can adopt a similar attitude of taking care of each other (Ansell & Young, 2004).

## *Revisiting cultural norms*

Cultural beliefs also impede HIV prevention strategies and exacerbate stigma (Kalichman & Simbayi, 2004; Kalichman et al., 2005). Pekarsky (2009) suggests 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). Penelope (1990) in her book entitled *'Speaking freely: Unlearning the lies of the fathers' tongues'* argues that in every culture there are conversational rules governing who can speak certain kinds of words. The use of visuals can overcome the language and cultural barriers, engage learners with visuals in a participatory way, and so open up talking about culture in relation to HIV and AIDS. Vygotsky (1978) argues that culture can be challenged and changed as new things are discovered.

## *Stigma and Gender*

HIV and AIDS strategies need to address the real contextual issues which affect communities. Central to this is gender-based violence linked to gender inequalities which are often rooted in community norms of sexuality, female and male roles and responsibilities, and acceptance of such doings (Duvvury et al., 2006; Wechsberg, Parry, & Jewkes, 2008). Studies show that stigma and gender-based prejudices has implications for the spread of HIV and also impedes HIV prevention programmes (Duvvury, et al., 2006; Nyblade et al., 2003; Ogden & Nyblade, 2005). Local people must be seen as the 'experts' in their own realities and the protagonists of sustainable change. Chege (2006) further draws attention to teacher's gendered identities in schools settings and this should also be addressed.

*Bridging gender digital divide*

HIV and AIDS is viewed as an obstacle to attaining the Education for All (EFA) and the Millennium Development Goals (MDGs) by 2015 (UNESCO, 2009; United Nations, 2008). If educators are to be instrumental in achieving the EFA and the MDGs which include addressing HIV and AIDS in schools as well as addressing gender inequality, the use of a digital archive should be encouraged. Both female and males should be encouraged to become agents of change and females in particular to participate in ICT-based interventions.

## 6.5 DISSEMINATION OF THE RESEARCH

While this research is meant to fulfill the requirements for a Master in Education degree and addresses HIV-related stigma in a rural community using a digital archive, the findings need to be disseminated in the community. I will take the following steps to disseminate the findings:

- The school will receive a copy of the research report in line with the CBPR approach adopted in this research.
- Articles will be submitted to appropriate journals for publication.
- Findings will be presented at local and international conferences.
- A parents' meeting will be held (suggested by the participants) allowing the educators to present the digital archive as a means to open up debate in the community.

## 6.6 SUGGESTIONS FOR FURTHER RESEARCH

- This work is exploratory; educators from two rural schools participated in this study. The digital archive with dataset was used to explore how HIV-related stigma could be addressed. This research could be replicated in other rural and urban contexts.
- The study was specifically aimed at educators and it would be significant to do a study with other groups such as the:
  - original participants on how they can contribute to re-coding the visual data in the archive,

       o  researchers on how they can re-use and work with the digital archive,

       o  community health workers for a more comprehensive picture of stigma that exists in the in the community,

       o  parents on their views about the messages which were created by their children in the earlier research,

       o  learners who took the photographs, to explore in what ways the photo voice activity made a difference.

- It could also be interesting to conduct a study with individual learners to work with a digital archive, and how they can contribute to the coding and recoding of photographs.

- Since issues of gender and HIV emerged, there is also room to research gender and HIV-related stigma as portrayed in the dataset, linking it to the gender digital divide because it is it true that ICT plays a major part in HIV intervention strategies, yet most women and girls are still not empowered to access it (Dralega, 2007; Forman, 2004). Females are protagonists in the fight against HIV and AIDS and most intervention strategies are designed and implemented by them (UNAIDS, 2006).

- Ethical issues of using photographs and the constructed nature of photographs can be explored. This study has opened up possibilities for research using the digital archive as a computer-based tool with pre-existing visual data, more specifically for novice researchers to minimise complications on issues of ethics.

## 6.7  LIMITATIONS OF THE STUDY

I make no claim that the themes which emerged are exhaustive and therefore acknowledge limitations linked to sample size, time constrains, and computer literacy.

- The study is limited to fourteen members from two senior secondary schools in a rural district of KwaZulu-Natal.

-  A certain level of computer literacy was required by the educators to use the digital archive and develop their activities. As a result some educators could not design their lessons using the computers.

- Time constrains posed a challenge, as the participants highlighted on several occasions that they needed more time to engage with the archive. They had

busy schedules and could not spend more time working on the project. Being in a rural area required them to travel long distances to and from the school.

## 6.8 SYNTHESIS

The research has revealed that the use of the digital archive has potential for agency, is a powerful form of communication, and provides opportunity to think forward in addressing HIV-related stigma. In making a case for the use of a digital archive in the two rural schools, I believe it holds the potential to contribute to 'saving lives' the same way as ARVs do, through bringing much needed information to rural communities. The findings suggest the use of ICTs can enable people to share digital material, and access locally relevant and realistic, individually tailored, information, to contribute to diminishing the stigma of HIV and AIDS in rural communities. Visual and arts-based approaches are participatory and provide opportunities to learn more about participants' experiences and viewpoints. The digital archive through technologies can facilitate community participation in the production of further local knowledge and perspectives. Literacy and access continue to be a barrier to effective use of such sophisticated technologies. At the same time, I make no claim that the identified themes are exhaustive. I want to foreground that in an ever changing technological environment, we can look forward to the possibility of making ICT impact significantly on HIV-related stigma in years to come. Thabo Mbeki, former President of South Africa noted the importance of ICTs and commented that South Africa must continue to fight for the liberation against not only poverty, underdevelopment and marginalization, but for information and communication technologies which are critically important tools in the struggle (Department of Education, 2003). However, I concur with Muchie and Baskaran (2006) that technology is not an object to be aimed at, limited to specific areas, but a tool to be used for the benefit of all and in this case, to benefit people living with and stigmatised by HIV, also in rural schools. This study was merely a beginning towards exploring the use of ICT in addressing HIV-related stigma.

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# APPENDIX A: Letter of consent – Principals

**UNIVERSITY OF KWAZULU-NATAL**

**PERMISSION TO DO RESEARCH IN DOE SCHOOLS**

We wish to request permission to undertake our project *"Digitizing Data: Giving life (to data) to save lives (in the age of AIDS)* in your school.   In this project we are exploring the digitizing of visual data and are trying to gain a deeper understanding of how teachers might use the visual data in a teaching and learning context in addressing issues around HIV/AIDS.   Your school's participation is voluntary and you will be allowed to withdraw without any disadvantage.

The project runs from 2008-2011 and will entail contact sessions between the researchers and the participating teachers.   Consent will also be gained from the participating teachers. The venue for the contact sessions will be at your school and each contact session will continue for approximately an hour and a half, after school.    At the end of the project we provide feedback to your school and also ascertain ways in which we as researchers can further assist your school.

Anonymity and confidentiality will be ensured as no names of persons will be revealed, unless negotiated with them. The data from the focus group interviews will be securely stored in the Centre for Visual Methodologies and will be destroyed after five years.   The data will only be used for research purposes.

We would appreciate your permission to undertake this research in the above-mentioned schools, as we believe the participatory nature could engender a sense of agency in the teachers and their community.

Kindly yours

..............................
Naydene de Lange (Project Leader)     031-2601342
Thoko Mnisi (M Ed Student) 0844001137

Prof Claudia Mitchell, Prof Relebohile Moletsane, Dr Thabisile Buthelezi,  Dr Jean Stuart and Prof Myra Taylor  (University of KwaZulu-Natal in collaboration with Caprisa)

# APPENDIX B: Letter of consent - Participants



**UNIVERSITY OF KWAZULU-NATAL**

### INFORMED CONSENT

Dear Participant

We wish to invite you to participate in our project, *"Digitizing Data: Giving Life (to data) to save lives (in the age of AIDS"* which is an extension of the "Learning Together Project" in which you participated. In this project we are exploring the digitizing of visual data and are trying to gain a deeper understanding of how teachers might use the visual data in a teaching and learning context in addressing issues around HIV/AIDS. Your participation is voluntary and you will be allowed to withdraw without any disadvantage.

The project runs from 2008-2011 and will entail contact sessions between the researchers and the participating teachers. Consent will also be gained from the participating teachers. The venue for the contact sessions will be at your school and each contact session will continue for approximately an hour, after school. At the end of the project we provide feedback to your school and also ascertain ways in which we as researchers can further assist your school.

Anonymity and confidentiality will be ensured as no names of persons will be revealed, unless negotiated with them. The data from the focus group interviews will be securely stored in the Centre for Visual Methodologies and will be destroyed after five years. The data will only be used for research purposes.

We believe the participatory nature could engender a sense of agency in the teachers and their community

Your participation will be appreciated.

Kindly yours

……………………………
Naydene oe Lange (Project Leader)     031-2601342
Thoko Mnisi (M Ed student) 0844001137

Prof Claudia Mitchell, Prof Relebohile Moletsane, Dr Thabisile Buthelezi, Dr Jean Stuart and Dr Myra Taylor (University of KwaZulu-Natal in collaboration with Caprisa)

162

# APPENDIX C: Ethical clearance

UNIVERSITY OF
**KWAZULU-NATAL**

RESEARCH OFFICE (GOVAN MBEKI CENTRE)
WESTVILLE CAMPUS
TELEPHONE NO.: 031 – 2603587
EMAIL   : ximbap@ukzn.ac.za

5 NOVEMBER 2008

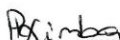PROF. N DE LANGE  (1626)
EDUCATION STUDIES

Dear Prof. de Lange

<u>ETHICAL CLEARANCE APPROVAL NUMBER:  HSS/0586/08</u>

I wish to confirm that ethical clearance has been approved for the following project:

*"Digitizing data:  How can we give life (to data) to save life (in the age of HIV and AIDS)?"*

PLEASE NOTE: Research data should be securely stored in the school/department for a period of 5 years

Yours faithfully

MS. PHUMELELE  XIMBA

# APPENDIX D: ICT-BASED FOCUS GROUP INTERVIEW GUIDE

**Session 1**

Greet participants and give them a background of the Learning Together Project. Ask how many of them had participated in the Learning Together Project. Then take them through the consent form for the project and ask them to sign if they were willing to take part.

Take them through the data set on the digital archive. Then let them explore the archive on their own.

The question:

- Having looked at that the whole collection, suggest how you can make use of the digital archive - the data set of staged HIV stigma photographs in an attempt to address HIV and HIV stigma.
- How can you use this collection together with a laptop and a data projector with your learners to help them understand issues around HIV and stigma?
- Will this be of any use to you? Will it empower, enrich, will it enable you to get into this discussion of HIV/ AIDS and stigma?

**Session 2**

The question:

Go over the whole collection using in the digital archive and select two photographs to design activities which would engage your learners in discussing issues around HIV stigma.

- Could each one of you now to say something about your designed activity? Why you chose that photograph? With which learners are you going to try it out with? What is the main aim for designing this activity?
- How did you find the whole exercise?

**Session 3**

Technical support as per educator's need

**Session 4**

After looking at the video recording the following question was asked:

- Commenting on how the digital archive has been used by this educator, what would you have done differently that you could have done?

Picture 025 - A girl beaten by a male student because of her HIV positive status, the male learner is claiming that it is the female learner that has brought the disease.

Educator activity

The lesson should be around the topic of ABC (Abstain, Be faithful or Condomise). Learners can be shown the picture and told that anyone who practice unsafe sex can be in a risk of HIV/AIDS. The best thing to use is the ABC approach to life. That females can choose to enter in relationships sexually at their own risk and be able to bear with the consequeases thereafter.

In conclusion, I can advise that anyone can be HIV positive and transmit the disease to other sexual partners. It does not have to be a male or a female. Everyone has to be tested so as to get treatment (ARVs) as early as possible.

Learner activity

Learners may look at the picture and say why are females usually beaten by their boy-friends. The answer may be around unfaithfulness. Then they can do a debate, whether it is correct for male learners to beat the females. Another debatable question in groups may be whether it is good to get tested for HIV or not.

**SAMPLE TRANSCRIBED DATA**

**INT:** Having Looked at the whole collection, suggest how you can make use of the digital archive with the dataset of staged HIV stigma photographs in addressing HIV stigma in you r classroom?...Mh..How can you use this collection together with a laptop and a data projector with your learners to help them understand issues around HIV and stigma?

**FG (1):** The ones that have eh...what did you call it ?

**INT** and **FG**:  Captions.

**FG (1):** Yes captions I like that because it has something that can open…open up some discussions, let them say what do they…Like the one the learner wrote that, I took this picture because this girl is HIV positive and the friends are running away.  I can project it; let them read the captions make them critique it, that is, is that the way people who are HIV positive should be treated?

**FG (3):** I have been thinking about the picture where the community is ill-treating the boy that learners can be reminded of human rights.  That even if a person is HIV negative or positive he has right to life.

**FG (1):** I am just thinking although I do not know how, but I am thinking of a possibility of using the whole collection. Especially because it concerns their school, they can give their views in trying to come out with an HIV and AIDS policy.  As we develop such a policy we try to project the photos allow them to talk about. Let them talk so that you can get some ideas or topic that they would like to include in the policy, get it from them.

**FG (2):** You remind me of something, I can use it for my Life Orientation class. When I want to teach about HIV, I can allow them to talk about the collection, take one picture and talk and just talk about this issue of HIV and anything you can say. Then they come

up with some ideas on the HIV stigma. Because even in subject you can use those pictures, because those pictures talk, they talk anything you want them talk.

**FG (1):** This photo means that there were no more children at school because of HIV. This one means that if things continue like, the classes will be empty because of HIV. In this picture we can see that learners are no longer able to attend classes because of the disease kodwa zathi zihamba zawashiya zabe zesiwabulalile amafasitelo namadesk. *(but they left desks and windows broken, before they left they had made damage in the classroom already)* translated from isiZulu. (*Participants laugh*). Kodwa ayosala anjena amaklilasi uma lingatholakali ikhambi. (*But on a serious note, classes will remain like this if the HIV cure is not discovered*). Translated from isiZulu.

**FG (3):** Can I add on that picture, I think I can bring to their attention that there are anti-retroviral now available so there is no need to wait until the classes are empty while there are ARV.

**INT:** How would you do that?

**FG (3):** I can inform the learners that there is the treatment that prolongs HIV because many people are dying because they lack the knowledge. Then they can even spread the news at their homes that people must come out and get tested so that they get the treatment sat the right time before we see empty classes. People should not be afraid to go and get the treatment.

**FG (2):** You know I remember this project since 2005, when we involved in this project. I could think when a person comes to me and tell me about his status because you see I couldn't imagine a person doing that. I don't know what I could have done during those years but now I sit with them and talk about it without any problem. I think this project has made some difference. Like now, I am thinking that most of the people who come to me as a pastor would females. I don't know whether it affects females the most or it is the females who prefer to talk about it. They would come and talk to me but they will say do not tell any other person. On rare occasions it would be men and they would say I should not tell their wives. Everyone is still afraid to confide their status to many people but I can use it to show that female can go for testing and they are

always willing to come out but men do not easily accept. That is why you see the rate of suicide in men is very high in men. Once a man finds out he is positive goes straight with a rope and hangs himself in a tree.