

**THE THOKOZANI SUPPORT GROUP'S CONTRIBUTION TO COMMUNITY
LEARNING: FIVE LIFE HISTORIES AROUND A CASE.**

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This thesis is submitted in fulfilment of the academic requirements for the Degree of
Master of Education, in the Faculty of Education, University of KwaZulu-Natal.

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DECLARATION

I declare that this thesis is my own unaided work. It is being submitted for the degree of Master of Education in the University of KwaZulu-Natal, Pietermaritzburg. It has not been submitted previously for any degree or examination at any other university, nor has it been prepared with any help, assistance or support of any other body, organisation or person outside the University of KwaZulu-Natal.

Suhana Jacobs

January 2006

Note to readers:

The data in this thesis contains sensitive personal information about people living with AIDS in Richmond. One of the greatest challenges faced in this research process was the issue of ethical considerations. Although still a grey area, many researchers prefer to shield the identities of vulnerable people. However, the dilemma I encountered was the insistence of the participants that their identities be known. They believed the information they were sharing with the University of KwaZulu-Natal would be of benefit to society and they were therefore proud to be acknowledged and recognised. Sadly, however, I had to confront the fact, that once in the public domain, I have no control over this information, thereby exposing some of the participants to potential harm. I eventually decided to replace the names of those both infected and affected by the disease, with pseudonyms.¹

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ABSTRACT

The generation and preservation of community knowledge have emerged as key factors in how rural communities deal with the consequences and ramifications of HIV/AIDS. Community-Based Organisations (CBOs) are responding to the disease and have a significant role to play in strengthening community education.

The Thokozani Support Group is a community-based organisation (CBO) operating in Richmond, KwaZulu-Natal, a rural town that was once the backdrop of a bitter and bloody political war. The town is now characterised by high levels of unemployment, widespread poverty and a spiralling HIV/AIDS epidemic. Many of Thokozani's members are people living with AIDS and they undertake volunteer community work involving outreach and education as well as home-based care.

This research takes the form of a case study with its focus on the Thokozani Support Group's contribution to community learning. Anchored in a qualitative paradigm, the case study is bimodal in that it utilises both the life history and photovoice methodologies.

The data, gathered from semi-structured in-depth interviews as well as participant interpretations of photovoice material, is approached and examined against the conceptual framework of community learning theories as espoused by Foley (1999) and Wenger (1998), and, in particular, examines issues and concepts including communities of practice, learning in social action, informal, non-formal and incidental learning.

The research outcome provides a detailed understanding of how the Thokozani Support Group contributes to community learning in Richmond, which feeds into the broader discourse on the role and challenges faced by rural CBOs responding to the HIV/AIDS epidemic.

Dedication

I dedicate this study to the members of the Thokozani Support Group who are making a difference against the greatest of odds.

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- My husband, Riquadeu Jacobs, for always making things possible in my life. I thank you from the bottom of my heart.

LIST OF ABBREVIATIONS:

A.C.O.R.D: Agency for Co-operation and Research in Development

ANC : African National Congress

AIDS : Acquired Immune Deficiency Syndrome

CBO : Community-based organisation

CBPWP: Community-based public works programme

CDC: CD 4 count. Medical test to evaluate the immune system.

COP : Communities of practice

CSO : Civil society organisation

Fahamu: NGO supporting the struggle for human rights in Africa.

FBO : Faith-based organisation

HIVAN: Centre for HIV/AIDS Networking

HIV : Human Immunodeficiency Virus

HSRC : Human Science Research Council

Idasa : Institute for Democracy in South Africa

| | | |
|---------|---|---|
| IFP | : | Inkatha Freedom Party |
| MAP | : | Monitoring the AIDS Pandemic |
| NAPWA: | | National Association of People Living with AIDS |
| NGO | : | Non-governmental organisation |
| NPO | : | Non-profit organisation |
| NRF | : | National Research Foundation |
| PAAU | : | Provincial AIDS Action Unit |
| PLWHAs: | | People living with AIDS |
| PWAs | : | People with AIDS |
| ROP | : | Regional Orphans' Programme |
| SADC | : | South African Development Community |
| SAHRC: | | South African Human Rights Commission |
| SARPN: | | South African Regional Poverty Network |
| SDU: | | Self Defence Unit |
| STD: | | Sexually transmitted disease |

- TB: Tuberculosis
- TRC: Truth and Reconciliation Commission
- UDM: United Democratic Movement
- UNISA: University of South Africa
- VCT: Voluntary counselling and testing

GLOSSARY

| | | |
|-------------|---|----------------------|
| Amagwinya | : | vetkoeke |
| Amakhosi | : | traditional leader |
| Babulewe | : | killed |
| Imbuya | : | edible herb |
| Imihosha | : | river valley |
| Induna | : | manager |
| Inyangas | : | traditional healers |
| Maas | : | sour milk |
| Madumbes | : | yams |
| Ukuthakatha | : | witchcraft |
| Umuthi | : | traditional medicine |

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Chapter One - Introduction

1.1 Focus of research

Focusing on the Thokozani Support Group, which is a Community Based Organisation (CBO) consisting of People Living With AIDS (PLWAs) in Richmond, this thesis seeks to illuminate the organisation's ability to contribute to community learning. Thus the study will probe not only issues pertaining to organisational structure and capacity, but also the concept of knowledge - environmental factors associated with its dissemination, how it is generated, shaped, as well as barriers to its dissemination.

1.2 Key question

1.2.1 How has the Thokozani Support Group contributed to community learning?

1.2.2 Sub questions

- 1.2.2.1 What is the context of community learning in which the Thokozani Support Group operates?
- 1.2.2.2 What forms of community learning does the Thokozani Support Group engage in?
- 1.2.2.3 What and how do the Thokozani Support Group participants learn?
- 1.2.2.4 How does the community respond to the Thokozani Support Group's community learning programmes?
- 1.2.2.5 What challenges confront the Thokozani Support Group regarding community learning?

1.3 Background

1.3.1 HIV/AIDS and the Emergence of CBOs

Sub-Saharan Africa, particularly the province of KwaZulu-Natal in South Africa, is facing one of the worst scourges of the HIV/AIDS epidemic globally (Jennings and Solomon, 2002). The proliferation of CBOs (Kraak, 2001) in response to the challenges created by this epidemic indicates a substantial delivery and response breakdown between government and non-urban communities that have been isolated by their rurality, prejudiced by their poverty and battered by the epidemic.

In the absence of a comprehensive health, education and social security infrastructure that can cope with the heavy burden of the growing epidemic (Interfund, 2003), CBOs have emerged as a final-level response to the most immediate and dire needs created by HIV/AIDS and the factors that feed the social challenges created in the epidemic's wake. *(See Chapter Two for a comprehensive definition of terminology pertaining to the voluntary sector.)*

1.3.2 Richmond

Richmond is a small town 35 kilometres south of Pietermaritzburg, KwaZulu-Natal. With its history of political violence and relatively high levels of poverty (Richmond Community Profile, 2001), the Richmond context provides the Thokozani Support Group with the ever increasing challenge of intervening and responding to the difficulties created by the epidemic.

1.3.3 The Thokozani Support Group

Although the group works closely with the local clinic structure, at the time writing, it was not a registered organisation and had no formal source of funding. The group was established in June 2001 by PLWAs, and according to the Regional Orphans' Programme (ROP) report (2001), it is the only locally-based organisation providing support to people infected and affected by HIV/AIDS in the area of Richmond.

1.3.4 Factors Influencing the Study

The direction of this study was influenced by my involvement with the National Research Foundation (NRF) funded study being undertaken by both the University of KwaZulu-Natal's Centre for Adult Education of the School of Education, Development and Training and the university's school of Psychology. This study was aimed at mapping barriers to learning in Richmond. The NRF project revealed the existence of the Thokozani Support Group.

1.4 Rationale for Study

The purpose of undertaking this study was to provide a window into community-based responses to HIV/AIDS in the rural community of Richmond, particularly within the framework of community education. The study will assist in the co-ordination and planning of HIV/AIDS interventions in Richmond at a community level. It will also provide the Thokozani Support Group with an objective reflection of its activities.

Data obtained from this exploration feeds into the broader discourse on HIV/AIDS education and management and the potential role CBOs can play..

1.5 Research Methodology

Using a qualitative approach and employing a combination of life history and visual methodologies, this study not only examines the organisation's genesis, structure and access to resources, but also takes an intimate look at the PLWAs who form the majority of the group's membership, and who are the ones who venture into the community providing home-based care, support and information to people affected by the disease. My primary data collection strategy is based on open-ended interviews which were converted into narratives that were then subjected to thematic analysis. The inclusion of photovoice, which is a relatively new research tool, provided the ability to access a deeper understanding of the participants' experiences.

1.6 Thesis Overview

1.6.1 Chapter One – Introduction

This chapter provides a cursory overview of the research question and the context within which it is located. This chapter introduces the Thokozani Support Group and provides a brief overview of the research design.

1.6.2 Chapter Two – Literature Review

Drawing from a variety of readings from respectable journals, reports and books the literature review examines existing literature on the major themes that emerge from the research study. Contained within the literature review is the conceptual framework which provides a theoretical platform from which to approach the concept of community learning.

1.6.3 Chapter Three – Research Methodology and Ethical considerations

In this chapter I explore and motivate the decision to locate the research design within a qualitative paradigm utilising a combination of the life history and photovoice data collection strategies.

This chapter also explores the complex ethical considerations the study encountered when dealing intimately with people who are affected by HIV/AIDS, and how the principles of autonomy, non-maleficence and beneficence were interpreted and applied to the study.

1.6.4 Chapter 4 – Data Presentation and insertion of photovoice material

In-depth interviews with the sample group are presented in the narrative which provides a detailed and significant account of the individual experience. Interwoven into the five sub-chapters is the photovoice material. All five of the participants were given disposable cameras and asked to capture images from their lives and field. They were then asked to interpret the images.

1.6.5 Chapter Five – Analysis and discussion of results

In this chapter I try to make sense of all the data gathered. Apart from presenting the facts, this chapter explores the patterns and perspectives that have emerged. It also deconstructs the Thokozani Support Group in a bid to illuminate its contribution to community learning.

1.6.6 Chapter Six – Conclusion

This provides a summary of the data and patterns that have emerged, as well as the researcher's definitive answer to the key research question and recommendations arising from the findings. The chapter concludes with an outline of limitations to the research study and examines the barriers and restrictions faced in gathering and interpreting the data. The nature and weighting of the barriers are acknowledged and evaluated to assess their impact on the validity of the outcome.

Chapter Two – Literature Review

2.1 Focus of Research

2.1.1 Introduction and Purpose of Review

In order to fully investigate the Thokozani Support Group and its contribution to community learning, this research encompasses a variety of themes and concepts, both related and pertinent to gaining a thorough understanding of the issues arising therein, most importantly, that of HIV/AIDS.

In order to do this, one of the first steps in the research process was to uncover published research on the various themes and concepts that I expected to encounter. By doing this, I not only subject published research to a critical evaluation, but also bring attention to what has and has not been published. This literature review, therefore, provides the background to and justification for the research undertaken, as well as a bridge between pieces of original and existing research.

2.1.2 Overview of Themes

Contained in the key research question are the broad themes and concepts of community, community learning and those of CBOs, specifically in this instance, the Thokozani Support Group. However, in order to bring these issues into focus, I had to pan the research lens across the broad thematic and conceptual environment within which this organisation finds itself. Thus to answer the research question, one had to look beyond the Thokozani Support Group. Therefore, in terms of the environmental context several fundamental themes and issues surface, the most important being that of HIV/AIDS, the challenges of which not only define the scope of the organisation's interventions, but also create the circumstances necessitating an evaluation of community learning within that particular community. The location of the organisation in Richmond in itself gives rise to a focus on important factors such as poverty, unemployment and the lack of resources.

2.1.3 HIV/AIDS in Sub-Saharan Africa

Researchers are largely in agreement that HIV/AIDS, particularly in Sub-Saharan Africa, has reached “catastrophic” proportions. Jennings and Solomon (2002) describe the epidemic in this region of Africa as being one of the worst globally. Current Southern African Development Community (SADC, 2004) figures suggest an HIV/AIDS prevalence of 21.5% in South Africa, 24.6 % in Zimbabwe and 37.3 % in Botswana.

Despite consensus on the magnitude of the epidemic, there seems to be less consensus on how to deal with the consequences. In its 1999 report, the South African Human Rights Commission (SAHRC) suggests that the window of opportunity to contain the disease has passed and that South Africa, which forms part of Sub-Saharan Africa, must now focus efforts on dealing with the social and economic consequences of the disease in a sustained, well-managed and participatory programme.

The Reverend Gideon Byamugisha of Uganda (2001: 199) described HIV/AIDS as not just a disease but a “symptom of something deeper which has gone wrong within the global family.” Furthermore, ramifications of HIV/AIDS “reveal broken relationships among individuals, communities and nations” and also exposes how we treat and support each other.

It shows us flaws in the way we educate each other, and the way we look at each other as communities, races, nations, classes, sexes and between age groups. AIDS insists that it is time for us to sit down and address all the things we have been quiet about - sexuality, poverty and the way we handle our relationships from the family level to the global level. (Byamugisha, 2001: 199)

In the midst of preparing this literature review, South East Asia was devastated by the worst natural disaster in living memory. Amidst the unprecedented chaos, destruction, misery, grief and despair, the world was united in solidarity, benevolence and hope. And this dichotomy, that of hope emerging from despair, illustrated within the context of the Tsunami disaster, brought my attention back to Richmond, its past, its present and the emergence of hope as the people rebuild their community.

2.2 HIV/AIDS in South Africa

The first two AIDS cases in South Africa were identified in 1982 (Whiteside and Sunter, 2000). By October 2000, a Ford Foundation-funded survey undertaken by the Institute for Democracy in South Africa (Strode & Grant, 2004) projected that 4.8 million South Africans were infected with the virus. The report further projected that nearly twenty percent of all 15 - 49-year-olds were at the time infected.

Current data indicates that the disease is spreading rapidly, particularly among young people aged between 15 to 25 years (Ramsoorooj, 2002). *Monitoring the AIDS Pandemic* (MAP, 2000) report, cited in Ramsoorooj, estimates that 1 500 people per day are contracting the virus, resulting in 50 000 new infections per month in South Africa.

South Africa (Karim & Karim, 2005) has experienced one of the fastest growing epidemics in the world and is home to ten percent of the current global HIV infection rate, and “in the 10-year period from 1990 to 2000, HIV prevalence among antenatal clinic attendees increased ‘explosively’ from 0.8% to 24.5%”.

Crewe (1992: 9) states that once HIV/AIDS enters a society “it veers towards the path of least resistance” and that, globally, that path cuts a swathe through marginalised, disempowered and impoverished communities. This natural socio-economic trajectory of the disease is confirmed within the South African context where it is found in high numbers in poorer and disadvantaged communities (Ramsoorooj, 2002).

2.2.1 AIDS in KwaZulu-Natal

It is generally accepted that KwaZulu-Natal has the highest infection rate of all the provinces in South Africa. Ramsoorooj found that by “the end of 1998 an estimated 750 000¹ people were living with HIV in the province” (Ramsoorooj, 2000: 9). At the time, this figure represented one third of the country’s total estimated three million HIV infections.

¹ A typographical error in Ramsoorooj reflects the KZN infection rate as 7 500 000 instead of 750 000.

Data collected from antenatal clinic attendees in the rural district of Hlabisa in KwaZulu-Natal (Karim and Karim, 2005) reflects that HIV prevalence rose from 4.2% in 1992 to 14% in 1995 and 36% in 2001. Karim and Karim further estimated that incidence rates for Hlabisa District were similar to that of the province.

These findings are further corroborated by Whiteside and Sunter (2000: 50) who found that KwaZulu-Natal “has consistently had the highest levels of HIV infection...”. Whiteside and Sunter further project that by the year 2008, AIDS-related deaths will peak in the province at 115 000 a year. By 2008 the projected number of AIDS orphans in KwaZulu-Natal would reach 410 000 per year, rising two years later to 460 000.

2.2.2 Richmond

Research unfolding in Richmond, which is a small rural town in the KwaZulu-Natal Midlands of South Africa, has found that the town has an exceptionally high rate of HIV/AIDS infection (Van der Riet, Hough & Killian, 2005.) With a population of approximately 70 000 people living in semi-formal and informal settlements, the unemployment rate is approximately 40% and at least 75% of households earn less than R1 500 per month.

Richmond was also a town afflicted by intense and prolonged political conflict, with an estimated 20 000 people killed, many of them becoming refugees over the last 20 years. This led to the communities being impoverished, fragmented and struggling for daily basic survival (Higson-Smith and Killian, 2000 cited in Van der Riet *et al.*, 2005).

Although the town has experienced a period of peace and reconstruction over the last four years, the high mobility, high unemployment rates and the continued social fragmentation have contributed to the extremely high rates of HIV/AIDS infections (Van der Riet *et al.*, 2005).

2.2.3 Political violence

“Armed conflict,” says Dorrington and Johnson (2002: 19), “has the effect of displacing those seeking to avoid conflict and destabilising the traditional power structures and value systems of the society”. Furthermore, Humbridge, cited by Dorrington and Johnson (2002), adds that violence leads to a collapse of social cohesion and a disintegration of parental authority and is a contributing factor to the high levels of HIV prevalence in KwaZulu-Natal.

In the case of Richmond, armed conflict and displacement have been a characteristic of the town since the late eighties. Taylor (2002) traces the start of the violence back to 1988 at a time when the Inkatha Freedom Party (IFP) and the African National Congress (ANC) were waging a fierce territorial battle. Both sides, he says, received increasing paramilitary training and by 1999, already over 140 people were killed.

With the rise of well-trained SDUs (self defence units) ... Inkatha was ousted from Magoda and Ndaleneni in the early 1990s – but not before both sides sustained heavy casualties in attacks and counter-attacks, and Magoda was reduced to a wasteland. Inkatha retained control of Patheni, but some 60 percent of residents decided to flee the area. At the height of the Richmond war, some 20 000 refugees crowded into Richmond, living in tents, makeshift shelters and on the streets. (Taylor, 2002). www.wits.ac.za/csvr/papers/papvtp6.htm#richmond

With the advent of democracy in 1994, relative calm prevailed in Richmond as peace rallies between the two political parties encouraged displaced people to return to their homes. However, the era of violence was far from over as a new political power struggle erupted when the ANC’s Sifiso Nkabinde was expelled from the party and launched a branch of the United Democratic Movement (UDM) in Magoda. Nkabinde had fallen out of favour with many senior ANC leaders who did not approve of either his weapons dealings or his tight grip on SDUs in Richmond. He was also accused of being an apartheid spy (Taylor, 2002).

Nkabinde fought a hard and dirty war to retain his hold on power; his expulsion from the ANC marked the beginning of a two-year reign of terror in the Richmond area in which orchestrated hit squad activity was to claim more than 120 deaths. (Taylor, 2002).

Despite being arrested in 1997 and charged with 16 counts of murder, Nkabinde was acquitted of all charges seven months. The violence continued and in January 1999, Sifiso Nkabinde was shot dead by three attackers.(Taylor, 2002).

Just like the preceding war between the ANC and IFP, the violence emanating from the conflict between Nkabinde's UDM and the ANC resulted in a wave of displacement and created further community divisions and mistrust in Richmond.

2.3 Understanding the Voluntary Sector in South Africa

2.3.1 Overview of the Sector

In the quest to explore and examine the role of the Thokozani Support Group within the context of community learning, an understanding of the non-profit sector (NPO) sector in South Africa was needed. Apart from being able to navigate the complex terminological terrain of this sector, this understanding was also required to draw clear distinctions between the different types of organisations and to isolate or come close to isolating a definition of a CBO.

However, instead of providing the clarity required, the available literature suggests that the researchers have encountered difficulties in tying down definitions, perhaps because the sector is continually evolving to meet the rapidly changing challenges of a transitional society.

It is estimated that there are between 54 000 and 100 000 NPOs in South Africa, the bulk of which are smaller CBOs. An early 1990s estimate suggests that an income of R10 billion per year is generated by the sector (Everatt, 2001).

2.3.2 Non-Governmental Organisations

NGOs, says Ntsime (1999: 115), are just one group of Civil Society Organisations (CSOs) and are “rarely found in significant numbers in the deepest and most depressed rural parts of a country”. Various observers have noted that the NGO sector in South Africa has its genesis from CSOs that played an essential role in countering the apartheid state. In post-apartheid South Africa, the advent of democracy created new challenges and CSOs had to refine their identities and roles within a legitimate, constitutional democracy (Motala and Husy, 2001).

Dealing with these new challenges and adapting to the changing environment is something that NGOs dealt and coped with differently. Narsoo (2001) states that there were three distinct strains of NGOs, firstly, those that were almost exclusively committed to the anti-apartheid movement but were now struggling in the post-apartheid era to develop new positive roles; secondly, service delivery NGOs that were mainly independent during apartheid; and thirdly, NGOs that co-operated with the apartheid state, either by free will or constraint in their welfarist efforts.

Cawthra, Helman-Smith and Moloï (2001: 114) use the terms voluntary sector, non-profit sector, voluntary (sector) organisations and NPOs interchangeably to refer to both NGOs and CBOs throughout their publication, *The Voluntary Sector and Development in South Africa*. The authors suggest that when reference is made to “NGO” or “CBO” the following definitions are implied:

NGOs are understood to be NPOs which provide some kind of professional service to community groups (such as civic associations, para-legal advice offices, or women’s organisations) or a particular constituency (youth, farm workers, PLWAs).

CBOs are organisations that bring together constituencies at a grassroots level to take action and to make representations on issues of common interest and are often the recipients of services provided by NGOs. They include, for example,

civic associations, tenants' organisations, or groups seeking the return of land confiscated under apartheid.

However, Ntsime (2001) finds the following distinction between NGOs and CBOs: the former are formally constituted not-for-profit organisations that work in a range of development-related areas while the latter are not formally constituted and include manifestations such as community committees, stokvels and church groups.

NGOS are an important part of community empowerment. In terms of pragmatics, networks are critical to the existence of NGOs and grassroots interventions. Therefore, an important role of NGOs is to affect the way that networks are created and how they operate. Therefore, the success of an NGO is dependent on a stable and peaceful environment that facilitates the development of such networks.

Dunpath (2003) admits that he uses the terms CBOs and NGOs with the full knowledge that the definitions of the above are neither exclusive nor exhaustive. He also states that, depending on the context, one organisation can assume many identities, acting as a service organisation in one setting, a CBO in another. However, in the context of this research, the terms CBO and NGO are not interchangeable. In fact, the potential to adequately assess the Thokozani Support Group's ability to impact on community learning, requires that a firm understanding of CBOs emerge.

2.3.3 Community Based Organisations

Apart from the distinctions provided between the various NPO-type organisations, the bulk of NPO data seems to be weighted heavily in favour of the NGO sector. This leaves a significant gap of literature surrounding CBOs

A reason suggested for this gap in HIV/AIDS literature, seems to be the explosion of the AIDS epidemic in sub-Saharan Africa and the fact that both government and non-government agencies and resources are struggling to cope with the challenges left in the epidemic's wake. Whiteside (2002: xi), in his foreword, states that, until recently, "no-one, from international agencies through to local departments in welfare in the national

and provincial government, had begun to grapple with the magnitude of the problem, the resources required to respond to it, and the mechanisms with which to do this”.

Despite the lack of concrete research into the CBO sector many contemporary observers recognise that CBOs are in fact emerging as a final level response to many of South Africa’s socio-economic challenges, including poverty, hunger, HIV/AIDS and crime.

Coombe (2000) states that in many communities there are already established community committees and CBOs that are rendering a service, often despite the absence of official strategy in that area. They are providing counselling and support, education and training, and working hard to reduce abuse and violence. They are also saving lives and form the core of care and support in those communities. Coombe and Kelly (2001: 8) emphasise the importance of community participation “to every innovation aimed at adjusting the education delivery system in response to the challenges of HIV/AIDS.”

The most immediate effects of the disease, Coombe (2000) says, are experiences at household and community level. These levels have already seen an unprecedented manifestation of different coping strategies, including self-sacrificing home-based care for the sick and the integration of orphans into already stressed extended families. In coping with the disease and its impacts, communities were shown that the “real potential for combating HIV/AIDS lies in the resourcefulness, strength and courage of the people themselves” (Coombe, 2000: 6).

Community involvement, adds the Centre for HIV/AIDS Networking (Hivan, 2005), is the way to bridge the gap between theory and reality. Hivan’s social science researcher investigating how people in rural areas respond to HIV/AIDS, explains that despite inadequate resources, including a lack of basic infrastructure and access to health care facilities, high unemployment and illiteracy, the involvement of local stakeholders proved critical in the implementation of prevention campaigns (Naidoo, 2005).

From my exposure to the sector through the Thokozani Support Group, a CBO appears to be a grassroots response to either a series of challenges or a particular community challenge, in this case HIV/AIDS. However there also appears to be a disparity between urban CBOs such as neighbourhood watch groups, and rural CBO such as the Thokozani

Support Group. The former are well organised, networked and have access to funding while the latter appear to receive little or no support and funding and survive primarily on the volunteer spirit prevalent within the community.

2.3.4 Challenges facing the NGO sector

Everett (2001), in his summary of the state of the voluntary sector, says the crisis facing the NGO community extends beyond funding and highlights capacity as a significant influence on sustainability. These difficulties primarily manifest themselves on three levels:

- high staff/member turnover and shortage of skills;
- organisational problems such as weak administrative, management and communication structures and processes;
- lack of financial management skills, this being the most serious of the three.

A report by Fahamu (2004) identified challenges faced by CBOs working in the community settings as follows :

- Funding and money;
- Material supplies and logistics, for example office and other equipment and transport;
- The difficulty of keeping good workers and attracting them to the organisation;
- Sustaining support group;
- Communicating with members;
- Keeping members involved.

Again, these are all critical indicators that must be evaluated at a micro-level within the context of the broader research unfolding in Richmond. As I mentioned earlier, very little, if any, data and, in particular, qualitative data, exists on CBOs. Should this study achieve its objectives, I have no doubt that the findings will provide the first rays of illumination in this critical area.

2.4 The Thokozani Support Group

2.4.1 An overview of the Organisation

Returning specifically to the Thokozani Support Group, which was started in June 2001 by PLWAs, very little literature (as is the case with so many CBOs) exists relating to its constituency, the levels of support it provides as well as levels of support it receives. In all my readings, only one reference to the organisation, in the Regional Orphans' Programme (ROP) report of December 2001, was made. The report confirms that the Thokozani Support Group is a locally-based organisation providing support to people with HIV in the area. The report cites another organisation, the Sakhisizwe Youth Organisation, as providing HIV/AIDS support, particularly to children and youth in Richmond, but my field investigation revealed that within days of establishment, the Sakhisizwe Youth Organisation folded, pointing to the enormous challenges facing emerging community based interventions.

The ROP report further states that the Thokozani Support Group, too, faces several significant challenges, among the most important and inhibiting being the lack of funding, especially as the CBO, which at the time of the release of the report, was not a registered organisation.

Unfortunately at least 50% of the members cited in the ROP report are now dead, a mere three-and-a-half years since the organisation's establishment. During a preliminary interview with Greta Mcamu, one of the members of the Thokozani Support Group, she revealed that the "face" of the organisation is constantly changing as people die and new members join. From a research point of view, apart from stressing the urgency required in conducting the interviews, this startling fact also points to potential challenges in undertaking an accurate excavation of the CBO's genesis and early development as many of the founding members would by now have died. I suspected that there existed, within the Thokozani Support Group, no documented evidence of its history and development,

and I had to rely on in-depth interviews that were cross-referenced and tested against other such interviews, for any reliable historical data.

2.4.2 Objectives of the Organisation

Despite the lack of literature on the Thokozani Support Group, the ROP has managed to document what were then the objectives of the group:

- Educate communities about HIV AIDS;
- Recruit more PLWAs;
- Identify infected people;
- Organise and conduct workshops;
- Organise AIDS awareness campaigns for the community;
- Assist in home-based care.

The need to further explore the interventions of the Thokozani Support Group is obscurely motivated for in the publication *Positive Development, Human Rights and HIV/AIDS* wherein it is argued that PLWAs and their organisations are important components of any intervention, and that their potential contribution is often underestimated.

Ala (2001) challenges our idea and understanding of concepts such as "experts" as traditionally formal approaches have placed bureaucrats, health workers and researchers as the experts, alienating the community sector by confining our expectations of this sector's abilities.

The report states that in order to achieve an effective response, the people closest to the epidemic - peer educators, home care workers, volunteers, PLWAs and their families - need to play decision-making roles.

2.4.3 The Thokozani Support Group and Community Learning

From the research conducted by the ROP's co-ordinator, it is clear that community education/community learning is one of the fundamental objectives of the Thokozani Support Group and that to successfully probe the organisation's interventions, one has to examine community learning from the perspective of culture, history and political status quo. Answering the key research question: "*How has the Thokozani Support Group contributed to community learning?*" created the basis from which to explore the role and ability of PLWAs within the group to mobilise, educate, inform and support.

2.5 Conceptual Framework

2.5.1 Theories of Learning

There are various definitions of communities and theories of community learning that assist in developing a conceptual framework from which to probe the Support Group's role in community learning, the most notable being those of Wenger (1998) and Foley (1998).

The concept of community learning, as expressed by Wenger (1998), is a social theory of learning. Its primary focus is on learning as social participation. This learning is not generalised from unrelated and incidental events but rather from actively engaging in what he calls social communities or rather communities of practice (COP). COPs are formed when groups of people who share common challenges or passions further their knowledge and draw benefits from interacting with each other regularly (Wenger, McDernott & Snyder, 2002: 4).

Political sociologist Robert Bellah and his colleagues conceive of a community as a "group of people who are socially interdependent, who participate together in discussion and decision-making, and who share certain practices that both define the community and are nurtured by it" (Bellah *et al*, 1985: 333). His sentiments are similar to those of MaKinster and Scheckler in Barab (2003) who also define a community as a network of people who share similar experiences, values and history and who use this commonality to their advantage by sharing and generating new knowledge among each other.

While there is nothing distinctly contradictory among the various discussions around the concepts of community and community learning cited above, Wenger's theory, which takes expression in communities of practice, appears to be relevant to the genesis and evolution of the Thokozani Support Group.

2.5.2 Learning in Social Action

Foley's learning theory is similar to that of Wenger (1999) in that Foley bases his outcome on the way people learn as they experience life. Thus the context and environment of the participants plays a fundamental role in determining the discourse and learning practices. What I believe Foley is implying is that, notwithstanding personal individuality, people, to a large extent, are shaped by their environments. Therefore how a person interacts with his or her environment shapes what they do, how they define themselves and how they interpret their actions. Foley also views education as a "mutual development process between communities and individuals, one that goes beyond socialisation" (1998: 263).

Although both Wenger's and Foley's theories are, as I have stated, similar in certain respects, perhaps the most important distinction between the two, and specifically in how these theories relates to the Thokozani Support Group, is the distinction between the different layers of community. Wenger approaches the concept of community learning within the confines of a community of practice which manifests itself as a distinct group of people who learn through social participation within that specific group. Foley, however, views the broader community and environment as having the ability to have a profound effect on community learning.

Wenger (1998:266), cited in Smith (2003: 31), details the components necessary for social participation as a form of learning:

- Learning as community (learning as belonging);
- Learning as practice (learning as doing);
- Learning as meaning (learning as experience);
- Learning as identity (learning as becoming).

Similarly, Foley suggests that the most significant learning occurs:

Informally and incidentally, in peoples' everyday lives. And some of the most powerful learning occurs ... as they struggle to make sense of what is happening to them and to work out ways of doing something about it. (Foley, 1999:2)

Smith concludes that Foley's theory of learning allows people to become aware of "their ability and right to act and to the fact that their actions could make a meaningful difference" (2003: 25).

Foley (1999:3), again cited in Smith (2003: 25), recommends five questions pertinent to the exploration of learning as a social theory. The questions listed below are addressed in detail in Chapter Five.

1. What forms do education and learning take?
2. What are the crucial features of the political and economic context? How do they shape education and learning?
3. What are the micro-politics of the situations?
4. What are the ideological and discursive practices and struggles of social movement actors and their opponents? To what extent do these practices and struggles facilitate or hinder emancipatory learning in action?
5. What does all this mean for education? What interventions are possible and helpful?

Foley's theory also raises the question of terminology, prompting the need for a distinction between informal and non-formal learning. His theory hinges on the former, in that it is both "tacit and embedded in action" (1999: 3) and at times not even recognised as learning, yet still significant.

Wenger (1998) provides us with the lens to examine the theory of active participants in a social community that ultimately, as he suggests, creates a process of mutual development between the individual and the community. His theory, however, presupposes the probability that an "active participant" is one that had gained an entry

point into the community. This sense of belonging empowers the active participant to engage in social practice that generates knowledge, experience and meaning which in turn helps shape both the individual and the community.

Although both theories, that of Wenger and Foley, share conceptual similarities in that they both emphasise the importance and significance of para-formal education, they have important distinctions, primarily in the fact that Foley's theory underplays non-formal learning, while the theory of Wenger embraces both informal and non-formal learning.

For the purpose of this research, particularly in so far as the Thokozani Support Group consists of PLWAs, both learning theories (that is, Wenger's and Foley's) provide a sound conceptual platform from which to approach the examination of community learning, which is the topic around which my thesis is framed.

2.5.3 Organisational Theory

In evaluating the efficiency and effectiveness of NPOs and in this instance a CBO, Dunpath (2003) provides a shopping list of organisational check points with which to probe and evaluate. These include organisational capacity, planning (both medium and long term), monitoring mechanisms and reporting systems, prevalence of "a victim mentality, fundraising, availability and loss of skills" (Dunpath. 2003: 13).

While these are all important factors to consider within the parameters of organisational theory and legitimacy, the question I am forced to ask is: Are these factors relevant to CBOs and, in particular, the Thokozani Support Group? Perhaps this is why the inclusion of the life history approach, as Dunpath states, has the "potential to act as a catalyst for the generation of the new sociological understandings" (2003: 52).

Hence, our understanding has to move beyond the definitions and limitations we impose on more formal interventions made by organisations such as NGOs, for example. By excavating biographical data we are able to gain insights that are far more profound. As Dunpath states, we are able to see organisations as collectives of individuals who are constrained and shaped by their contexts and explore the ways they are empowered to

overcome such constraints. Moving outwards, therefore, biographical interviews enable us to understand the institutional structure and its behaviour.

Unfortunately, as Baxen and Breidlid (2004) argue, the bulk of HIV/AIDS research within the education sector is largely dominated by discourses from medicine, economics and epidemiology thus largely ignoring the social and cultural “embeddedness” of the disease. The authors appeal for more research that would shed light on where and how knowledge is produced, reproduced and expressed.

Chapter Three – Research Methodology

3.1 Introduction

As with any study, finding the most suitable research methodology provides a significant challenge for the researcher. In terms of answering the question posed within our key research question: “How has the Thokozani Support Group contributed to community learning?” it becomes clear that the research required encompasses a realm far more profound than catered for by statistical or quantitative approaches in that our purpose is to explore, describe and understand people, perceptions and experiences.

3.2 Research Objectives

- To gain an understanding of the socio-economic factors that shape life in rural Richmond, particularly the impact of poverty and HIV/AIDS;
- To investigate the concept of community learning: the creation, generation, reproduction and expression of knowledge within the Richmond context;
- To explore specifically the Thokozani Support Group’s ability to contribute to community learning;
- To determine whether the members of the Thokozani Support Group are able or are sufficiently empowered to mobilise themselves to educate, inform and support communities affected by HIV/AIDS.

3.3 Paradigm Location

To realise the above objectives and to understand the institutional structure and how it behaves within this context, the research will be lodged within the interpretivist paradigm. The interpretivist paradigm sees social reality as consisting of individuals who construct meaning and create interpretations through their daily social interactions. According to Terre Blanche &

Durrheim (1999), Interpretivist researchers aim to make sense of feelings, experiences, social situations or phenomena as they occur in the real world and examine how people construct meaning in their daily lives. Thus, the interpretivist researcher aims to learn what is meaningful or relevant to the people being studied within the organisation.

In order to gain an understanding of both the institutional structure and its behaviour, Dunpath, (2003) argues that we must be able to see organisations as collectives of individuals who are constrained and shaped by their contexts. Therefore, within the parameters of the interpretivist paradigm, I have opted for a bimodal form of both the life history and photo voice methodologies.

Life history is a research tool that aims to reconstruct the life history of individuals by focusing on the story of a person as told and expressed by the person him or herself. The technique falls in the genre of narratives and provides researchers with a written picture of “real people in real situations struggling with real problems” (Dunpath, 2003: 50).

Photo voice is a relatively new research tool that empowers participants to provide a relatively unfiltered glimpse of their world. Participants are given cameras and asked to bring back images relating to themselves and their community. Schratz and Walker (1995) liken the technique to a “can-opener” because it provides access to a “deeper” and sometimes different meaning than one would arrive at using just words. However, the value of photo voice is not in the physical content of the image, but rather in the participant’s interpretation of the image.

The rationale for employing a bimodal approach in the research design was not only the need to triangulate data contained in the narratives, but also to provide depth and perspective other than the researcher’s and to broaden our understanding of the individual nature of each participant’s experience.

In terms of the research design, subjective corroboration occurred at a data level with the photo voice material inserted directly into the narratives, rather than triangulation being obtained from the comparison of two separate analytical outcomes from two separate methodologies. Simply put, the bimodal design is a cross-validation of data collection methodologies arriving at one conclusion, rather than two methodologies arriving at separate but potentially corroborative conclusions.

Returning to the Thokozani Support Group, my understanding of the CBO's intervention lies in my ability to understand the individual nature of each person's experience within the broader context of the environment. What we are seeing, within the context of this and perhaps other CBOs as well, are community responses to community challenges created within the broader framework of unfolding events in the socio-economic landscape, in this case HIV/AIDS specifically but not exclusively. Our understanding of this response therefore, lies in the ability to understand the individual nature of each person's experiences within the broader context of the organisation and the environment.

3.4 Case Study Approach

I have opted to use the qualitative case study approach as the research relates to one particular subject in a particular context, i.e. the Thokozani Support Group. Bogden and Biklen (1982), cited in Rule (2003), state that a case study is "a detailed examination of one setting, or one single subject or one single depository of or documents or one particular event". However, Walton (1992), cited in Rule (2003) recognises that the terms "case" and "case study" imply not only particularity but also a level of generality which suggests that many of the issues and factors affecting the Thokozani Support Group may in fact be relevant to other CBOs that focus on HIV/AIDS interventions and that are located in impoverished rural areas.

3.5 The Value Qualitative Methodology

Schratz (1999: 3) argues that "quantitative measurement, variables, experimentation and operationalisation usually transfer the original 'voices' of its research subjects into statistical data, mathematical relations or other abstract parameters", thus fading out potentially useful information that cannot be coded in the quantitative methods listed above. Furthermore, particularly in educational research, allowing the emotive qualities of individuals in their culture to penetrate the research process enables a positive change in the approach to and nature of pedagogical knowledge (Schratz, 1999).

This research aims to provide an understanding and deconstruction of the Thokozani Support Group, not so much in assessing its perceived successes and failures, but in exploring and

understanding the group within society and the myriad socio, political and economic factors which shape individual, group, community and societal development.

3.6 Primary Data Collection Strategy – Life History Methodology -- Narratives

3.6.1 Narratives

Beginning with the narrative, Patricia Clough (1992) cited in Dunpath (2003) takes the view that all factual representations of reality, even data derived from quantitative methodologies, are ultimately constructed in the narrative, rendering so-called technical data inadequate when it comes to issues of emotional reactions and responses.

Babbie and Mouton (1998) define the qualitative design paradigm as a generic research approach in social research according to which research takes as its departure point the insider perspective on social action. Qualitative researchers attempt always to study human action from the perspective of the social actors themselves. Therefore, the primary goal of such design is to provide insight and understanding, rather than an explanation.

To obtain knowledge about a culture, anthropologists often use narratives, states Dunpath (2003). Clearly, my unfolding understanding of the Thokozani Support Group specifically, and CBOs more broadly, suggests that their responses and social interventions, point to a deep-rooted culture of community and social activism. Adding weight to this, Barone observes that: “Great stories enable readers to gaze in fresh astonishment upon a part of their world they thought they had already known” (Barone, 1992: 20, in Harwood, 2001).

The basic elements of a narrative are people, either individually or collectively, depending on the circumstance or scope of the research. Thereafter, elements include, among others, incidents, language, meanings, personal histories, etc. Participants are described as individuals who have different personal histories and who display different physical, emotional and intellectual characteristics in various situations (McMillan and Schumacher, 1997: 100).

Narratives, by their nature, are subjective as the focus is not on historical accuracy, but rather on the meanings derived from the stories told. However, juxtaposed against the historical chronology of the community in question, a powerful understanding can emerge. For this to happen, and here I concur with Dunpath (2003), individuals must be located within the broader context of community and society. Notwithstanding the methods I have selected for my approach, the utilisation of this form of research creates an intimate relationship between the researcher and the subject or subjects. Although I will confront this in more detail later, it must be acknowledged that this methodology can create emotional attachments.

3.6.2 Life History

Since its early use, particularly to document the biographies of American Indian chiefs, the approach has been increasingly adopted by sociologists and other scholars working in the humanities (Goodson and Sikes, 2001: 6): “One of the main landmark developments came in the 1920s following the publication of Thomas’s and Znaniecki’s study, *The Polish Peasant in Europe and America* and this pioneering work established life histories as a bona fide research device.”

Talking about Shaw’s 1930 account of a “mugger”, the piece *The Jack Roller* in Becker, (1970: 71) states that the provision of this kind of voice (life history) from a culture and situation that are ordinarily not known to intellectuals generally and sociologists in particular, provides researchers with the ability to improve their theories at a “most profound level”. Putting “ourselves” in the skins of our subjects creates an awareness of the biases that permeate our thinking and exposes the assumptions that researchers are often guilty of making. “Life history, by its nature, asserts and insists that power should listen to the people it claims to serve” (Goodson and Sikes, 2001: 8).

Attempting to deconstruct the Thokozani Support Group’s identity, one has to always return to the fact that being a CBO, Thokozani Support Group has very little by way of formal constitution. Its cohesiveness has always been the people, and in this case primarily the PLWAs who have responded to the immediate and direct challenges created in the wake of the epidemic in this community.

By its very definition, the life history technique is a significant methodological tool, the main aim of which is to reconstruct the life history of individuals having its focus on the story of the person as expressed and told by the person him- or herself. Life histories that fall into the broad genre of narrative research help in “facilitating a deeper appreciation of the individual’s experience of the past, the present and provides a means of challenging the future” (Mearor & Sikes, 1992, cited in Dunpath 2003: 50). Therefore, this approach, according to Cortazzi (1993: 5) “can make provision for both the reconstruction and interpretation of subjectively meaningful features and critical episodes of an individual and institution’s life, allowing us to see unities, continuities, discontinuities, images and rhythms”.

The illumination of the Thokozani Support Group using the life history approach is reliant not on documentary sources such as committee meetings, evaluation reports, funding proposals, or examples of programmes, but on in-depth interviews, thereby providing useful perspectives of the experiences of the organisation and its members. Data was collected using semi-structured and open-ended in-depth interviews that were conducted to further explore critical issues and themes that emerge.

The use of the life history approach, according to Witherall and Noddings (1991: 280), has a number of potential benefits.

Telling our stories can be cathartic and liberating. But it is more than that: stories are powerful research tools. They provide us with a picture of real people in real situations, struggling with real problems. They banish the indifference often generated by samples, treatments and faceless subjects. They invite us to speculate on what might be changed and with what effect. And they remind us of our persistent fallibility. Most importantly, they invite us to remember that we are in the business of teaching, learning and researching to improve the human condition.

My approach to the structure of the life history approach was based on “open-ended in-depth” interviews because the very nature of the group’s existence is based on largely informal and immediate responses and interventions. From the very beginning I was

acutely aware that the members of Thokozani Support Group have neither the time, capacity resources nor, most importantly perhaps, the willingness to digress from their immediate community challenges in order to entertain the need for paperwork. In any case, I was more interested in their stories. Seidman (1998: 1) says that when people tell stories, they select details of their experience from their stream of consciousness and that this “consciousness” gives access to the most “complicated social and educational issues”.

3.7 Application of Primary Data Collection Strategy

3.7.1 Site Selection

The site for this research is Richmond, a small rural town, approximately 40 kilometres south of Pietermaritzburg in KwaZulu-Natal, South Africa. The town has high levels of poverty, illiteracy and unemployment, as well as a high prevalence of HIV infection.

3.7.2 CBO Selection

The Thokozani Support Group was the only active CBO engaged in HIV/AIDS intervention programmes in the vicinity. Community education formed part of the organisation’s agenda.

3.7.3 Purposeful Sampling

Participants were selected on the basis of the extent and duration of their involvement within the organisation to ensure the involvement of members who would provide rich qualitative data to the study.

3.7.4 Sample Size

Given the depth of data required, the sample was restricted to five members “based on expected reasonable coverage of the phenomenon given with the study” (Patton, 1991: 186.) The sample comprised African Zulu-speaking participants from both rural and peri-urban backgrounds. The participants ranged between 26 to 50 years of age and were

active in the organisation at the time. The sample consisted of four females and one male. All played a key role in the organisation.

3.7.5 Data Collection Methods

In order to achieve the objectives of this study, data was collected using two primary techniques, that is, open-ended in-depth interviews and photovoice. Participants were tape-recorded. The data was collected over a period of roughly two weeks. The estimated duration of each interview was at least two-and-a-half hours. A break of 15 minutes was permitted in which time refreshments were served.

With regard to the photo voice method, participants were handed disposable cameras which were in their possession for a period of four weeks until such time as they were collected by the researcher. A presentation of the chosen photographs by the participants was a means of collecting data using the photovoice method.

A translator was present at the interviews with the permission of the participants, as four out of the five participants requested a preference for the interview to be conducted in Zulu. All participants consented to having their interviews tape-recorded for the sake of convenience and so that no important information might be lost. Tape-recorded interviews were translated into English, which took a period of at least two months to complete. The transcodes were converted into transcripts and then into narratives.

3.7.6 Semi-Structured Interviews

In semi-structured interviews respondents were asked questions using an interview schedule. These face-to-face interviews were aimed at getting in-depth information, observing non-verbal cues and the environment as a whole. Open-ended questions were used. The advantages of using semi-structured interviews are the flexibility they offer and detailed data they provide (Brewerton & Milward 2002: 70). Furthermore, it is possible to explore and probe in more depth, certain areas of interest in semi-structured interviews. Data collected were thereafter converted into narratives.

Interviewing, in the context presented above, can then be seen to be a basic mode of inquiry, and one that has provided people with a way not only to record history, but also to make sense of the interviewees' experiences. The interview sessions with the Thokozani Support Group sample encompassed biographical data, their experiences within the support group and, lastly, their personal health profiles which created space for them to review life experiences and contextualise these in terms of their immediate environment.

As I noted earlier, the purpose of the study was not necessarily to find answers but to develop an intimate understanding of life experiences very different from my own and within an environment detached from my own reality. In order to do so, it became clear that the richness I sought was to be found at a sub-surface level made more accessible by my willingness not merely to record these experiences, but to share in them.

Having said that, it must be emphasised that as much as researchers in general seek to understand, it would be presumptuous, disrespectful and insulting to imagine or claim to imagine, that we can ever exhaustively grasp the experiences we seek to understand.

3.7.7 Observation

My own observations and reflections during interviews were an important source of information, particularly in attempting to understand how issues such as personality and character impacted on the group as a whole.

3.8 Secondary Data Collection Strategy – Visual Methodology: Photo voice

The use of visual methods, according to Van der Riet (2004: 1) helps to make what is implicit explicit so that the researcher can have a greater understanding of the local knowledge and the local people can engage in a process of reflection about their own lives (Boettiger, 2004.) The role of images is not to replace words, but rather to be used in conjunction with them (Schatz & Walker, 1995). The authors liken visuals to a “can opener” because they give the researcher access to a deeper and different kind of meaning than one would reach by just using words. According to Boettiger (2004), pictures can often depict a problem, an experience or an idea in

such a way that could be difficult to explain through words alone. When one uses a picture to represent something or explain something, it helps the researcher in gaining a better understanding of the community's local knowledge and to identify the strengths and weaknesses in the community fabric (Boettiger, 2004).

Utilising a bimodal methodological approach by incorporating the photo voice research tool, I have hoped not merely to add-on to the research but to provide an additional dimension by allowing the participants themselves to provide a glimpse of their world through their eyes.

Much of the mistrust of visual methodology stems from issues of reliability and validity. The question of how the researcher mediates between what is represented and the participant is important (Boettiger, 2004). How is the dilemma of the researcher imposing his/her interpretation on the visual representation overcome? This comes with the craftsmanship of the researcher. It is important for the researcher to constantly clarify the participant's intended meaning in his/her visual representation (Boettiger, 2004.) The researcher should constantly ask the participant if he/she correctly understands the intended meaning; has he/she "got it right?" (Kelly, 1999c). The researcher should be constantly aware of the difference between the participant's intended meaning and his/her own interpretation of a representation (Boettiger, 2004). Interpretive meaning is valuable as long as it is situated in relation to the intended meaning of the participant (Boettiger, 2004). The researcher's role in the participatory research inquiry is crucial to the success of the research.

Photo voice is one technique within visual methodology, and, says Carol Wang (1999: 185), talking about the methodology as applied to research pertaining to women's health, "is a participatory action research strategy which, as the name suggests, empowers communities to deliver their message forcefully".

It becomes apparent that notwithstanding the literal meaning of voice, the images obtained speak loudly and clearly and paint a picture of a reality that words can never express.

In her paper, Wang (1999: 186) identifies several key concepts relating to photo voice. Below are just two of these points:

1. Images Teach: Images with their messages both hidden and explicit help to shape our concepts of what is real and what is normal. Images contribute to how we see ourselves, how we define and relate to the world.

2. Policy influence: Images do not influence policy in a linear way but rather influence our focus and world view. (1999: 186)

Describing his fascination with photography in education, Walker (1993: 72) says:

One of the reasons why I am intrigued by the use of photographs in educational research is that their use touches on the limitations of language, especially language used for descriptive purposes. In using photographs, the potential exists, however elusive the achievement, to find ways of thinking about social life that escape the traps set by language.

My initial interest in the photo voice methodology stemmed from a workshop conducted by Professor Claudia Mitchell at Edgewood College in March 2004. She said the methodology provides a basic understanding that words sometimes struggle to express. The idea of allowing members of Thokozani Support Group to express themselves in this manner made immediate sense to me, and created the possibility of an even deeper exploration of the social realities that I was only beginning to piece together from my encounters in Richmond.

Utilising photography in research, Fattal (2004) suggests, can be woven in many different ways depending on the researcher's design and implementation. I have opted to use the photographs in conjunction with the narratives.

I have opted to leave the photographs "untouched" with any derived interpretation being left up to the reader after noting the comments of the photographer. Apart from both prescribed time and space constraints, the images, to paraphrase Wang (1999), speak loudly and clearly in a way that words themselves would struggle to express. However, to further interpret the images, the photo voice participants, were asked to provide a brief description of the photographs they had taken.

By doing this I hoped that the participants would contextualise the experience depicted in their images.

3.9 Application of Photovoice Technique

3.9.1 Methodology

The photovoice technique was used in this way:

- A. An initial meeting was held with the key participants of the Thokozani Support Group regarding the overall research process and specifically their participation in the photo voice methodology.
- B. Participants were briefed on the photovoice method, their involvement in the process, as well as accepting responsibility and commitment in handling that process. Ethical issues as well as the required consent documents were discussed.
- C. At a subsequent workshop, a demonstration was held with the participants on the handling and management of the disposable cameras as well as a brief outline of what constitutes subject matter. On this point, I informed the participants that photographs underpinning social realities in communities in the context of HIV/AIDS as well as their role in community participation and HIV/AIDS needed to be captured. Participants were also asked to photograph five images of personal interest which they were allowed to keep at the end of the research process
- D. Members had the disposable cameras in their possession for a period of four weeks in the month of February 2005. Thereafter, the film underwent the process of being developed and printed.

3.9.2 Workshop: Interpretation of Photographs

A further workshop was held with the participants (April, 2005) where each of the participants were given sufficient time to study the photographs that they had taken and choose at least five photographs (out of a selection of approximately 20) about which they wished to talk and write, as well as present. During this phase of the workshop, participants were requested to keep five of the photographs taken.

The participants' description and presentations followed this sequence:

- A. Participants were given sufficient time to study photographs and decide how best they would present each photograph.
- B. Materials such as A3 paper, glue and writing utensils were handed out to participants.
- C. Participants were asked to stick each chosen photograph on the A3 sheet of paper. Each participant had to give every photograph either a caption or title.
- D. A small written exercise proceeded thereafter wherein each participant wrote down, briefly, reasons for having chosen that photograph. Participants could start off by saying, "The reason I chose this photograph is because..."
- E. Once that process had been completed, refreshments were served. During the break, the researcher and the facilitator/translator went through the written text about the photographs (written in Zulu) to facilitate an understanding which was used to design a short and standardised set of questions for a photo-interview to probe further into the participants' interpretation of the photographs. This interview was carried out with each participant after each presentation. (See attached questionnaire.)
- F. Upon resumption of the workshop, participants were given the opportunity of making their presentations, which consisted of a general talk about the image as well as their associations or relationships with themes such as community learning and HIV/AIDS.

3.9.3 Analysis of data

The foundation for the analysis was based on a thorough deconstruction of the key research question in order to extract and understand the primary thematic framework underpinning the study.

In terms of the life history data, interview audiotapes were transcribed verbatim into transcodes before being converted into transcripts, which included additional observed

contextual information such as environmental and emotional factors. The transcripts were then rewritten into life stories (narratives). Thereafter, the narratives were purposefully read and re-read to identify, extract and code themes. These codes were first grouped individually for each participant and later collectively for the entire sample. This double-layered process allowed me to search for patterns, trends and anomalies, first individually, and thereafter for the entire sample group. Given the size of the data sets, analysis of the codes was restricted to the thematic outcome of the key question deconstruction process. During the deductive process data was evaluated for “adequacy, usefulness and centrality” (McMillan and Schumacher 1997: 518), as well as for its relation to the conceptual framework of the study. The patterns derived formed the basis for the reporting of the findings.

3.10 Ethical Considerations

The initiation of this research process set into motion a plethora of ethical considerations, questions and dilemmas, particularly as the research process and the data anticipated required the researcher to penetrate into the most intimate and personal recesses of peoples’ lives. Given the levels of disempowerment and vulnerability among the majority of the participants, coupled with their HIV-positive status, the research process could be likened to the navigation of a minefield.

Despite having sifted through volumes of literature on ethics in research I have come to the conclusion that there is no research standard on best ethical practice, particularly when utilizing the life history approach, as the variables are too complex and dynamic to allow for the extraction of any particular ethical research law. However, perhaps the greater ethical dilemma is the impact of the resultant relationship created between the researcher and the participant. Having taken due cognisance of the prevailing ethical climate pertaining to this type of research, I have also been guided by my relationship with the participants, and their expectations of the outcome of the many hours they spent sharing their life stories with me.

For research to be considered scientifically and socially acceptable, Durrheim and Wassenaar, (1999), Emmanuel, Welder and Grady (2000) and Mason (2004), argue that it must include considerations of three major ethical principles: autonomy, non-maleficene and beneficence,

particularly when dealing with disempowered and vulnerable population groups. Below, I consider each principle in turn.

Autonomy: The concept of autonomy in research requires the study to be independent of any factors or influences that have a vested interest in a particular outcome, or would attempt to influence the outcome of the process. (Definition extrapolated from Encarta® World English Dictionary © (2003).

Beneficence: The ethical principle of beneficence requires that the research be of social benefit, even though the subjects themselves may not directly benefit from participating (Van der Riet, Hough and Killian, 2005).

Non-Maleficence: This principal demands that the researcher be sensitive to the potential harm that may befall subjects, and to take the necessary steps to avert detrimental consequences of participation

Given the dynamic nature of life history methodology, I have found the concept of situated ethics, as described by Simons and Usher (2000), to be most appropriate in that ethical principles are determined by the prevailing context and location of the research site and the participants. Within this framework two ethical issues arose: a) informed consent procedure; and b) confidentiality.

Regarding the former, written consent was required from the participants. Preceding this request, participants were fully briefed about their role, the nature of the research and the procedures to be used. *(See detailed transcript of procedure below.)*

The issue of confidentiality also presented a research paradox. Despite the obvious factors weighing heavily in favour of strict observance to this consideration, particularly in light of the vulnerability of the participants and their HIV/AIDS status, there are equally considerable factors pertaining to the issue of trust that has arisen out from the researcher-participant relationship. Early in the data- gathering process it became evident that all members of the sample group displayed strong evidence of being “empowered” individuals in that they believed their actions and participation within the scope of the research undertaking, would ultimately contribute positively to the prevailing environment and context of Richmond.

All participants indicated that they wanted their names contained in the data, thereby creating a tension between the need for the researcher to avert any harm to or detrimental consequences for the participants and the need to be mindful and respectful of the participants' requests. Invoking the situated ethics concept referred to earlier, this would mean taking into account the prevailing scenario in Richmond within which this study, as well as the participants, are located. Apart from Aunty Greta and Sister Mtungwa who are non-PWLAs, the balance of the people in the sample have all publicly disclosed their status and all actively engage in knowledge transfer based on their own experiences. It was therefore an important extension for their names to be attached to the data. Of particular concern to me was the impact and possible conflict this would create in my relationship with the participants, as well as the potential betrayal of trust in terms of their participation and expectations.

Taking all of these issues into consideration I eventually decided not to reveal the names of the PLWA participants. My decision was based on the fact that once in the public domain I would have no control over the use of the data, which contained sensitive information, such as sexual behavioural patterns. I did, however, reveal the identities of two participants who are not PLWAs and who provided specific consent.

3.10.1 Ethics of Life History Data Collection Methodology

I conducted the study in my capacity as a researcher within the broader NRF project in Richmond on "Mapping Barriers to Basic Education". The research team approached all sectors in the area in order to gain entry in a respectful manner, by means of a stakeholders' forum meeting held in March 2004. While a large part of the above research included the involvement of schools, learners, school governing bodies, government and non-profit organisations, the Thokozani Support Group was identified as one of the organisations that could assist the project in assessing the contributions the organisation has made in respective communities with regard to the research topic. My task, therefore, was to assist the project team in obtaining this information, both for the larger NRF project and for my degree purposes. Ethical clearance for the larger project was approved by the research office, University of KwaZulu-Natal.

Hence an independent meeting was arranged with the prospective participants at the support group's offices. A full explanation of the nature and purpose of the study, as well as confidentiality issues, were discussed. The consent forms were translated from English into Zulu as participants had previously indicated preference for Zulu. All consent forms were read out and explained to the participants prior to them signing the forms.

Since the research involved entry into the private spaces of participants in a community, the challenge was to find ways to afford an opportunity for participants to participate and to decide if they wished to participate. I considered the basic guidelines for working ethically with adults and then developed strategies to apply these within the research context.

It was important, therefore, that in terms of the study, the selected participants understood that:

- All information would remain the property of the University of KwaZulu-Natal;
- Information would be handled sensitively;
- To ensure that no important information was lost, the interviews would be tape-recorded and the tapes would remain in a safe place at the university which would be accessible only to the researcher and the task team;
- The participant could withdraw from the project at any time with no negative repercussions;
- The participants were not obligated to answer any question they did not wish to answer;
- A translator/facilitator would be present due to language barriers.

3.10.2 Ethics – photo voice

Being a relatively new field of research within the qualitative paradigm, the photo voice methodology also raised several ethical considerations.

A lengthy discussion over the use of this method was outlined to the participants. At the introduction of the method, the participants showed keen interest and enthusiasm for this methodological approach.

Participants were made to understand that the purpose of this study was for the researcher to obtain a greater understanding of the local knowledge and people as well as affording the participants an opportunity to “show” their involvement in their respective communities with regard to community learning in the context of HIV/AIDS and the social realities that underpin these communities. It may also be regarded as a process of reflection on the part of the participants about their own lives (Boettiger, 2004).

An understanding and acceptance was reached among the participants regarding their involvement and participation in the photo voice procedure. Participants were requested to take their disposable cameras into the communities and photograph specific subject matter only under the following conditions:

- a) Permission must be obtained from the community member, that is, a parent, caregiver or the individual/s that the participant wishes to photograph.
- b) The participant could not take photographs of individuals or groups of people should they choose not to be photographed.
- c) Participants consenting to be photographed had to be briefed on the research project as well as the purpose of having the photograph taken.
- d) Participants had to confirm with community members that the work could be reproduced but in a way that would safeguard the privacy and dignity of the participants.
- e) Participants had to ensure that the nature of the photographs that they chose to take were directed by a set of guidelines, that is, social realities underpinning communities with respect to HIV/AIDS and/or their contribution as a member of the Thokozani Support Group towards community learning.
- f) A full demonstration on the use, management and correct handling of the camera was undertaken.
- g) Participants were allowed to keep the cameras in their possession for an extended period of time (in this case: four weeks.) Thereafter it was collected and kept in a safe place by the researcher.

- h) Once the photographs were printed and developed, the participants were given the opportunity of viewing the photographs they had taken.
- i) Participants were given carte blanche regarding which photographs they wished to present at a photo voice workshop.
- j) Participants had to place a cross at the back of the photographs that they did not wish to present during the photo voice discussion or not want to form part of the researcher's thesis.

- k) Each participant was allowed to keep in their possession five photographs of their personal choice, a choice which the researcher requested be done at the time of their going to the communities.

3.11 Limitations to the Study

3.11.1 Life History Limitations

- a) The researcher's barrier to the language, Zulu, which was participants' language of preference.
- b) The conversion of the transcodes from Zulu into English was a tedious, time-consuming process. It took at least two months for the transcodes to be converted into transcripts before being translated into narratives.
- c) Participants' work commitments and other obligations resulted in time delays for the project.
- d) Transport to the venue for the interview was a barrier. Participants were compensated for public transport and refreshments provided. The NRF bore these costs.
- e) The researcher's difficulty keeping in-touch with the participants for extended periods due to the lack of tele-communications on the part of participants. Arrangements for meetings or clarifications with participants were made telephonically at times with messages sometimes reaching participants approximately two to three weeks later.
- f) The distance of the researcher to the selected site
- g) The researcher's fear of entering the field, considering Richmond's history of crime and violence.

3.11.2 Photo voice Limitations

- a) The flashes of at least two disposable cameras did not function properly which resulted in indoor photographs being largely obscured. Neither the researcher nor the participant could tell that the disposable cameras were faulty until the photographs were developed and printed.
- b) Because it was the first time participants had actually held a camera in their hands, further demonstrations on how to use the cameras had to be conducted for the participants to feel confident enough to carry out the directed process.

- c) The cost of the photo voice method proved steep. (*The NRF bore the costs of this exercise with regard to the purchasing of disposable cameras and the developing and printing of the photographs.*)
- d) My enthusiasm and passion for this methodology as well as the photo-interviews with participants in my study led to a huge volume of data being collected. Due to time constraints and the limit on the length of this thesis, data from the photo-interviews, which further probed the interpretations of the participants concerning the photographs, were not used in this study.
- e) The researcher, because of the impeding factors in (d), used only the participant's choice of photographs and their written texts of the photographs leaving the rest open to the reader's interpretation. (Excess photographs and photo-interviews are kept in a safe place.)
- f) The written texts, discussion of photographs and photo-interviews were presented in Zulu. This became a time-consuming exercise between the translator and researcher, especially in drafting the questions for the photo-interview; as each photo text had to be re-read by the translator from Zulu into English.
- g) Given the sensitivity of information contained in the narratives, the identities of some of the photo voice participants had to be concealed.

Chapter Four – Narratives

Five members of the Thokozani Support Group agreed to be involved in this research process. Each of the five members spent on average three hours with me, providing me with detailed life histories as well as their role and contribution to the Thokozani Support Group.

4.1 Greta Ncamu

4.2 Nozipho Langa²

4.3 Lucas Ndlovu³

4.4 Sister Mtungwa

4.5 Zanele Zuma⁴

The real name has been replaced with a pseudonym
The real name has been replaced with a pseudonym
The real name has been replaced with a pseudonym

4.1 Greta Ncamu Narrative

“We do not interfere if people who do not believe in AIDS do not want us to help. We do not argue. We just see the poor victim lying there helpless on the bed and we leave. There is nothing we can do.”

I first laid eyes on Greta Ncamu while waiting at the Richmond Drop-In Centre. We – the four students undertaking research for the NRF project -- sat idly chatting under the shade of the run-down prefab building while waiting for her. We wanted to go to the Gabangolawzi School in Inhlazuka, 22 kilometres into the most rural part of Richmond, and she was the woman who not only would accompany us there, but who also, as it would turn out, would play an increasingly important role in my life.

Although up until that day I had not laid eyes on Greta, I had heard much about her. It seemed that her reputation preceded her.

“Aunty Greta” is how I chose to address her eventually. I gathered that she was a well-liked person, and the journey through dense forestland to get to Inhlazuka proved how popular she was in her community. Scores of plantation workers lined the winding gravel roads as Aunty Greta cheerily drove along, zealously raising her hand every few metres to return the warm greetings from all the people we passed.

Before we could leave the school, a gentleman from at least 700 metres away waved to her. In a flash she was gone. I would have offered to take Greta as we were leaving but no sooner could we say goodbye to the school principal, than she was back. She was proudly jogging along with a two-litre container of *maas* (sour milk) that a community health care worker had given to her. A lady sitting outside the school gate running a little tuck shop offered her *amagwinya* (Vetkoeks) to Aunty Greta free of charge. I told Aunty Greta that day that she was a woman whom everyone seemed to like.

“These are my people of Richmond, and I love them,” she chuckled in reply.

"This is I, Greta Ncamu"



Photographer unknown

I wanted to have this photograph of me taken. This is I Greta Ncamu. I want to thank God who gives me this job. I started work as a cleaner many, many years ago in August 1984 and then as a general assistant and today I am very proud to say that I work with the Thokozani Support Group volunteers and I am a community health care facilitator. I work hard and I love my community. I am very worried about the people who are just dying of HIV and AIDS. I feel very sorry for the children who don't have food and parents. As a member of the organisation, we try very hard to reach out to people and children. I also put a lot of pressure on the volunteers to go out there and identify and help and support the people and their families who are affected by the disease.

As you can see I am posing in the van. I use this van everyday to go to the communities. I want to thank God for the gift He has given me to love my community. Without this van, I won't be able to reach a lot of people. I use this van to go to Baynesfield, Nhlazuka, Hopewell, Patheni, Nkumani, Gengesha, Ndaleni and Ezimozimeni.

If people come to the clinic, I'd talk to them nicely. I don't choose whom I am going to talk to. People also look for me at the clinic; they don't leave without my help. I think it is important to

have my photograph here because I felt good about taking out the photograph, and I want the people who read your work, Suhana, to know it was I, Greta, who took the photographs.

Thokozani Support Group is my pride too. I really, really want to see the group become a registered organisation but we are finding it very, very difficult. My dream is to one day see Thokozani Support Group a registered organisation.

Helping people living with AIDS was the reason Aunty Greta said she joined Thokozani Support Group in 2001, but as one delves deeper into her life, its complexity reveals an individual whose destiny was shaped by a history far longer than perhaps she even acknowledges herself.

The last in a family of seven, Aunty Greta was born on April 24, 1950 in Phateni, Richmond. As a rural family, the Ncamus were happy. Her father owned 50 head of cattle, and for a long while the family was short of little. The cows provided milk that was also turned into *maas* (sour milk) and the family garden yielded a ready supply of beans, potatoes and *madumbes* (yams).

All of that changed on June 6, 1966, the day her mother died. Five months after their mother's sudden death, their father remarried and brought home a 22-year-old bride. Life would never be the same again.

“He loved her because she was young and I think he ended up not liking us anymore ... even when we told him something he would not respond nicely. He would say to us, ‘You don’t know that you buried your mother’. That made us feel bad and guilty.” *(Tears well up in her eyes.)*

The young stepmother soon produced five more mouths for the family to feed. She bore Greta's father four sons and a girl. The girl baby was the youngest. She had barely reached five months of age when the young mother abandoned her children.

“Father was too old then.” *(Greta giggles)* “She wanted someone else. She went to Durban and left my father alone at home. That was the hardest part because Father was by then very old and sickly. We tried many times to force her to come back home, but in 1982 father died.” *(Shifts her eyes to the floor.)*

As I tried to probe further about the fate of her young stepmother and whether she had ever returned to her children, Greta started to shake her head excitedly and raised her right hand, promising to come back to that story. Her own marriage was an equally painful chapter in her life, and I sensed her anxiety to deal with this matter swiftly. As for the mother of her stepbrothers and stepsister, Auntie Greta never did return to that story and, as far as I can gather, that chapter closed the day the young mother abandoned her family.

During the time Greta's father was still living with his newly married wife, Greta herself got married. The marriage bore three children. Greta's second child was the same age as the youngest child of her father's. Being the only breadwinner in the homestead at the time, Greta had to provide for all the children.

"She (our step mother) left home when the girl was the same age as my second born. I was the only person working at home and if I was taking care of my baby I had to buy two of everything. Two napkins, two vests ... If I was buying milk for my child, I'd have to buy milk for the other baby as well," said Greta, reminding me that at the time her father was still alive but very sickly.

"It was my sister and me who were taking care of him. After we finished work we needed to stay at home with him to wash him, clean the house and find him something to eat. I was married by then but had to sleep at my father's house to look after him."

Remembering Greta's earlier attempt to talk about her marriage, I gently asked her again if there was anything about it that she wanted to share with me.

"Uph, uph, uph!!!" (*Greta holds her hands to her mouth.*) "It was a bad one. My husband used to beat me. I was physically abused in my marriage."

It came as no great surprise that Greta's marriage failed miserably. Her husband was scarce and made no contribution to the financial upkeep of the three children Greta bore him. But again, Greta's unconquerable determination rose to face another challenge in her young life. She took her husband to court in a bid to force him to pay her maintenance. Little did she know that this courageous step was the beginning of another sad chapter?

Greta, as the court heard, was not this man's only wife. He was married to another woman and had fathered many more children.

"I was shocked, shocked, shocked." (*Holds her head in her hands and speaks agitatedly.*) The court ordered her husband to pay, which he did, fearful that he might have been thrown into jail for failing to comply.

In May this year (2005) her former husband's wife died. Greta was deeply saddened by the news of her death, although it came as no shock to her, as the woman was visiting the clinic regularly.

"I never had a problem with his wife because she loved my children. She once sent someone to pick them up from Richmond and take them to Umbumbulu where she was staying. So tomorrow I am going to her funeral." (*Melancholy sigh.*)

Greta's life was unfolding in Richmond, a small town where cataclysmic political forces gave rise to one of the bitterest and bloodiest civil wars in South Africa's history.

I asked her about the violence but she remained silent. After all that she had shared with me, I had finally arrived at ground zero, so to speak. After a while and with another heavy sigh, Aunty Greta was ready to talk about Richmond.

"Hey, it was very difficult ... while at work the police or the security forces would come and ask me if I knew so-and-so ... and they would ask us where we were coming from or where we were going. One day they asked me if I had seen the dead person near where I stay and I said, 'No'. They told me to go home and that I would see the blood on the grass next to my home."

"Ndaleni was a bad, bad place to stay. People were killing people daily and I was afraid for my children."

There were many terrifying nights when she and her family had to flee their home to stay at the clinic, but even then the security guards there refused to let them sleep inside, and so they had to spend the night out in the cold.

“No-one cared about our children. We just slept in the open. During the day I would leave the children at the clinic to go home and cook food. I left the children there because there were many other people living outside the clinic. But one morning people told me that the soldiers had come and went to where the children were sleeping. We mothers were very frightened for our girls because we knew the soldiers wanted to abuse them.”

Politics in Richmond then was not a matter of democratic choice. It was a matter of life and death as hundreds of innocent people were needlessly slaughtered night after night, all in the name of power. To this day and despite the determined attempts of the Truth and Reconciliation Commission (TRC) to unearth the truth, we may probably never know or understand the forces that devastated Richmond during the late eighties and early nineties.

But for people like Greta and hundreds like her, politics was irrelevant; it was the stark reality of life and death that ultimately counted as families prayed that they would live to see the next sunrise.

“It was around four o’clock in the morning. My son was knocking on the window. ‘Ma, did you hear that they shot the whole family?’ The Nxumalo family were our friends. They lived close by. The wife, husband and friend were all killed. Only one little child lived because she hid in the cupboard.” Wiping away her tears, she told me that former state president Nelson Mandela had visited Richmond the day after the Nxumalo massacre.

“Mandela came to see what was happening in Richmond. He went to visit that house and he saw people’s brains scattered all over the house.”

Not really knowing how to respond to such an overwhelming tragedy, I remained silent as Greta shook her head and cast her eyes to the ground. I told her how sorry I was for her and others like her and then left the subject alone.

As I mentioned earlier, Aunty Greta said she joined Thokozani Support Group because she wanted to help people living with AIDS, but my probe into her life thus far confirmed my earlier premonition that her complex life experience had shaped Greta into the woman she is today, a woman wanting to help everyone, and the woman to whom so many people in Richmond turned to for help.

Greta joined Thokozani Support Group shortly after her sister died of AIDS. Her sister (actually her half sister) was the last born of the five children her father fathered with his second wife, following the death of Greta's mother. As Greta told us earlier, this child was roughly the same age as her own child, and when the child's mother abandoned the family and her children, Greta's relationship with the child changed from sisterhood to motherhood.

It was inevitable that Greta would become mother to her sister. For 24 tough years, Greta mothered her extended family, doing for one only what she could do for the next.

At the age of 24, however, her half sister became very ill. This was Greta's first encounter with HIV/AIDS, and the disease would leave a lasting impression on her.

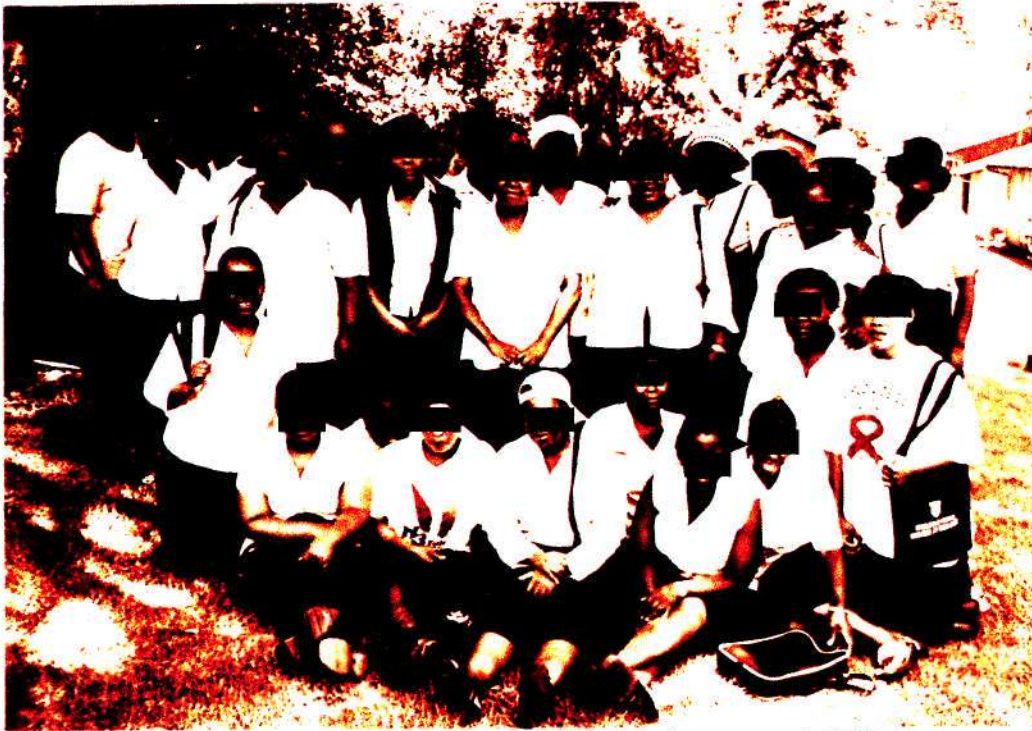
"I stayed with my sister but I did not know what we were supposed to do. At first she got the flu and would cough a lot. Sometimes she just couldn't walk. She would become very, very weak. She would often complain of sore feet. Later she went for more tests and discovered that she was infected with HIV.

Not knowing how to help her sister, Greta turned to the local community clinic for help. Nurses there asked her to bring her sister in so that they could help her. But the disease intensified its siege of her body and before long, her sister was dead.

"She got sick very quickly. We took her to the hospital and admitted her, but she died soon thereafter," says Greta. Her sister's death had a tremendous impact on Greta, and having met several knowledgeable nurses and health care workers at the clinic, Greta resolved that she, too, wanted to make a difference and to provide the help, which she was unable to give her sister.

"At that time the Thokozani Support Group was very active and it had several community health care workers as members. I joined the group and soon was accompanying other members going out into the community to help people infected with the disease."

The Community Health Care Workers



Photographer unknown

I took this photograph because I think it is important to talk about the community health care workers. They play a very, very important role in our communities. I am fully trained to work with the workers; I received a one-year training in Amatikulu in 2001.

Some of their jobs include speaking to people in the community who do not want to take treatment, for example. The workers will refer that person to me and we go back to the community to speak to that person. We tell that person that it is only this type of treatment that is going to help him/her. 'Is it true?' some people will ask. They say they go to the traditional healer because of the coughing and coughing that wouldn't stop.

Hey, these people take the muthi (traditional medicine) about four litres one time and then vomit the whole thing out again. They say that they are taking out the sickness. I mean we blacks believe in traditional healing but we say to the people that it is the medicine from the clinic that is going to help you. After a few days they come back and say that they are feeling better.

Another example is when they are referred to the chest hospital. People refuse to go there because they say that there are too many people there that have Tuberculosis (TB). So I have to place a Health Care Worker at their homes to look after these patients, to stay with them, to offer support and to administer medication.

Apart from an innate desire to assist her community, Aunty Greta's entry into Thokazani was encouraged by the local clinic nurse, Sister Mtungwa. Having noticed that Greta had great compassion for her community and a burning desire to help AIDS sufferers, Sister Mtungwa suggested to Greta that she was "just the person" Thokozani Support Group needed.

"Sister Mtungwa and I were talking one day and I said to her that if my sister was alive that day, I could have helped her through her terrible ordeal of AIDS. Sister Mtungwa looked up at me and said, 'You know, Greta, I am just thinking that you must become part of the committee in Thokozani Support Group because, for one, I am very busy, and, secondly, I think you can sit and talk to these people all the time to support them and give them love.'" *(Folds her hands across her chest and swaying her shoulders happily while the sound of a crying child just outside the window drifted to our ears.)*

For Greta, the opportunity to become involved in the organisation was, in her words, "a dream come true".

HIV/AIDS was gaining momentum in the community. Each day more and more people would come to the clinic seeking answers. Apart from the clinic and its limited resources, Richmond at that time had no facility whatsoever to provide HIV/AIDS counselling and support.

To the people of Richmond, the isolation and lack of support is a terrible bitterness. Despite her enthusiasm and energy to help others, Aunty Greta herself, cannot help but feel despondent

"Oh, no, no, no, nothing happens in Richmond. Not in Richmond. People here are suffering. There are some people who live far away who do not even have money to come to the clinic and they are too ill to even walk just a few metres. You must speak to Thina Bantu at the Drop-in Centre or even to the community health care workers. They will tell you how bad it is out there," said Greta.

I have to help people in my community



Photographer unknown

As you can see in this photograph, today I got the trailer attached to the back of the van. There is a huge board on the trailer that has information about TB. I put on the loud speaker and hired a driver who will take me to all those communities talking about everything on TB and tell people that they must come to the clinic for testing. These are some of the ways we spread knowledge and uplift the community members.

A lot of people get messages in this way. It is an easy way to get the message across to people. One time while I'm in the communities, if people have any questions, they just come and stand around the van and ask me.

But sometimes I even work in places where the van can't go to see how the community health care workers are doing their job. Sometimes I have to park the van off and walk. I sometimes walk for about five kilometres. When I know I have to go to Nhlazuka, I make sure I wear soft shoes because I walk long distances there. I make sure that my workers go out far and wide.

I wanted to probe this issue further as I found it hard to believe that neither the government nor the NGO sector was providing a formal response to the pandemic and its social ramifications for the Richmond community. But the wailing of the child outside grew more intense and I found it too distracting to ignore. I asked Aunty Greta if she knew why the child was crying and she said that they were used to it as every day mothers with babies come to the clinic for help.

“That mother and baby have been here since six in the morning. If you want to see the doctor, then that is the time people have to come. There is only one doctor who comes on a Thursday and we never know what time he will be here. Sometimes mothers and babies wait the entire day. I don’t know why the child is crying. Maybe it’s sick or maybe it’s hungry,” said Greta, glancing out of the window.

Thinking about the baby wailing outside, I was unable to focus my attention back on the interview. I suggested to Aunty Greta that we break for lunch, and then stepped outside to meet the little child whose throat must have been very sore by now from all that crying. I walked up to the young mother and offered her a banana for the child. I cannot tell whether it was the banana or whether all the crying that fatigued the baby, but soon after, the child settled down, and I could return to Aunty Greta.

From what I gathered, virtually anybody in the community can become a member of the Thokozani Support Group. No prescriptions or restrictions exist, apart from the fact that those wanting to join must have a sincere desire to help the community. It’s not surprising that the group opens its door to whomever may wish to join, but there doesn’t seem to be a great rush of people willing to join. Yet Thokozani Support Group seems to labour on, held together at times by fewer than a handful of members as people come and go.

At times this proves problematic, particularly when people who join have agendas other than helping with the group’s work. Take, for instance, what happened about four or five years ago when, after a sudden exodus of members, those left behind plundered the organisation’s bank account.

“At that time we had some very good people belonging to Thokozani Support Group. There was a woman called Faith⁵. She and her husband were HIV-positive. During the World AIDS Day event here in Richmond she stood up and told everyone that she had AIDS. She was a very active woman, and would encourage people not to be afraid of disclosing their status. She later died. Then we had a man called Jabu⁶ join us. He, together with Bongani, was very active. When Faith died, the group started to break apart and there was much in-fighting. Eventually the two of them left as well...

“The people who remained were left in charge of the bank book and were able to withdraw all the money.”

The money in the Thokozani Support Group’s bank account came from the Roman Catholic Church. Father Dominique, aware of the role, which the organisation was playing in the community, committed the church to providing financial support. However, when the church heard about the conflict within the group and that money was missing, the church withdrew its support.

“That was such a pity because the organisation was just starting to establish itself,” Greta recalls pitifully.

Apart from attracting people wanting to exploit the organisation for personal gain, the open-door policy also created the risk of interpersonal conflict among members, which, in an organisation as structurally fragile as Thokozani Support Group, can have devastating consequences.

Aunty Greta recalled one incident when a man, Lucas, joined the group. He was an angry man, prone to sudden mood swings. He had a particular dislike for another member, a woman, who, like him, was infected with the virus. Whenever she was around, Lucas would disappear. Apparently, he felt that Sister Mtungwa liked this member more than she did him.

“I know why he did not like that member.” (*Waves her finger dramatically in the air.*) “It is because she knows her work and when asked to do something, she does it correctly ...

⁵Not her real name.
⁶Not his real name.

“...That is why she was chosen to go to a workshop and not Lucas. He was very angry that week because he believes that he is the man and therefore he is the boss and leader.”

But the Thokozani Support Group has managed to survive. One of its core functions, said Greta, is to recruit PWAs, but the difficulty here lies in convincing people to undertake voluntary testing and thereafter to feel unafraid about disclosing their status.

There are many die-hards who refuse to come to terms with the disease. Some, said Greta, retort that they would rather die than know their status.

“It is so important that we identify PWAs so that we can provide them with the necessary support and information they require. But before that can happen, the person has to know their status. More often than not, people will only go for the test when they are very ill... and when they do not recover from their illnesses. That is when they join us.”

Those who do join are encouraged to share the information they receive with other people in their community, said Greta, adding that the Thokozani Support Group does not have a formal structured programme but that members share their knowledge with each other.

One of the pivotal reasons the organisation does not have a formal structured programme, is the lack of money. Since the loss of funding from the Catholic Church, Thokozani Support Group has had to make do on a shoestring budget.

“We wanted members to go out to out-lying communities but it became very difficult because we do not have enough money. It is even difficult to get members to come to meetings because they need money for taxi fares. Sometimes if we are having a meeting, only a few members will turn up ... some walk from far to come. If it’s raining, forget it. Nobody will turn up. But, on the other hand, if one person turns up, our door will always be open,” Greta said warmly.

Apart from encouraging members to exchange knowledge, the support group, where possible, also provides material support to those in need. Members visit AIDS patients to “provide love and show support” as well as to distribute napkins, linen savers, gloves, Vaseline, spirits and Jik.

“We explain to the families that after a sick person has had their bath, they must rub themselves all over with the spirits as it protects the body from germs. If we have parcels to give, then we do this but at times people plead with us for items they need but we have nothing. It is very sad, especially when grown people ask you for napkins.” *(Raises her eyebrows while asking whether I knew why adults would need nappies.)*

“Diahorrea,” I replied and Greta nodded.

“Yes, it is so sad to see adult people wearing napkins, but what else can they do? Sometimes the sickness is so bad they have no control of themselves.”

At present, Thokozani Support Group receives most of its health supplies from the PMB (Pietermaritzburg) district office. When I mentioned this office, Aunty Greta’s face broke into a broad smile.

“Oh, oh, oh,” said Greta, clasping her hands together. “She is too good,” she said, referring to Mrs Msimang who runs the office and who sends supplies to the Thokozani Support Group.

“Mrs Msimang sends us the supplies and we distribute them, teaching people how to use them and why it is important to be hygienic.” I used the opportunity to question her on which other state department provides assistance. She replied that the Thokozani Support Group had been waiting in vain for months and months for the Department of Health.

As we continued talking, the conversation drifted to other volunteers I had met during my research. I told Aunty Greta about a young volunteer I had encountered. His name was Scelo. I was fond of him, particularly after he selflessly helped to co-ordinate a series of workshops with volunteers. I told Aunty Greta that I had phoned his mother wanting to speak to him one evening but she had told me he was out. I jokingly enquired whether he was out with friends, but she told me that he was spending the night with an AIDS patient who was sick and very old.

I eventually did reach Scelo that evening and he told me he needed to stay awake that night to care and pray for the old man. That evening I thought of Scelo’s selfless deed. Before I turned in for the night, I said to myself: “Heaven is most certainly missing an angel.”

Richmond Drop-in Centre



Photo by Greta Ncamu

I chose this photograph because I think that the Drop-in Centre is a very important place here in Ndaleni. Thina-Bantu manages the place. It is in this place that you will always find orphans with the volunteers and together we play a big role in the community.

I work closely with the volunteers here. Orphans come here every day to get their meals, which are given three times a day. The Social and Health departments started this. I have meetings every Fridays with the volunteers. The volunteers also go out to the communities and do home-based care, help to identify people and children infected and affected by HIV/AIDS and assist children with homework, as well as looking after the sick and very old.

They help and support others, like use the skills they have, similar to what the Thokozani Support Group used to do. The volunteers come from all over different communities in Richmond like Phateni, Nhlazuka and Magoda.

Caring for AIDS patients is an emotionally draining sacrifice. Daily, volunteers have to confront the ugly effects, which AIDS has on the body – rashes, festering sores and violent bursts of phlegmy coughs.

“Some have a rash all over their bodies and even when it clears up it leaves behind black spots. Other become very thin, get thrush on the tongue and are unable to swallow any food. Many AIDS patients have TB and although there is a cure for TB, if the person has AIDS, then it is very difficult to cure the TB”, said Greta.

Despite the overwhelming symptoms of the disease, people refuse to come to terms with their condition, and, as we heard from Greta earlier, denial is common, with many people refusing to test for HIV. In its wake, the disease has also created many social problems. Instead of accepting that AIDS is the cause of death, many in the community prefer to attribute the deaths to supernatural or sinister causes.

“You will find that if a person dies, the neighbour will not attend the funeral. When you ask why, they reply that family and friends of the deceased have accused them (the neighbour) of killing the deceased, and therefore avoid attending the funeral for fear of being killed”, said Greta.

There is also the belief that witchcraft is the cause of illness. Many in the community believe that a witchdoctor may have cast an evil spell. Sometimes sick people in desperation visit a traditional healer who in turns blames the sickness on neighbours.

“These people are such liars. We all know the truth that it was AIDS that killed a person and nothing else. People cannot accept the truth. These people say ‘*babulewe*’ (witchcraft). Our people in the Thokozani Support Group know the truth... they know that no-one wants to kill them.” (*Speaks angrily.*)

At times Greta and members of the Thokozani Support Group will go to homes to volunteer their help if they know there is someone in the household suffering from the disease. But instead of being welcomed, the reception is sometimes cold and intimidating as families try to curtain them off from the victim, scoffing at suggestions that their sons and daughters are HIV-positive.

“We do not interfere if people who do not believe in AIDS do not want us to help. We do not argue. We just see the poor victim lying there helpless on the bed and we leave. There is nothing we can do.”

Talking proudly about the Thokozani Support Group, Greta acknowledged that the organisation has succeeded in its mission to educate members about the disease. Many people who join bring with them misinformation and myths, but open and frank discussions soon dispel these misconceptions.

“Our members are doing their best. They don’t expect anything in return, just the solace from knowing that they have made a difference. If people are willing to listen, we are willing to talk to them to try and help. We operate like a community-based organisation. We do not wait for any handouts or money because we know we will end up waiting forever.”

Once again Greta’s frustrations had surfaced. It is not easy wanting to do so much with so little, and perhaps she had realised just how powerful the Thokozani Support Group could have been had there been the support that it needed.

“We try to make a difference now, not tomorrow,” she declared fiercely, filling in some of the blanks that were missing from our earlier discussion on the subject of support and resources. The municipality, it turns out, had been one of the Thokozani Support Group’s greatest disappointments. Perhaps expecting the municipality to be their primary source of support, the group’s appeals for assistance have fallen on deaf ears, and despite developing a constitution and lodging it with the local council, nothing but silence followed.

Yet the Thokozani Support Group is not entirely alone. It has attracted the attention of Pietermaritzburg-based NGO Siyaphila, which regularly visits the Thokozani Support Group and provides encouragement and information support. Siyaphila also conducts workshops with the Thokozani Support Group, outlining other initiatives such as case studies for the Thokozani Support Group to draw from.

For Greta, the relationship with Siyaphila is a bittersweet one. The irony that Siyaphila gets paid for coming to talk to the Thokozani Support Group does not escape her, and she wryly comments that the Thokozani Support Group has never been paid to talk to people.

“It is so painful because I sometimes think there is no way forward in the Thokozani Support Group. There are those members who are interested in coming and then there are many who are tired of coming when nothing happens.” (*Greta laments.*)

Empty promises are something with which Aunty Greta is familiar. At the moment an official in the Department of Agriculture who has suggested that the Thokozani Support Group makes ceramic roof tiles has raised the group’s hopes. The official told Greta that Telkom is willing to support the project, but that the group needs to find premises. Thokozani secured permission to use an abandoned school in Ndaleni. The building has no roof or windows, but it is there should the project ever get off the ground. Thokozani Support Group has been waiting for almost a year for the project to start.

Despite the disappointments, Greta has remained confident and happy. Her work with Thokozani Support Group and exposure to the needy has transformed her into a woman who is larger than life in Richmond. Wherever she goes, she is greeted with warm hugs and enthusiastic waves. The love, which many feel for her, is what drives Greta.

Her work with the Thokozani Support Group has also helped her become a better parent, a mother not afraid of talking openly with her teenage son about life and the challenges it has in store for him.

With the creases of earlier frowns long gone from her now smiling face, Greta proudly begins talking about her son.

“My son does not smoke or drink. He always concentrates on what he wants to achieve. As I became more aware of AIDS, I began talking to him about the disease and I encourage him to use condoms,” said Greta, beginning to giggle as she explained how she placed a pack of condoms on her son’s bed, and when she went to check later they were gone. “Now when he requires them, he asks me to bring more condoms.” (*Greta smiles.*)

Talking about children and the worries of a parent, I almost fell off my chair when Greta told me she was worried about her “little one”.

“Your little one?” I asked and Greta replied, “Yes, my little one.”

It turns out that one day Greta was at the clinic when she picked up a crying infant to comfort her. The child was an orphan who was being cared for by Home Affairs in Pietermaritzburg. The social workers were desperate for somebody to look after the child.

“I saw Phindile⁷ and I fell in love with her. (*Greta claps her hands joyously.*) She was two years old at the time... and, oh Suhana, I love her too much. All my family loves her.”

Phindile



Photo by Greta Ncamu

Not her real name.

This photograph makes me laugh. It is Phindile. I love her so much. I found Phindile at the age of two. I chose this photograph because she is very important to me and I want to tell you about her.

While I was working in the community, the social worker asked if there was anyone who wanted to 'adopt' children for the December holidays. I said to them that I would love to adopt one child. I said that I can only afford one child and they gave me Phindile. The way I loved that child after that. She came to me when she was two and now she is six years old.

When it was time for her to go back to the social worker she just cried for me. I asked the social worker to let Phindile stay with me forever. They told me that Phindile came to the hospital when she was a baby as she was sick. While she was in hospital her mother did not come back to see her. She stayed in hospital until they took her to a children's home. When they went to Phindile's mother's house, the social workers found out that the family was not living there anymore. They even asked around the community but no one knew where they had moved to.

She stays with me now. I do everything for her. I didn't apply for her child support grant because I love her too much, like my own child. She is mine and not because I want money. I would love to stay with her until the end of my life. This dress she is wearing was donated by Suhana. Thank you, Suhana

.....

Greta remains confident about the future. "Yes, there is a lot of passion to continue with the group and we can be successful. We remain hopeful that the ceramic tile project will happen. If it does, the group will be motivated, we will have the money we need," said Greta.

We had come to the end of the interview, but I knew that my relationship with Aunty Greta was just beginning, and my mind returned to Greta's opening words of the interview: "These are my people of Richmond, and I love them."

4.2 Nozipho Langa Narrative

“Being HIV-positive has changed my life forever. I cannot believe that I am helping not only myself but others as well ... it has become so important to me that I let people in my community know about it.”

I was most excited to see Nozipho that morning. I had waited a long while before the day finally arrived to interview her. As I drove the 42 kilometres to Richmond village, I told Zinhle, the facilitator, about my first encounter with Nozipho.

I had parked my car at the Richmond Clinic that day and walked across to the Agricultural Hall where the Thokozani Support Group offices are situated. I briskly crossed the busy road to enter the gates into the grounds. At least three workers in blue overalls loitered at the front of the hall, staring dully at me, prompting me to hurry across the wet grass to the far end of the hall until I reached the office.

That was when I met Nozipho for the first time. As it was in the middle of winter, the members had decided that they would have their meeting outside so that everyone could enjoy the sunshine.

Nozipho sat on the bench, seemingly unmoved by my presence. She carried in one hand a hardcover notebook while she used her other hand to support a ballpoint pen that she was chewing. I smiled at her, but did not get a response.

The purpose of the meeting that day was to inform the Thokozani Support Group members about the project that the university was carrying out in Richmond. Over and above briefing them on the project, I had also to inform them of my intention of doing research into the contributions that the group was making to community learning.

Halfway through my discussion, Nozipho interrupted to speak for the first time. Her hair was pulled back into a small ball which rested on the nape of her neck. Her hairstyle certainly brought out the broadness of her face, and as she began to talk, her lower lip quivered. She was angry.

“Why are all you people coming here saying that you want to help us? We have no food, we are hungry, and our children are hungry. Many people come to visit the Thokozani Support Group, they say they want to help, but we never see them again.”

I was stunned by her statement but clearly understood the members' predicament. Nozipho shared her views passionately, and it was that morning that I decided that she would be one of the five members of the group that I would interview.

Walking into the offices of the Thokozani Support Group that day was a welcome relief from the sweltering mid-January heat outside. The one-room office housed a long narrow bench, one rectangular table, two broken office chairs and a rusted old filing cabinet.

"Yes, power," I said to Zinhle as she brought in the huge tape recorder. As Zinhle accompanied me to all the interviews, we kept our fingers crossed that there would be power at the chosen venue so that the interview might be tape-recorded.

Soon after I had settled down, I peeped through the door only to see Nozipho running towards us with her handbag swinging over her shoulder while in her other hand she carried what seemed to be a folded white sheet. I wished she didn't have to run as it was really hot. She entered the room, laughing. Upon seeing me, she reached out her hands and I held on to them. Then she hugged me, a ritual that would often precede our many encounters.

As usual, her mouth was occupied, not with a pen this time, but with bubble gum. I knew she had no intention of getting rid of it. I didn't mind. She unfolded the clean, freshly-ironed white sheet and placed it over the wooden table.

"Greta said that I must put this on the table for the interview. I'll take it back to her after the interview," said Nozipho excitedly.

When we eventually settled down, I introduced Zinhle to Nozipho, saying that Zinhle would be doing the Zulu translation for us.

"Suhana, please, please don't worry. I want this to be done in English. I want your people at the university to know that I am a clever lady," she said, tapping my shoulder and giggling. She was definitely in a good mood today.

"You mentioned previously that you didn't mind being tape-recorded. Is that still okay?" I asked her.

“No, I don’t have a problem with that. Even with that name thing, you know, not using my name. Please, the whole of Richmond knows that I am positive, I have nothing to hide, so you go ahead and do what you have to do. I don’t mind,” she said with a more earnest look on her face now.

Born in 1979, Nozipho Langa is 26 years old. She is a single mother with three sons fathered by two different men, and doesn’t really like to talk about her childhood. I gathered, however, that she had lived all her life in Ndaleneni and attended Ndala High, her education coming to a standstill at Standard Eight when she fell pregnant.

“So I decided to leave school when it was time for me to have my baby. I would have loved to have finished my matric, but the father of my baby did not want me to go back to school. That was a big disappointment in my life. I know that I would have done very well in school because I am clever. You know, I speak English very well.” *(Nozipho giggles as she taps me on my shoulder once again.)*

“But now I have three beautiful sons. You must see them. They are too cute and I love them so much.” *(Nozipho says proudly.)*

I love my family



Photographer unknown

I took this photograph of myself and my family at home in Ndaleni. I want to talk about my family, my sisters, my aunt and our children. The reason I took this photograph was to show the love I have for these people and for my children especially. Maybe you can listen to how bad things are in my family. There are many, many more families living like this in Richmond. These are the people I want around me when I am going to die.

We are a poor family but through God, we can survive. Sometimes we sleep without food. That is why I choose to be a prostitute so that I can get money to buy food. But now I can't continue with this life of selling my body because I am HIV-positive. If the government refuses to give me money to buy boosters, I will continue to sell my body.

My sister in this photograph was chased away from school because she had no money to pay the school fees. She was feeling so sad. She sat me down and told me that she is also thinking of selling her body so that she can get some money. I feel sad for her because she was a good learner. I begged her and spoke to her often about not starting that type of job and that she will end up like me because it is frightening living with HIV/AIDS.

“The father of my first son lives in Umlazi and I have no contact with him now. He doesn’t care and never came back to look for his son. So I don’t worry. Then I had a new boyfriend. He is the father of my two younger sons aged eight and six years. We are still seeing each other.”

It was in 1995, the year in which Ayanda⁸ was born, that Nozipho learned that she was HIV-positive. She showed her results to her boyfriend and encouraged him to go for testing, but he refused.

“He denied giving me the virus and refused to go for testing. He said that he was leaving me to go and stay with another girlfriend because I talked too much. That was the last I saw of him.”
(Buries her tearful face in her hands.)

“I went for the test because I somehow knew that my boyfriend was positive. I knew that my baby’s father carried the virus. We were hearing about this disease and how people were getting it, so that is when I decided to go for testing. I know he knew that he was positive but he didn’t tell me. He did not even use any condoms. When I asked him to use condoms, he would say if he used a condom, then no sex and I must go away.”

At only 20 years old and with a young fatherless baby, her life was thrown into greater turmoil by the positive tests. At her request, the blood tests were repeated at a different hospital, but both results confirmed that she was HIV-positive.

“I was still young and the boys used to tease me and treat me very badly. It was worse because I was so young and I had this baby. But I just told them that they must go and check themselves. Now I have heard that some of the same men that used to tease me are already dead.”

Even before becoming a member of the Thokozani Support Group, Nozipho took the brave decision to openly disclose her status to both her family and to her community. It was a decision that not only prepared her for her role in the organisation, but a decision that exposed her to great scorn.

⁸Not his real name.

“There are some people that I know who used to give me a hard time when they found out my status. But now it has happened to them, too. Yet I feel sorry for them. I try to support them instead of mistreating them as they did me ... but there is only so much I can do.” (*Nozipho sighs.*)

“There was this one woman whom I knew. One day I met her in the street and she revealed her status to me. I later saw her in the pension line, I couldn’t believe how big her glands were. I didn’t even want to say hello so I just put my head down and walked away.” (*Casts her gaze at the ground again.*)

“I then said to myself, ‘Oh, my God, one day I will be like that’,” continued Nozipho, who decided then and there that she would assist the woman. Days later when Nozipho encountered the woman again, she stopped to talk to her.

“She told me how sick she was, and that she was afraid of using anti-retrovirals (ARVs) because she was told that the medicine would kill her. She was so afraid and seemed helpless about her life.”

Thinking about her own life, Nozipho had no regrets about disclosing her status.

“Now when people ask me about my status I just say: ‘I am free because I know my status’,” she said, adding that people now look to her for advice and support. But while some people are eager for information, many PLWAs are still very cautious about their status being made public. Some even refuse to go to Nozipho’s home because they fear that their association with her would be enough to stigmatise them within the community.

“I tell people that they cannot live not knowing their status. By the time they eventually learn about the sickness it will be too late.”

Nozipho remembered joining the Thokozani Support Group about three years ago. Concerned nurses at the clinic encouraged her to become part of the group, and it was just what she needed.

Thokozani Support Group Members



Photographer unknown

These are some of the members of the Thokozani Support Group members and I love this support group. It is nice coming here and telling members your status, especially when you are in this group, you feel so loved.

When you are a member of the group, we can talk openly and share all our experiences. Some of the members here helped me to stop selling my body. They supported me and they gave me love. This is my other family that makes me feel free of all my worries. The problems that I have, they help me face it and offer me support all the way. I would like the government to remember those people who are living and those who are dying with HIV/AIDS, that is why I took this picture, so that they can see that in Richmond there are PWAs. The government must not forget about us.

The Social Welfare Department disagreed that I am positive. Sometimes I don't know how I am going to survive. How do we take medication on empty stomachs? How do we buy healthy food to keep us strong?

“At the time the Thokozani Support Group was actively involved in home-based care. I was shocked to see that there were other people in the community who were also positive. I was happy that they accepted me so openly. It was just what I needed.”

“It was not easy to do home-based care. The sight of stark poverty, children scavenging for food while their parents lay bed-ridden and covered with festering sores, was not easy to deal with, yet the group persevered.

“In some houses, the mother is so sick that she cannot even look after her baby. The baby is hungry and always crying for food. Sometimes we felt so helpless, not really knowing what to do... but we still tried. We washed them, cooked them food, maybe potatoes or mealie meal...

“I knew what they were going through because at times I had no food for my children. Sometimes I would get angry that no-one was helping me, but I told myself that only I could make a difference, and that if I sat down, nobody was going to bring the food to me.” *(Remarks in a low tone.)*

Unfortunately, the provision of home-based care was soon to come to an end. Several members of the Thokozani Support Group plundered the group’s bank account which resulted in the Catholic Church cutting off its funding. The withdrawal of this vital source of income, and the subsequent suspension of home-based care, made Nozipho bitter and angry.

“There are many people in the communities who are sick but how can we help them if we have nothing to give them? People haven’t even got food, let alone soap to wash themselves and clean their houses. Now the Thokozani Support Group group has got nothing.”

Despite the withdrawal of home-based care, which up until then appeared to be the group’s primary goal, the Thokozani Support Group still laboured on, shifting its focus to awareness and emotional support.

“During our meetings we decided to invite people to come to the Thokozani Support Group for educational talks. People have to come here because we do not have the money to take a bus or taxi and go to them. We don’t even know what is happening in places like Inhlazuka and Phateni. Those places are too far out.”

The lack of money struck a discordant chord in Nozipho and, once again, I saw her anger resurfacing. Placing both hands on the side of her head, Nozipho couldn't contain herself any longer.

“Sometimes I get fed up with life. Look at the people in Richmond. People are crying for food. People are sick and they are dying. There are children looking after children. I have such a big family and I have three babies, too. What will happen to them if something happens to me? Where is our government? What must we do if we cannot get jobs?” *(Nozipho wails.)*

Funeral of mother who died of AIDS



Photograph by Nozipho Langa

These photographs show a mother who died of AIDS. I volunteered from the Thokozani Support Group to go to this funeral. The lady that passed away was a member of the Thokozani Support Group. She was only about 26 or 27 years old. She has left three children behind. She died in February at the time you gave me the camera.

I took this photograph to show that this funeral is taking place in a classroom at the school. The coffin is placed on a desk. I took these photographs because I wanted to show that there are so many other families living like this one here. In one weekend there are so many funerals. The people that are dying are the people who are helpful and caring and they support their children.

I hope that the government can see these photographs and see what is going on and do something to help them. That is why I took this photograph so that the world can see that there are people who are in need and who live below the poverty line. This family did not have a problem at all in me taking the photographs and only said that maybe someone who sees what is happening will help the people.



Photograph by Nozipho Langa

Just look at how sad the photograph is with the father sitting like that. I think it is very sad. I feel sorry for him. In this photograph the van is transporting the coffin. The van was hired. After that, the owner of the van will slaughter a chicken to wash away any bad luck brought to the van.

I also feel sorry for the father because the farmer where they are staying took care of them but now a new farmer there refuses to employ them. This farmer closed all the taps off which gave this family clean water and told the family to fetch water from where the cows drink.

Nozipho then admitted to a role in her life which it seemed she would rather have put behind her. Desperate to feed her hungry children, Nozipho had turned to prostitution.

“I have got food sometimes but at other times I have no food. But I can’t tell anyone, not even my neighbours. But sometimes one neighbour would send mealie meal for my small baby. Sometimes my babies go to bed so hungry. They say, ‘Ma, can I have some food, please?’ All I can say to my babies is: ‘Just drink the water and sleep and we will see tomorrow.’ Even the first-born baby, he said to me at Christmas time: ‘No, mother, don’t buy any Christmas clothes for me. Just buy me the school uniform because I know you don’t have the power to do everything’. I said to him: ‘Now you are growing up’.

“Yes, mum, I see that you are not working and everything is so hard and my brothers don’t get any grant, only R170,’ he said. In that month I didn’t buy anything. I used the grant money to buy the school uniforms only and I said I would try to give him money for school fees at the end of February. My life is hard but I don’t want to show some people. I can see so much of the pain when I see my babies. Look at my life, my future and the people in Richmond.”

Paralysed pensioner looking after orphans



Photograph by Nozipho Langa

This photograph here is a grandmother who looks after five orphaned grandchildren. The mother of these children died of AIDS. I feel angry because at the time she died, she had no knowledge of the disease and she was my neighbour I could have helped her then. The grandmother is sitting on her bed. She looks after her grandchildren from this broken down bed that is supported by bricks.

On this bed there are clothes stored there as well as some food for cooking. Everything is stored on this single bed so that the grandmother can reach for things. This grandmother can't even walk. She makes a fire next to her bed on the floor so that the children can get food. This grandmother needs help. The children don't receive any child support grant. She uses her pension to support the children.

I help this grandmother by going to the Welfare Department and picking up her pension every month. I visit the children to see if they are well. I had to teach the bigger children how to lift the grandmother off the bed and put her on the wheelchair and take her to the toilet. I really worry about that bed. I also told the children that if granny gets very sick, or if there is any problem, even at night, they must run over to my place and let me or my mother know.

I really took this photo because I wanted to show the world that there are thousands of people like this grandmother and her grandchildren living in just one room, sometimes cooking if there is food, or even sleeping without anything. So when this grandmother bends over one day to cook her food, she will get burnt with the fire together with these small children, so I hope she can get help before this happens.

“Sometimes I was so desperate for money to feed my children that I often worked as a sex worker. So my friends and I used to get paid for doing that, you know, selling our bodies.” *(She adds with a long pause, looking at me to gauge my reaction.)*

I prompted Nozipho to go on only if she wished to do so.

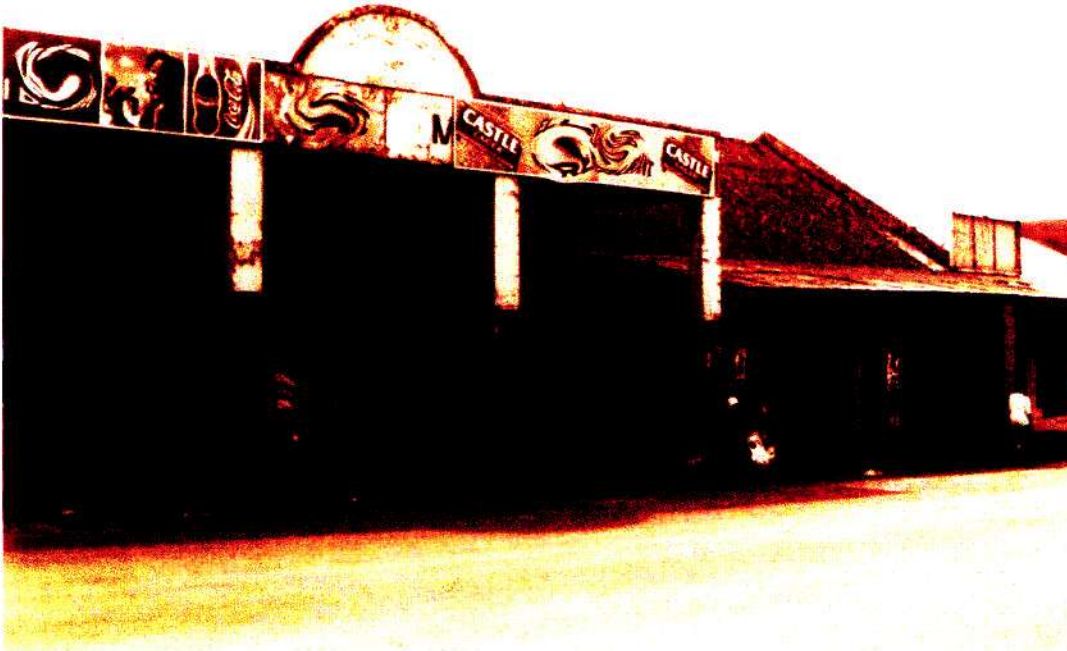
“Ja, everybody, especially the boys, knew the ‘spots’ where we stood. This used to happen at night. We girls used to wait outside the tavern and wait for the drunk men to come out. Then that was our chance. We were told that we would get R10 or R20. The girls in our group, we used to say that is the good life because we haven’t got any money, we haven’t got anything to help ourselves. We needed some clothes and our babies needed some food and clothes, too. So we used to say, that is the good way to go...

“Even the soldiers who were here during the violence used the girls. Even after they had left Richmond, the soldiers left the contact details of their girlfriends with other men to ‘take over’. So things were really bad.”

“But now, I regret that life and sometimes I feel like I don’t have the right to tell my friends to stop selling their bodies. It is not easy to tell people how to live their lives, especially because I did the same thing. Once, as a member of the Thokozani Support Group, I tried to help those girls and encouraged them to stop, warning them that they were spreading the disease, but I almost got hit. It is very hard for people to listen.

“That is why I am so confused sometimes because of the way people don’t want to accept this disease. Sometimes I feel that I have no right to tell other people how to live. I can only tell myself because I know the truth about myself ... and the truth is that if I had stayed a sex worker I would have killed other people.

Working at night



Photograph by Nozipho Langa

This is my town. Somewhere along this street, my friends and I sell our bodies. If the men finish drinking, they find us waiting here outside for them and then we go with them. What we are doing, we don't like it but we do it. We do it for our childrens' stomachs. On this street, more and more people will be infected with the virus.

I took this photograph because I want more and more people to know about what happens here and to avoid this place, especially the stupid men who get drunk and don't know that their lives will be over soon. If they are drunk we can sell our bodies easily to make money.

“In December (2004), I worked for the municipality picking up dirt from the streets for R35 a day. What now? I can work, I am healthy, I am a good person, I can work hard but where is there a job for me to buy the food for my mother and my babies? In my life I tell myself that the white people will help us to find a way to finish this virus. You'll see ... the black people will not help

us ... the traditional healers don't even know how to make medicine nicely." (*Admits passionately.*)

Nozipho made it patently clear that she had no respect for traditional healers, and it became quite obvious that her fierce dislike of them was based on some unpleasant previous encounter.

"Phew! Never again! I don't care about the traditional healers and their medicine. I am happy going to the clinic and getting my medication to boost myself. The traditional medication does not even taste nice and I told myself I would never use it again. Those people lie to us. There is plenty of proper medicine at the clinic but some people they don't listen to us and are stubborn. You must see what happens to them when they drink those bottles. They get even more sick and start vomiting and have running tummies. I know of at least three people who died after taking those medicines from the healers. My neighbour is a traditional healer and I am not going anywhere near there."

Despite the frustrations and anxieties of being a PLWA in a poverty-stricken community, Nozipho remained confident and committed to helping others.

Disabled boy's mother dies of AIDS



Photograph by Nozipho Langa

This child is an orphan. When I was taking this photograph, I started to feel very sad just by looking at him.

His mother died when he was very young. His grandmother is taking care of him with the money she gets from temporary jobs. The grandmother hoes gardens, plants the seeds and does washing to get money to support this child. What is painful about this child is that he has a disability. He cannot speak and doesn't walk very nicely. This child is always dressed like this. I took this photograph so that people in Richmond can maybe help him.

Because I took this photograph, it was my duty to find out more about him. His granny did not mind me taking out this photograph because I had to find out about this boy from her. I found out that there are always people teasing and mocking him because they think that he is mad. The children laugh at him. I feel so sorry for him.

He never went to school. I feel so sad for him because he doesn't have any clothes. I think if you are twelve or thirteen years old, you will need something like underwear to wear. I have not done anything to help this boy but when I look at this photograph, I am thinking

that maybe I should help him because nobody should be living like this. I would not want my sons to live like this.

“Being HIV-positive has changed my life forever. I cannot believe that I am helping not only myself but others as well. The disease has changed my life. It has become so important to me that I let people in my community know about it. I want to be there for them, to answer their questions about the disease because I myself have been through so much. Things that I share with people are what I have learnt being part of the Thokozani Support Group.

“The skills and knowledge that I have learnt during the past three years have taught me stuff like how to keep myself happy when you are feeling depressed, I know how to handle somebody if they admit their status and I’ll offer them support. I will share my experiences of living positively with them; I will comfort them and pray for them. I can speak openly to people and they can feel free to ask me any questions about my experiences living with the disease and to describe what happens when I get sick. When you are in front of people, you can just talk. In terms of a person who is HIV-positive, sometimes you can’t really see it. See, even if you look at me, I have no marks, I haven’t got anything.” *(She proudly admits.)*

Despite the setback of having to stop home-based care; the Thokozani Support Group occasionally gets assistance from the municipality, an NGO in Pietermaritzburg, and the odd donation of money.

“There is an NGO in Pietermaritzburg called Siyaphila. Two members from there regularly visit us and conduct workshops and share their skills and knowledge on HIV/AIDS with us. Thokozani Support Group members enjoy their company, and we in turn learn how to live healthier and more positive lives. We share this information with the people we talk to.”

In addition to providing the Thokozani Support Group with information, Siyaphila has also conducted agricultural and beadwork lessons in a bid to make the Thokozani Support Group self-sustaining.

“Hanson showed us how to do beadwork. He is very good. We made the beadwork but no one is buying it from us. We made rings and bangles and taught people in the community how to make them but who do we sell it to?” (*Laments Nozipho.*)

But the agricultural lessons have been put to good use and, according to Nozipho, the Thokozani Support Group established a garden on a vacant piece of land next to the clinic.

“Vegetables such as spinach, cabbages, beetroot and beans are grown on the property of the clinic. Many of the vegetables are made available to the members as well as to those AIDS sufferers in the community where members can prepare a healthy meal for themselves.”

As for the future, Nozipho is anxious about whether the group will remain together without any funding to help them. But as is her nature and despite her quicksilver moods, she remained confident.

“I hope that the Thokozani Support Group doesn’t fall apart. I still think that the members need each other and they need the support. I want Thokozani Support Group to grow to get more money so that we can go and help people with home-based care, not only in Ndaleni but also in the other communities.

We know what’s happening in Ndaleni but what about the other communities? We don’t know what’s happening there. We want to invite other people from other communities to join the support group. I also hope that people can do something quickly for those children and babies. What are the rights of children and babies who have got HIV/AIDS? My heart is so sore about the babies,” (*She adds sadly.*)

Nozipho’s brave decision to confront the disease head-on has given her the strength required to make a significant difference in Richmond.

“I wasn’t very scared then. I am strong. I have to be strong. I am free, I know my status and I am getting the help. I feel happier, too, because I go all out to learn about the disease and I know how to cope with it. If I didn’t know anything about HIV/AIDS, I wouldn’t feel so strong. I tell myself that I must wake up and start living my life now or I will be finished. I do still feel sorry

for those people who don't want to admit that there is this disease, but I am willing to help anyone who asks for my help.”

Her focus now is on her children and her mother.

“My life is focused on my mother, my house and my babies. That is my future. The idea of getting married and having a husband, I can't even think about that. I'm not even going to worry about it. My hopes are to find a job so that I can look after them. I want to send my babies to school and pay the school fees so that one day they can have jobs. That will make me proud of them.

“When I wish something good for my family, I also like to wish good things for the people in Richmond. With my own life, I will always be worried about my health, even though I have to be strong for my children. I am also very worried about other people. I only wish I had a job and if I get paid I'd like to help myself and then the people. It is very difficult to help people if there is no income.

“When I'm at the Thokozani Support Group, I am happy with the love and support I get. I talk and talk with the members. They talk to me and I feel better. Thokozani Support Group keeps me going.”

• Nozipho refused to have the refreshments that we served. Instead, she wrapped her share of the sandwiches, fruit and cool drinks and said: “I'm taking this for my children.”

4.3 Lucas Ndlovu Narrative

“I was a driver at that time. I knew about the disease but I kept telling myself I would not get it and I continued sleeping with these coloured and black women without using any condoms.”

I was pleasantly surprised by the hordes of people strewn about on the streets of Richmond. Women had their little tables selling goods like vegetables and sweets while others had flimsy rails on which they proudly displayed items of clothing to be sold. Some women found shady spots with patches of grass where they merrily tried to sell their heaps of second-hand clothing. Men, women and children all seemed to be dressed for the occasion. One could not dispense of the smell of raw meat that was now ready to be thrown into the huge pots, in eager anticipation of lunchtime. It was pension day in Richmond.

As I tried driving towards the Agricultural Hall to conduct the interview, I was firmly instructed to halt by a group of armed security guards. After being questioned on my intentions, it became clear that I was not welcome on the premises. I swung my car around and headed for the clinic, hoping that Aunty Greta or Sister Mtungwa would find an alternative venue to conduct my interview.

During this time, I fervently looked out for Lucas, constantly dodging my head through crowds of people. As I approached the clinic, I couldn't help but smile as I saw Aunty Greta with a loudspeaker busy informing people passing by about tuberculosis (TB) and the importance of being tested. Next to her, sitting on the curb, was Lucas, patiently waiting with a matchstick in his mouth.

Alternate arrangements were soon made by Sister Mtungwa for the use of a small room behind the clinic. I was grateful.

Lucas is a thin, lanky character. His torso could often be mistaken for a sheet of cardboard. I smiled at him and he returned a smile with an obvious cough, a cough that I heard every time I had an encounter with the Thokozani Support Group members. We proceeded to the room and began the interview.

Lucas Ndlovu is an apt example of a person seeking acceptance and purpose in life, and either wittingly or otherwise, the Thokozani Support Group is his means towards that end.

Having said that, however, it would be unkind to suggest that his involvement in the organisation revolves solely around himself and his emotional needs. Lucas, as I have discovered, is a deeply

complex person and the complexities surrounding his troubled life often cast a shadow over the Thokozani Support Group, as Aunty Greta explained to me in her interview.

As is so often the case, Lucas had a happy, memorable childhood. Living with an extended family consisting of his parents, siblings and grandparents, he remembers carefree days as a child. Lucas was born in Rosebank, near Eston, and much later in life he moved to Richmond. But life in rural Richmond, as so many people have illustrated, is riddled with false dawns, disappointment, and despair.

Childhood happiness, for Lucas, came to an end when his grandmother died. Her death marked the end of the cohesion that had up until then steered their family on its course, and it wasn't long thereafter that his schooling ran into trouble.

“I started smoking dagga while at school and then I decided to quit school. So I never got a chance to continue with my schooling ... but I know how to write my name,” he added urgently before pausing as if he had something more to say.

“My family was willing to do everything for me concerning school. They were a very supportive family, but at the time dagga was more important and I feel like it destroyed my life.”

Apart from the growing drug problem, his brief experience of school was negative for other reasons, too. Being almost two years older than other pupils, other children would often make fun of him while others would accuse his family of involvement in witchcraft.

“Some children just talked bad things about you, teased you ... you know saying things that would make you sad. They talked bad things about your parents that make you feel bad. When I tried to say something back to them they would hit me and say that I am too talkative and that I must shut up.”

Talking to Lucas about his childhood and the abrupt end to his schooling, I sensed quite clearly the regret and bitterness he now felt, and I wondered to myself whether, in the Thokozani Support Group, Lucas perhaps sees a way of redeeming himself.

When Lucas heard about the Thokozani Support Group, he moved from Nhlazuka to Ndaleni, as Nhlazuka was too far away for him to attend the regular meetings.

“I wanted to be closer to the group, so I rented a house in Ndaleni. Places like Nhlazuka are far out and the Thokozani Support Group does not have the money to send people out there to talk to us. Much of the support we get and give are from people that we see around us.”

Lucas probably contracted the disease while working in the then Ciskei. He had many girlfriends and often slept around.

“I was a driver at the time. I knew about the disease but I kept telling myself that I would not get it and I continued sleeping with these coloured and black women without using any condoms.

“I also know now that I had TB then. We used to share cigarettes freely. Perhaps I even got the disease while helping people. As a driver you came across many, many accidents and I helped people who were bleeding.”

Returning to Richmond, Lucas found employment in Gobiqolo cutting grass and trees in a timber plantation.

“It was a job for positive people and I got paid about R25 to R30 per day. It was very hard. You see, we had to work 15

days and could only collect our wages after about three months. Maybe they were hoping we would die before being paid, or maybe they wanted to make sure we kept coming back to work.”

(Sighs heavily.)

With the disease progressing in him, Lucas heard about the Thokozani Support Group from another member of the group who encouraged him to join it. Around the same time, Lucas fell in love with an HIV-positive woman who was also a member of the group.

“This woman from the group came to me and proposed to me after I became sick. I had that rash all over my body and my feet were swelling up ... the skin on my hands and feet were also starting to peel. That is when I went to the clinic for a blood test.” *(Coughs.)*

Sister Mtungwa and Aunty Greta were at the clinic the day Lucas arrived for his tests. Sister Mtungwa asked him to wait, as the clinic was very busy that day. Later, the two women came and sat with him, talking to him about why he wanted to know his status.

“We spoke for a long time, and I told them that I wanted to know where I stood in terms of this disease. They were concerned as to how I would respond if the results were positive and I told them I could handle it. They asked me whether I would consider ‘anything stupid’ like suicide, and I reassured them I wouldn’t.

“I said no-one had forced me to come here and do the blood tests. I went to the clinic because I love myself and I want to help myself. If I know my status, then I will know how to look after myself.”

He signed the required consent form and returned to the clinic two weeks later to check his results.

“I was anxious. Sister Mtungwa asked me how I was feeling and I told her I was fine, but I wasn’t. She then told me that I was HIV-positive.” *(Shrugs his shoulders.)*

“I just accepted the fact and never really thought about it after that. I was only thinking about how I was going to handle my life ... you know, no school, no education, no work and no money. And now AIDS.”

Lucas took the printed results from the clinic which surprised Sister Mtungwa as most people opt to leave them behind for fear that other people may read them and learn about their status. Lucas told her he wanted his results because he was going to show them to his family. If anyone doubted the facts, he intended showing them the results.

Lucas was fortunate that his family was supportive of him.

“Yes, I do get support. If I am coughing too much they will take me to the clinic and get treatment. If I am sick, they will visit me and ask me if I need food. My mother will scold me and tell me that I am not eating the right food. Then she will go and buy food for me from the Spar. Even my brother supports me.” *(Smiles proudly.)*

After learning about his status, Lucas told Sister Mtungwa and Aunty Greta that he had heard about the Thokozani Support Group from his girlfriend. They both encouraged him to join as he would receive additional support. They explained that the support group was a group of people who also lived with the disease.

“So one day I went to the group and told them I was positive. They saw my test results and accepted me. I was so happy. It was important to me because I knew that I was not alone, that there were others like me. I knew I could get help from them.”

Thokozani Support Group offices at the Agricultural Hall



Photograph by Lucas Ndlovu

This is the office where we meet on Thursdays. The members love coming here and being together. Although the office is very small we are satisfied that the municipal offices could arrange for us to meet here. It is very nice coming together and talking about what is happening to the people in Richmond, but sometimes there is very little we can do to help them but to go and see them and talk to them and offer them some help.

Describing his experiences with the Thokozani Support Group, Lucas says that the group used to have regular meetings at which members openly discussed the disease and how people had found ways of dealing with the challenges. Lucas often shares his experiences with other people affected by HIV/AIDS.

“I often tell people who I meet what I have learned by being a member of the group, and they appreciate it. We hear a lot of stories about traditional healers. Some of the *muti* (traditional medicine) can help people, but we now know that the medicine cannot cure you of the disease.” Prior to joining the support group, Lucas knew very little about the disease, how it is spread and what can be done to avoid infecting others. As he so readily admits, it was the members of the support group that educated him and empowered him to help others.

“Once my friend came to ask me for help. He said he was worried that he may have the disease. I asked him if he had a girlfriend and he replied that he had five. I told him: ‘My friend, you have to cut down ... You have to reduce it. Are you even using a condom?’

“He told me he didn’t believe in condoms. I told him he should leave those girls alone and concentrate on his health or he would die. He said he would try, but it was going to be tough.

“I attended his funeral at the end of last year. He died of AIDS. It was very sad. We were close friends.”

Meeting place in Richmond



Photograph by Lucas Ndlovu

I chose this photograph because this is the place where many people were killed during the violence. Even these days you can find someone dead here because of stabbings. There is no security around these areas. We thought that this place was going to get better but it is still the same because there are people who are dying and now what I even notice now is that I see some young girls hanging around this road. I visit this place now and then. I meet some of my friends here. Usually over here, they will ask me questions about HIV and AIDS so I share my knowledge with them. Some of the men will take me seriously and listen but others will just tease me and laugh, but I don't mind.

Denial seems as prevalent as the disease itself and, as Lucas describes, many of the people the Thokozani Support Group tries to help cannot accept the fact that the disease infects them.

“Sometimes you try to create awareness, but I tell you it is difficult because people keep saying that there is no such thing. They say there is no HIV/AIDS in Richmond. Even when you tell them that AIDS will kill them, they do not believe you. Some, however, do believe.

At the place I am renting in Ndaleni, there are people there that have AIDS and they also know my status. They come to my place and we talk about the disease. I had a book, which I gave them and told them to read. Sometimes my girlfriend reads to them. We sit outside and discuss this book. By sitting and chatting we come to know more from other people who are also suffering.

It is my duty to help these people. You have to show that you are a leader in your community. You cannot turn away a person who needs help. At the Thokozani Support Group we learn to embrace people with the disease, no matter what. We know that we must love, support and show concern for people living with AIDS.”

Scared HIV-positive woman



Photograph by Lucas Ndlovu

I chose this photograph because this woman is HIV-positive. She doesn't know if her children are also positive. She has not had them tested. This is the house where she is renting as she is not staying at home. Her family chased her away when they heard that she was positive. The two children are learners and the other one is still too young to go to school. Only the young one gets a child support grant. I have encouraged this woman to become a member of the Thokozani Support Group but she said no because people would tease her. She wants to be left alone. I go to her home and keep her updated on what is happening on HIV/AIDS in the community. I usually take her children to the clinic for check-ups when it is their time to go. We all have a good relationship.

Like other members in the group, Lucas actively tries to recruit PWAs into the Thokozani Support Group. Having himself benefited from the support and education available from the group, Lucas proudly promotes membership.

“There is so much they can learn by joining. We all have something in common. It’s just so nice when we come together. We feel stronger and happier. We don’t feel lonely. We give advice and we take advice. Thokozani Support Group means to be happy, and when we leave in the afternoon, we actually feel happy.” *(Smiles broadly.)*

Apart from the group discussions, the Thokozani Support Group members often venture into the communities to talk to people, often exposing themselves to ridicule and sometimes anger. But for Lucas, these actions come at a price and perhaps, given his circumstance, one needs to keep an open mind and refrain from being judgmental.

“People like you to admit that you are positive and then they don’t stop asking you questions. Sometimes if you do not tell them that you’re positive, they will think that you are playing with them and they will get angry. But if there is someone who will stand up and say, ‘I am positive’, then people will believe in this disease.”

Lucas does not disclose his status freely. He only does it if he is paid to do so.

“When you are attending a meeting in the community and when you have to stand up on stage in front of a crowd of people, you can’t talk without money because you spread (disclosure of status) your name. But there is an agreement that we will talk as they challenge us, but they must try to give us something. Even R50 is enough for us,” *(Starts to cough again.)*

People, he says, want to hear from someone who is positive.

“And it must come from your mouth that you are positive. By doing this, people will understand this sickness and take it seriously.”

According to Lucas, there is a significant demand for AIDS awareness information. During a World AIDS Day event at Phateni last year (2004), he was paid to publicly disclose his status. After the event residents of the area came up to him and congratulated him on his courage.

“After the programme people asked me to talk to them separately and they shook my hand and said it was the first time they had seen a person who was not afraid to talk in front of other people about AIDS. People are very interested to know what can happen to them.” (*Continues coughing.*)

During a routine AIDS awareness programme, Lucas and the Thokozani Support Group first gained the trust of the residents by disclosing their own status as PLWAs. Then, the Thokozani Support Group members talk to the residents about symptoms, access to testing and support as well as methods to reduce the spread of the disease in the community.

“I go over the symptoms like constant flu, coughing, body aches and warn them to look out for rashes on the body or sores. My main advice to them is to determine their status by having themselves tested at the clinic. The clinic is right there and the sisters are very helpful. I know because I went through it myself,”

Fear of death, rejection and stigma are some of the reasons people do not want to have themselves tested. Sometimes, says Lucas, the symptoms are plain to see but people still refuse to be tested.

Grandmother looking after orphans



Photograph by Lucas Ndlovu

This is a grandmother at the back. The grandmother's children have passed away from AIDS. I was around this family offering support to the son and daughter who died. It was very sad for me because I grew very close to this family and saw the son die and, soon after, the daughter. The grandmother of these children, gets temporary jobs. Most of the time there is no money to buy food. They get food only once I think from the Drop-in Centre. Rain causes a lot of damage to the rooms of this house. I really worry about the older people like this grandmother because they are busy looking after the children of the children who have died or who have gone away.

They asked me why I am taking this photograph and if they were going to get help. For me, it was very difficult to say that they are going to get help. I just had to tell them the truth -- that it is for research purposes and I told them that maybe by the university seeing this, they could get help. They had no problem being photographed.

It seems that the disease has different rates of progression. For some, the onset is slow, but for others, the disease seems to rapidly result in a deterioration of health, which is why, says Lucas, the Thokozani Support Group members stress to residents that they must seek help from the clinic as quickly as possible.

“Sometimes the results take a long time to return and we encourage people to keep going to the clinic so they can receive some treatment for the illnesses they have. Some do go to the clinic. I see one or two of them come back to me to thank me for my help. These are generally the people who volunteer to become members of the Thokozani Support Group. I tell them to speak to Sister Mtungwa or Aunty Greta.”

Child-headed household



Photograph by Lucas Ndlovu

The grandmother of the children staying in this house passed away. She died of AIDS at the beginning of 2004. She used to look after the children there are three children staying in this house. They do not know where their mother or father is. Three children in this photograph get no support or grant. I took them to the social welfare offices so they could get help. I also spoke to the volunteers to sort out their birth certificates because they don't have any.

The lady in the back was so excited about the camera that she brought her children from next door to be part of the photograph.

Despite the willingness to spread their message across Richmond, the lack of resources, particularly money, has dampened the group's capacity to take their programme further than Ndaleni.

“We do not have the money. We cannot take the taxi; it costs money and the Thokozani Support Group has no money for that. So we cannot reach people. People from far away have to come to us, but they have no money either.” (Shrugs his shoulders and shakes head.)

Apart from the lack of resources, the Thokozani Support Group has to tread carefully to avoid conflicts with community leaders and even traditional healers. Failure to do so, says Lucas, may result in a conflict that would threaten the continued existence of the Thokozani Support Group.

In addition to information and training received from Sister Mtungwa and Aunty Greta, the Thokozani Support Group members rely primarily on their own experiences and the sharing of information that takes place within the group.

Members of an NGO from Pietermaritzburg, Siyaphila, occasionally visit the group, but even this help is received with skepticism by members such as Lucas.

“They hold talks about HIV/AIDS, but why must we wait for formal training? It will never come. The Thokozani Support Group was formed because we know there is a big problem in Richmond. We need to get together and help ourselves. When people say I need formal training, I get angry. You think people care about what is happening here in Richmond?” *(Asks defiantly.)*

Lucas’s cynicism is valid. He says many people have come to the group and have made rosy promises, but nothing has materialised. Their hopes have been raised and then dashed far too many times.

“We are still waiting. Our people are desperate. They need us and if they come to us we will embrace them, and if we go to them we will help them as much as we can,” *(Tone of voice is raised.)*

Returning to the issue of how the Thokozani Support Group helps PLWAs, I ask Lucas to give me more information about how he helps people. He begins by saying that he encourages people to use a condom when having sex.

“They must understand that it is important to use a condom, and it is important not to fall in love with many girls. Over here there are too many girls to one man. You know, it’s like playing a big game here. Everything for them is fun. They are not serious. I tell them as well that they must not smoke or drink.”

I remembered seeing Lucas smoking on more than one occasion. Surprised, I asked him why he hadn't stopped smoking, yet was encouraging others to do so.

Looking up somewhat sheepishly at me, Lucas replied that he had tried but could not.

"I was trying to stop smoking but I failed. I can stay half the day not smoking but when I start feeling sad or angry, then I smoke."

"But what makes you angry and sad?" I asked.

"When I think about my life and that I do not get a grant and there is no money to buy food, I get angry. Maybe if I get a grant I will stop smoking. Here in Richmond I don't know why the government finds it so difficult to give us a grant. We need it. The sisters often scold me about my smoking and I have been trying to stop but these things prevent me from stopping."

Social welfare in Richmond



Photograph by Lucas Ndlovu

I am happy that I had the camera to take this photograph. I took this photograph of people waiting outside the Social Welfare office for their pension and to register their children for their social grants. I wanted you to see that people need to wait outside

where there is no shelter. If it is raining or very hot they stay there and wait outside for a long time. It is very difficult for people and children to get a grant. Most of the children don't even have birth certificates. The people are desperate for money especially to buy food and pay for school fees. People who are HIV-positive come here hoping that they can get a support grant but we are always turned away by officials who say that we are very healthy. First, they will tell us to bring the paper that proves that we are positive. When we give them a copy of our results from the clinic, they look at us saying that we are very healthy and that we must go away. I think that it is unfair. We are not healthy people and we have no jobs. The disease is going to kill us very quickly.

Wondering how much of what he preaches he actually practises, I then asked Lucas whether he himself always used a condom when having sex. Again, with another sheepish look, he started explaining why he didn't.

“Yes, sometimes I use a condom, but sometimes I do not use a condom. But I need to tell people that they must use condoms so that they can be protected.”

Hoping for a brighter future for the Thokozani Support Group, Lucas, and the other members, have each pledged to donate R30 a year towards the organisation. This money, says Lucas, will be used to buy Vicks, StaSoft and other detergents which the group is hoping to resell at a small profit.

“The other dream I have for the group and that I am very excited about is buying a machine to make blocks. The church may donate two machines to the group, and they said they will send two of us to Durban for training. I think if we make these blocks people will buy them. At least it is something for us to look forward to.”

4.4 Sister Mtungwa Narrative

“People felt lost and I had a deep urge to want to do something. We couldn’t just leave our people like this. Clearly, nobody was doing anything to help our people, so we decided to help ourselves.”

Context

That morning was one big rush. I had spent at least ten minutes walking around the Richmond Clinic looking for Sister Mtungwa. It was no ordinary day at the clinic. The waiting rooms were filled to capacity and many of the men, women and children had now spilled over to the outside, patiently waiting for assistance. I enquired from at least three nurses about Sister Mtungwa's whereabouts. A short while later a nurse returned and pointed me in the direction of a room where I was told I would find Sister Mtungwa. I apprehensively approached the room expecting Sister Mtungwa to postpone the interview, given how busy the clinic was.

Getting the interview with Sister Mtungwa was not easy. Despite her agreeing to speak to me and even consenting to participate in the NRF research study, her long working hours had made it difficult for her.

I stood outside the door hoping that she would see me. She was seated at a table with a bundle of files in her hand. I always admired Sister Mtungwa. She is a pretty, sophisticated, middle-aged woman, who is always neatly clad and proudly shows off her nursing attire. Her hair is always neatly combed back into a bun, and for today, as she peered out at me, her spectacles rested gently on her nose.

Her disposition was stern and conveyed the air of an austere hospital matron. She exuded authority.

After a brief discussion on the duration and scope of the interview, Sister Mtungwa invited me to sit before uttering a few rapid Zulu instructions to a waiting nurse and closing the door to signal the start of our interview.

"It is not possible to take a break as I am in charge of this clinic and I need to go back to do the things that need sorting out," she pointed out politely just before I could formally thank her for the opportunity and begin the interview. I understood.

Despite wanting to probe Sister Mtungwa's life history, I decided to focus directly on the Thokozani Support Group, knowing full well that Sister Mtungwa had played a pivotal role in the CBO's genesis.

"How did the Thokozani Support Group begin?" I asked.

Explaining the emergence of HIV/AIDS in the community at the time (around the late nineties), Sister Mtungwa said that the spread of the epidemic was rapid and that more and more people were beginning to die.

"During my years working at the clinic, we nurses were very much aware of the HIV/AIDS disease. The chest hospital had a steady flow of patients. Tests for the disease confirmed that many of the patients were positive, but when we told them that they had HIV, they would stare blankly at us. It was clear that people did not know much about the disease. We knew that the more time we wasted, the greater the spread of the disease."

In around 1999 or 2000 (Sister Mtungwa cannot recall precisely), members of the community approached her and asked her for more information about the disease and what she could do to assist them.

"People felt lost and I had a deep urge to do something. We couldn't just leave our people like this. Clearly, no-one was doing anything to help our people, so we decided to help ourselves."

This bold decision resulted in the birth of the Thokozani Support Group in June 2001, and immediately attracted the attention of several community health care workers experienced in helping sickly patients. They wanted to be part of the group.

"We formed a good, experienced team of members in health care who were willing to offer support and help to others, not only as part of the Thokozani Support Group but from the clinic as well. That is why we even called the group, the Thokozani Support Group, meaning 'be happy'. We wanted everyone to be happy and feel comfortable even though we knew that so much pain was being experienced, not only from the disease but also from the political violence that had just ended."

Lady on drip under a tree



Photograph by Sister Mtungwa

“We were supposed to put her on the couch. Shame! She was so sick that day but we did not have enough bed space to make her lie down. She had her testing done at Ndaleni Clinic.

That day, I remember, I had to refer her to the hospital for admission. She was very weak and her blood pressure was very high. She was actually sitting there waiting for an ambulance to take her to the hospital. I asked her permission to have her photograph taken out as it was going to be used for the research study and she agreed. She did not mind.

She was supposed to attend the Ndaleni Clinic because her files were all there. But I don't know why she came to us. But then I could not turn her away. So I helped her even though her files are not at the clinic. I, as well as counselors, have informed her about the support group. She said she would think about it.”

Like everyone else who lived in Richmond, Sister Mtungwa and her family were directly affected by the violence that swept through the town during the late eighties and early nineties.

She and her family had to flee their home in war-torn Magoda and ever since, have been living in Richmond town.

The establishment of the Thokozani Support Group provided Sister Mtungwa with a direct way of providing meaning for her fellow residents of Richmond.

“We were happy to know that the group could help to teach people more about the disease, to teach them how to look after themselves and how to prevent other people from becoming HIV-positive.”

But despite the dire need for community-based intervention, it was difficult for the group to mobilise resources.

“I clearly remember approaching the local municipality early in 2001 to demand some type of office space so that we could hold our meetings. It was long, almost a year, before they gave us a room at the side of the Agricultural Hall which we could use to meet. Before that, members would meet under the tree outside the clinic. I also remember Thina-Bantu from the Drop-in Centre trying to make arrangements for us to meet there, but it didn't happen. We did not want our members to only come from Ndaleni, where the Drop-in Centre is located. The municipality advised us to become a registered organisation but that took too long and we had problems along the way. We found it difficult for someone to draw up a mission statement and to do the paperwork to become registered. Our main intention was more to reach out to people who needed our help. ‘Registration and all that will come later’, I said to myself.”

After the initial uphill battle of trying to find a home for the Thokozani Support Group, in 2002 and 2003 things started running reasonably smoothly for them, with sporadic funding enabling them to provide community support services.

“We received monies from the municipality and also Father Dominique's church. The mayor at the time and his councillors also gave us some money, about R800, to continue our work. We kept the money in a bank account. Of course, the more money we have, the more support we can offer ...

“But even the little we used to get every month, perhaps R400 and sometimes even R500, would take us a long way. We knew that we would never have a steady income. Sometimes we have money and sometimes we have to wait.”

The money the Thokozani Support Group received from donations, said Sister Mtungwa, is used primarily to conduct home visits. Within the group, the responsibility of identifying PWAs and potential recruits falls on the shoulders of Sister Mtungwa. She does this by identifying PWAs from the outcome of their HIV tests at the clinic.

“Where we can, members of the group will visit people that are really sick and suffering. We will attend to them and provide them with whatever support that we have. Sometimes, just looking at the condition of the sick person and the condition of their home is very, very sad.

“Sometimes we’ll just look at the person lying down on the floor, helpless, sick and in pain. We will be shocked, shocked, shocked. Sometimes we wouldn’t even know what to do or where to start.” *(Sister Mtungwa, shakes her head and adjusts her glasses.)*

Appreciating the enormity of the situation and just how daunting the task sometimes is, I asked Sister Mtungwa how she and the group respond in such severe circumstances.

“Firstly, we would ask other members of the family staying with the patient to be present there so that they could learn what to do as well. We then air out the room while at the same time make a fire to heat water.

“When the water is ready, we wash the patient using antiseptic to clean any festering sores on the body. We then give the patient some nourishing soup, which must be drinkable as they often have great difficulty in chewing and swallowing solids.”

Apart from treating the patient, the Thokozani Support Group members will not leave a patient’s home without first ensuring that they give the place a thorough clean-up, using disinfectant to kill germs, before having a final meeting with the family of the patients explaining all that needs to be done.

“We always try to leave some detergents, porridge, antiseptic and gloves, so that family members can continue to provide the patient with assistance. The last thing we do is pray and ask God to give the patients and their families strength.”

What little money the Thokozani Support Group manages to get every month is used for transporting members to the homes of patients and to buy antiseptics, detergents, porridge and sometimes even vegetables. Apart from this, according to Sister Mtungwa, Thokozani Support Group only dips into its bank account when a member dies and money is needed to attend that person’s funeral and to buy some flowers and food for the family of the deceased.

After making the necessary interventions, the Thokozani Support Group generally assigns either a member of the group or a community health care worker to periodically check up on the patients they have assisted, but more often than not, the odds are stacked against the disease’s victim which often shrouds the Thokozani Support Group’s efforts in despair and frustration.

“Sometimes we wouldn’t have to go back too often. The terrible living conditions, starvation and lack of medication swiftly take its toll on the patient and they die. It is often a very emotional time for us, especially when there is a flicker of hope that our efforts are actually helping the patient. Death is always very sad,” said Sister Mtungwa gazing contemplatively at the wall behind me before quickly recomposing herself.

Like so many of the people I had spoken to in Richmond, and even those I had formally interviewed, Sister Mtungwa battles to make sense of the prevailing despair and sadness enveloping Richmond and contemplates the involvement of witchcraft. Given all that has happened in Richmond, even educated people like Sister Mtungwa cannot be blamed for wondering whether Richmond has in fact been cursed.

“We used to just say that Richmond is ‘bewitched’. Nothing ever goes right in Richmond. It’s always one thing after the other. You heard of the violence here, so many people were killed and many children don’t have parents. Children walk around aimlessly. You don’t know where they are supposed to be, whether they are in school or if they even have a family. But here in Richmond we see this so often that we don’t see it as a problem any more. People and children are trying to fend for themselves. That’s it in Richmond,” said Sister Mtungwa sadly.

Sister Mtungwa has been through it all in Richmond and her attachment to the town and its people stems from the fact that this is the town of her birth. She was born in a place called Madudusini, walking distance away from the town where many of her relatives still live.

Despite a burning desire to educate herself and forge a destiny away from the suffocating poverty that would otherwise be the birthright of those born in rural Richmond, the road towards her goal was littered with obstacles that forced Sister Mtungwa to draw strength, courage and inspiration from deep within herself.

“When I was in Standard 6, I was forced to leave school because I had to go to work on the farm. I worked there for six months and then went back to school. The following year my mother told me that I was needed back on the farm. I was so angry, I just ran away. Eh, eh ... There was no way I was going to work on the farm.” (*Shakes her head frantically.*)

Getting an education, according to Sister Mtungwa, was the most important thing for her, and her desperate flight from the entrapment of farm labour was her first step towards realising her dream.

“I hated living on that farm. We were very poor as my parents earned very little. We had to get *uphuthu* (mealie-meal) from the farm and then we had to go and pick up *imbuya* (edible herb) from the garden. That is how I remember spending most of my childhood. I remember attending school at Ndaleni. I had to walk such a long distance from the farm to Ndaleni and then back to the farm. After school I had to look after my father’s cattle and all those things and I didn’t like that. I walked barefoot without shoes because my parents couldn’t afford to buy shoes or anything. My happiest moment was when I ran away from the farm and moved to Magoda with my brother and finished my Standard 9 at Pholela High School,” said Sister Mtungwa, proudly attributing this to her “wonderful and caring” brother.

Sister Mtungwa initially worked at the Nkomane Clinic run by the Dutch Reformed Church in the mid-eighties. Thereafter, between 1989 and 1992, she worked at Fort Napier Hospital in Pietermaritzburg where she completed her psychiatry training. She then returned home in 1992 and in June 1994, she took up a permanent post at the Richmond Clinic, bringing her face to face once again with the sadness of Richmond.

Although the Thokozani Support Group seemed well on the way to success between the years of 2002 and 2004, it was almost inevitable that the convergence of so many different people with such complex backgrounds and circumstances would give rise to internal conflicts that would present the organisation with challenges far more complicated than perhaps a lack of funding, and which would also ultimately result in the group suspending home-based care.

“You see, the Thokozani Support Group, as an organisation, experiences many problems. The members are happy but there are many problems that cause tension and fights ...

“At one point there was money coming into the organisation, and despite this blessing, members were divided over the money. Some wanted to share the money among the members, but the committee did not allow this. The other members then got hold of the bank account details and withdrew all the money.”

The lack of organisational control which resulted in the theft of the group’s funds had consequences far more serious than just the loss of the much-needed money. When news of the theft spread, the municipality withdrew all financial support and were soon followed by the Catholic Church.

“Sometimes,” said Sister Mtungwa, “I feel that they don’t know what they want or what they need. Sometimes they have all these ideas and plans but they don’t know how to carry out these plans. The members have the motivation, but I don’t know. We are going to meet tomorrow (January 27, 2005.) I said to them that they needed to draw up an agenda to tell us what their plan was for the year.”

But why, I asked her, did she not seize control of the group and develop the plan for the upcoming year, given all the in-fighting and feuding taking place among the members?

“You see,” she began, “the members are the ones who must draw up the plan. Greta and I are overseeing the Thokozani Support Group because they need some kind of direction and motivation. I was one of the founding members but I can’t make the plans simply because I am not a PWA. When the organisation was running smoothly, I used to really participate. Many of the actions and responses would come from me but then at a committee meeting, the chairperson said that all the work done must be driven by PWAs. So, if any plans come from me, the group

wouldn't follow that. It must come from them," she said, adding passionately that such an approach contributed to the empowerment of the group.

But did it? I asked.

With a sigh and then a slight pause, Sister Mtungwa said: "You see, there is this one girl, Nozipho,* and Lucas*, who is this man. These two members are dominant and they are always disagreeing on things. I said to him, 'No, Lucas, you mustn't think that you can't take orders from Nozipho. She is a very good person and she is doing what is best for the group. You cannot argue about your own personal issues', I would tell him.

"You see, Nozipho will go all out to try to help the community. She would even go to schools in Ndaleni and give talks there to children about HIV/AIDS. She would talk to them on how the disease is contracted and what precautions they should take in school. Nozipho will do that for nothing in return, but Lucas now will argue and say, 'Why is Nozipho not charging for talking?' That's how the fight starts. Nozipho gets angry and stops doing community awareness programmes."

Thokozani Support Group's main player: Nozipho



Photograph by Sister Mtungwa

'You do know she is pregnant now?' I opened my eyes and said, 'What is this now?' She cried. 'Oh, shame!'

She is such a hard working somebody, so good-hearted. She loves to help people with all the information on HIV/AIDS. She has guts. She is very dedicated. Now she is finding it very difficult. Now her work has become affected somehow.

This is bad because her job at the clinic is to inform women about VCT and how they should not be sleeping around without using a condom and now she is pregnant. It's sad. I told her she must try to accept it and not get stressed because her mother was not happy about this. There is nothing we can do.'

Sister Mtungwa went on to say that during World AIDS Day, like the one held in Phateni in December 2004, there were huge arguments in the group. While Nozipho and a few other members decided that they would reveal their status to the community members there and give talks to the people about HIV/AIDS, Lucas refused, saying that he would only do it if he got paid to say so. A total contribution of R250 was made by the organisers to the members of the Thokozani Support Group.

“Some of the other issues that worry the members are that they arrange for members from other non-governmental organisations to visit the group, like the Provincial AIDS Action Unit (PAAU) and National Association of People Living with AIDS (NAPWA). Those members come here to educate the Thokozani Support Group members on issues around HIV/AIDS but that is not sufficient. These organisations are not providing many activities. These activities do not even last. I mean there is no follow-through. Our members have the knowledge, the skills and the experience but how do you take it back to the communities? How do you do home-based care? You need medication and you need detergents to clean the house. That is why the members now only concentrate on sharing the knowledge and skills that they have with other people in their community.”

I enquired from Sister Mtungwa if the group had kept any written records of the work they had done. She giggled in reply, saying that there was no time for keeping records. Their only records

were in their minds – records of knowing what took place in those houses. She stated that the Thokozani Support Group’s response to these problems was more immediate and that she never really thought that anyone would ever ask for any record sheets reflecting what the Thokozani Support Group was doing.

However, the group does try to maintain a formal schedule of meetings.

“They meet once in two weeks. They talk about the progress of the group, they share their problems with each other and talk about the expectations of the group. But it does not always go well. Sometimes it is difficult to get all the members together at the same time.

“We also have some kind of an executive committee that doesn’t work very well. That chairman said to me that the community health care workers and myself must step aside. This made me cross and nothing else ever comes out of those meetings.

“Shame, it is so hard. Everything costs money. Even the weather. If it is too hot or too cold, people won’t come together. Sometimes it’s just that a member can be doing a job on that day. We don’t blame the members for not coming. It is hard. But now Lucas told me that they have just drawn up some new rules. He said that they decided that if a member does not abide by the rules, he/she must be fined R5.

“ Hey, I told Lucas, that it is hard. If people come, they come and if they can’t make it, they can’t. Some people might not come because they are sick.”

But apart from the lack of records regarding the Thokozani Support Group’s activities, Sister Mtungwa has attempted to inject skills and support to help the group grow. Using her access to health care networks, she suggested that a representative task team sit in on the group’s meetings to provide technical assistance. However, her enthusiasm for such initiatives soon had cold water poured over it when the health district office asked her not to get too involved. It was an instruction to which Sister Mtungwa did not take too kindly.

“We have some very skilled and trained nurses who are knowledgeable and can handle almost any patient. I thought that their contribution and input were very important and that my plan could have run smoothly. But the district office felt otherwise and said that PWAs must learn to

do things on their own. I was told to step back because I wasn't a PWA." *(She adds disgruntedly.)*

"My hope for the group is that there is someone out there who will be willing to help them. The group deserves it."

Thokozani Support Group is presently an unregistered organisation. The group has filled in the required forms a long time ago, but nothing seems to have happened. Initially, she says, a social worker was assisting the group, but they have now been referred to a new social worker.

"We are meeting with her tomorrow. We have long since filled in our forms and faxed them off. Perhaps this lady will be more active and will speed up our registration."

Recruitment of members is another area in which Sister Mtungwa is directly involved regarding the Thokozani Support Group, and she strictly monitors this process to avoid the kind of problems they experienced earlier.

Counsellors at the clinic



Photograph by Sister Mtungwa

This team specialises in collecting the saliva for TB. A lot of patients come to the clinic very sick and coughing a lot. They don't associate their illness with HIV. They always come here saying that they are sick, they have TB. They are tested and found negative for TB but positive for HIV.

The team will examine them and ask them to come after four days and after that they refer them to us for care. Most of them have been referred to us by this team. The patients that are tested positive are referred to the counsellors so they can be checked again. From the counsellor they go to the doctor, then to us. All the counsellors know about the Thokozani Support Group and will tell patients that when they are ready there is a group to support them.

“You can't say that just because you are positive you must tell them about the Thokozani Support Group. It did happen earlier when a founding member of the group (it was a male) used to just grab people and say that he heard that they were positive and tell them that they must join the group. Some people did not like that.”

Despite the resistance of the district office to allow the nurses to attend the Thokozani Support Group meetings, Sister Mtungwa encouraged the NGO sector to help the CBO. Apart from several workshops that the group has attended, Sister Mtungwa has nurtured a strong relationship with Pietermaritzburg-based NGO Siyaphila.

“There are two dedicated members from Siyaphila. We know them very well. They offer their services free of charge to us. They sometimes run workshops or make arrangements for us to attend events so that we can gather information.

“Our members really benefit from these workshops. Recently our members were invited to attend a three-day workshop on basic knowledge and transmission. Other workshops cover topics such as nutrition, positive living, and planning. It is very important that our members plan for the future, that they know how to draw up wills and things like that.”

The problem for the Thokozani Support Group, says Sister Mtungwa, is that the membership of the group is always changing which creates a knowledge vacuum. The membership turnover rate

is high, either through death, debilitating illness or members abandoning their association with the Thokozani Support Group for personal reasons.

One of the greatest challenges, as Sister Mtungwa remarked earlier, is the desperate need for a stable income to fund the group's activities. Here again, Siyaphila has tried to assist by teaching the members bead-making skills, but the group soon discovered that there was no market in Richmond for their products, and anyway, they did not have the money to buy the beads.

“There was a place in Ixopo, a Buddhist retreat where people would buy our beads and then take them overseas to sell. But the centre stopped buying them, saying we needed to be more creative and make new things out of the beads, as other people were making the same things. It just didn't work.” *(Sister Mtungwa sighs.)*

Lack of funding is not the only source of frustration for Sister Mtungwa and members of the Thokozani Support Group. Despite their community education efforts, people continue to allow themselves to be either misled or ignore the important advice they receive.

“You know, we treat patients and before they leave we explain to them what they can and cannot do. Two weeks later they are back, suffering from a sexually transmitted disease (STD) because they slept around. They know they are supposed to use condoms but they refuse.”

Waiting Line at Clinic



Photograph by Sister Mtungwa

I chose this photograph because this is what Richmond Clinic is about. This is the paediatrics section waiting area for the mothers and children.

This is also the area that I visit at least three times a day during my working hours to talk to the parents about the services we render here. I also explain to them about the importance of testing, the importance of adherence to the information they receive from hospitals, the importance of adhering to formula only and not giving their babies too much unnecessary medication. So I give them a general talk on these important issues. We found that a lot of these mothers were giving their children enemas because they believe that this will make the babies better. Some mothers are informed, but others are not because they are coming from different areas like Nhlazuka and Ndaleni. So I give them information about the importance of testing and about the Thokozani Support Group. I tell them that we meet twice a month.

Sometimes there are queues and queues of people that come to the clinic and we are understaffed. All these people sitting here have clinics closer to their homes but they just prefer coming here. They even ignore the mobile clinics. Our policy here at the clinic is

not to turn them away. We also use this opportunity to tell them about the availability of services in the places where they come from because it will save them time and money. The Ndaleni Clinic, for example, is open from six to six but they all come here.

“Other people blame the disease on witchcraft and feel they are victims. They then go to the police station and report their neighbours. So I don’t know. We talk and talk but still they refuse to listen to us ... I sometimes wonder what more we can do ... we’ve even got a TV that provides information. I really don’t know what other approach we can take. At least our members know the truth.”

Another stumbling block for the Thokozani Support Group is the dependence of the community on traditional healers. Despite the increased awareness about the dangers of not properly treating AIDS-related illnesses, residents of the area still choose to visit the traditional healer rather than the local clinic.

Sister Mtungwa hastens to add, however, that the Thokozani Support Group members, because of their close relationship with their communities, and being PWAs themselves, are playing a pivotal role in convincing people to place their trust in the clinic and the medication available there.

VIP Lady



Photograph by Sister Mtungwa

This lady is in charge of the TB patients. She plays a very important role informing the patients about VCT. They stay at the hospital for two months and then come back to us for another four months, only to find that even if they have completed their six months' treatment, they are still very sick. She'll talk to them. If she is unavailable to talk to them, she will send them to other sisters or to me. Then we talk. We get food supplements here for those who are very sick. Not for everybody. We used to have beans but not anymore. But we have pap and porridge to give to those who are very sick. Sometimes the patients complain about the taste of pap but it is healthy. We used to give some of them vegetables from the Thokozani Support Group's garden, but we stopped that now.

“Yes, some of them are dead set on going to the *inyanga* (traditional healer) to get *muti* (traditional medicine). There was this one girl I met at the clinic. She insisted that she go to the *inyanga* for treatment. I spoke to her and told her about how the medicine at the clinic was helping the Thokozani Support Group members. She eventually agreed and two weeks later came back to tell me how well the medicine worked.”

As Sister Mtungwa stated several times in the interview, she is not a PWA. But this does not stop her from being tested regularly.

“I tested last year because I wanted to go overseas. Fortunately for me, I am negative. Being a single woman at present, I really do not have to worry too much. I am happy to be single.”

(Smiles broadly.)

Although Sister Mtungwa is confident about her status and seems to have few anxieties, she does worry about her son, especially after her niece contracted the virus.

“Oh, I really worry about him ... you know my niece in QwaQwa, she had just completed her studies through Unisa and nobody suspected anything. I didn't suspect anything, until one day she became very sick and I took her to the doctor. She was deeply hurt when they told her she might be positive. We then went to Grey's Hospital. By then she was so sick. They admitted her for three days, but she didn't make it...

“Now I hear that her sister is also sick,” continued Sister Mtungwa sadly. “She was the first-born and her sister who died was the second-born. She is very, very sick. I begged her to go for testing, but she refused. I said to them that you are positive until tested negative, but she still refused. She told me that she would rather die than hear that she has AIDS, and that if she was positive then she would kill herself. I just left her. She later got very sick. We took her to a private doctor who diagnosed her with TB. Even then she refused to be tested.”

I almost lost my niece



Photograph by Sister Mtungwa

This is a photograph of my niece. I chose this photograph because she eventually did get tested and she was tested positive. Her CD count was at two, very very low. Your CD count can be between 4 and 1 500. She was very sick.

I helped her and tried to explain to her because the doctor did not give her a deep explanation. Once she started using this medication, she felt much, much better. So I did talk to her, saw to her medication and you can see her now, she has gained weight, she is okay.

I was really grateful that I could be there for my niece. It is through my knowledge and skills and my years of experience that I was able to help her, although it did take a lot of convincing for her to get tested. She was so stubborn. She used to say that she would rather die than know that she is positive. She is my family and had we not acted fast enough, she would have been my second niece to pass away. Also, everyone at home is supporting her. I taught her mother how to look after her.

Given the shock of her nieces succumbing to the virus, Sister Mtungwa is justified in being anxious about her son. He is 26 years old and lives in Johannesburg. He works at a call centre for a foreign company and regularly phones home to speak to his mother. But he, too, refuses to go for voluntary testing.

“He is my son and I miss him and love him, but even he is afraid to be tested. You cannot force somebody; it is his decision. He is old enough to look after himself. I myself am not afraid of death. I know that I am ready to die when my time comes. God can call me today. I am not afraid. I told my son that when I die, he must not worry as he will benefit from all my money and my policies.”

As for the Thokozani Support Group, Sister Mtungwa has a deep sense of personal fulfillment and believes that she is doing all she can for them and for the people of Richmond. She hopes, though, that the group does manage to find funding to become self-sustaining.

“They need to know how to generate money so that the organisation can carry on working. They cannot wait for the government to give them money.”

We thanked Sister Mtungwa that morning for affording us her precious time to be interviewed. Although I felt responsible for using up her time, I was really glad to have spent it with her. She did not have a break and merrily went off with her sandwiches and cool drink to face the rest of the day at the clinic.

4.5 Zanele Zuma Narrative

“He was always hitting my mother and he eventually killed her one day. People told me that he slaughtered her like an animal and placed her in a dish. But I was too little to know much of what was going on...”

As I waited for Zanele in the cool shade of a tree outside the Richmond Clinic, I couldn't help but wonder about her life. Twenty minutes had passed and there was still no sign of her.

"Has Zanele not come yet?" yelled Aunty Greta from one of the clinic's rooms. Not wanting to shout back, I shook my head. Aunty Greta left what she was doing and walked up to the gate, shaking her head. With her hands on her hips, she peered down the busy road hoping to catch a glimpse of Zanele.

"There she is ... she is coming now," yelled Aunty Greta excitedly before going back to her work. I sighed with relief as Zanele was the first of five interviewees and I was anxious to begin the data collection process.

Zanele is a hefty woman who is always smartly dressed. That day she wore a red summer dress with white flowers and a bright pink netted sun hat that shadowed her round face.

I had given her money to take a taxi from Ndaleni to the Richmond village, but I soon gathered that she had opted to walk instead, claiming it was a nice day to do so. Looking up at her, I noticed thick beads of shimmering sweat roll down her cheeks. She was huffing and puffing, and I decided to offer her a cool drink now rather than to wait for a break.

Zanele Zuma lives in Ndaleni in Richmond. She is the mother of two children and is a widow. Her husband died of AIDS-related sicknesses, leaving her infected and all alone to raise her children.

Her childhood, it turns out, was just as sad. Her mother was killed while Zanele was only in Grade 1. She does not remember her father, but recalls stories of him being a very violent man.

"He was always hitting my mother and he eventually killed her one day. People told me that he slaughtered her like an animal and placed her in a dish. But I was too little to know much of what was going on." (Her eyes lower to the bare cement floor.)

I sat frozen to my chair, staring at Zanele, not knowing how to respond to the horror of her mother's murder. I took a deep breath and asked her to continue telling me about her life.

"I can only remember having three other members in my family but other people said there were nine of us. So I do have other brothers and sisters, but I don't know anything about them. People say I was born in Johannesburg but grew up in Botha's Hill in Durban. I only came to Richmond because I was married here. This is also where my husband died."

Zanele's husband died of AIDS in 2000. As soon as she realised that he was positive, she had her children tested.

"They were negative. Eh, eh, eh ... I was so happy." (*Smiles proudly.*)

"My husband was very sick. He was bedridden from August 2000 to October 2000, the month in which he died. I went to the hospital the next month for a blood test, and found out that I too was positive. I was very sad, but had to accept it."

As the disease progressed, more and more complications developed in her life. The virus made it very difficult for Zanele to keep her job and before long she found herself unemployed and unable to feed her children.

"We used to work in the forest cutting grass in *imihosha* (river valley.) While working, I used to get severe headaches and my legs would ache terribly. My supervisor told me to rest when these pains developed. But you see, the other workers did not like that. They too stopped work when I was resting, and this made the supervisor very angry and he told me I must leave."

I was shocked to learn that Zanele and others like her were only paid R5 a day to cut grass, and, to make matters worse, they would have to work for 20 days and thereafter wait for two months before getting paid.

"Well, you see, most of the people that worked there were people living with AIDS. So maybe the supervisor made us work and hoped that we would pass away before we needed to get paid. But what could we do? We need money and there are not enough jobs around for us to earn money. So we just have to take what we get, even if it means us having to wait for it."

Although the money she earned was paltry, it enabled her to buy food for herself and her children, something she is struggling to do at present.

“I always have a problem with getting money to buy food. The day before I received my grant I went to bed hungry. But now we are used to it.”

Occasionally, Zanele manages to find odd jobs in the village, which pay around R10 a day. At other times neighbours pay her the same to do ironing and other household jobs for them, which is ironic, as earlier in life, Zanele lived in Durban and was employed as a domestic worker. She left her job then because she felt she was being underpaid.

Zanele was looking much more relaxed and settled. I asked her about the Thokozani Support Group and how she became a member.

“I joined because I saw other people in the group who were positive and it made me happy to realise I was not alone. Although people in the group were HIV-positive, they looked healthy and happy and this encouraged me to join.”

“I felt very happy to hear that there was a group like the Thokozani Support Group. Actually I was very relieved. I didn’t know what AIDS was, but now I have learnt so much, I am now able to help other people and encourage them to live healthier lives.”

Joining the group in 2000, Zanele is now the last surviving member of the first batch of members. Over the last five years the disease slowly claimed the lives of the group’s founding members. Zanele’s statement sounded familiar and I recalled a previous meeting with the Thokozani Support Group in which I learnt that between 2002 and 2003, at least six members died. The high death rate means that the face of the Thokozani Support Group is continually changing as members succumb and new members take their place.

“But what does it mean to be a member of the support group?” I asked Zanele.

“Being part of the Thokozani Support Group is just about getting together and being together. We can all come together because we have the same disease. We talk, help and support each

other. So we share the same experiences. As members of the support group, we also look out for people in the communities who need our help. In our group, we can talk about their needs too and see where we can help them.”

Woman chased away by family



Photograph by Zanele Zuma

This woman is HIV-positive and her child has just died of AIDS. The family of this woman chased her away because she told them that she is positive. She is now renting in Richmond. I visit her and speak to her and tell her to join the Thokozani Support Group. I tell her how to live positively and how to take care of herself. I offered her support and prayer when her child died. I often do that when families find out that someone is HIV-positive and the family chases them away, but I do know that there is some place in Richmond where women who are chased away can go and stay. It's some church or organisation, I don't know.

Listening to her, I realised that the Thokozani Support Group was a source of great comfort and encouragement to Zanele. She told me that after disclosing her status, some people in her community became nasty to her, even accusing her of infecting her now dead husband.

“What can I say?” *(Looks sadly at the floor.)* “That is what a lot of people think. This is life in the community. Sometimes the community is your judge. You can't fight about it. You just have

to keep quiet. I try very hard not to worry about anything. I am happy in my heart because the Thokozani Support Group makes me happy. Thokozani Support Group means ‘to be happy’. The members are my true friends.”

Despite the personal hurt and anger she feels, Zanele has adopted a mature and responsible stance towards the discrimination she experiences. She believes that the members must try to educate people about the disease so that they understand that “it is wrong to discriminate”.

I was impressed with Zanele’s outlook and now saw in front of me a strong, confident woman who was striving not only to make a positive difference in her life, but also in the lives of other people in her community.

Hard times in Richmond



Photograph by Zanele Zuma

Shame! I feel so sad looking at this photograph. The woman of this house is HIV-positive and is my friend. She used to be a member of the Thokozani Support Group, but she left because she is too sick to come to meetings. I go to her home often to help her with any chores or if she needs me to go anywhere for her. I took this photograph while there were

heavy rains. And thank God I had the camera with me so that you could see how this house gets flooded. She has nowhere else to go. The house is always affected when it rains heavily. So many times the house has fallen down. The municipality only gave her a sponge and some food once or twice. So the next time there are heavy rains, I know that I have to get ready quickly to go to visit her and help her clean up.

Unfortunately, being a member of the Thokozani Support Group was not always easy, let alone pleasant at times. During her five-year membership, Zanele has encountered all sorts of people who have become members, many with interests and agendas other than to provide help and support to the community.

“Some people feel that if you are positive, then you have to get something for it. Many members left because they were not getting anything for it. They joined for the wrong reasons. You must be in the support group because you want love and support, not because you want money. With the Thokozani Support Group you will find people to talk to, people who will listen ... so that at the end of the day, you will leave happy.” *(Reaches for remainder of her cool drink before taking a hasty sip.)*

Now knowing that Zanele was one of the first members of the organisation, I quizzed her about the organisation’s genesis – who was actually behind the establishment of the organisation? She recalled a man named Mabongi, but couldn’t be sure.

“After I received my results and found out that I was positive, Sister Mtungwa and Greta asked me if I would like to join the Thokozani Support Group. I attended the first two meetings and haven’t stopped attending since then. *(Nods her head confidently.)*

Despite the occasional setbacks, including, as I was to later learn from her, some that jeopardised the very existence of the Thokozani Support Group, the members, under the guidance of Sister Mtungwa and Aunty Greta, made a valiant attempt to grow and strengthen the organisation.

“Well, we tried to make ourselves powerful as a group. Greta always tells the members that we must not sit back and do nothing because we are positive. Greta motivated us to start a vegetable garden and to keep busy doing things like that. So we started a garden.

“And we had some training in beadwork from two members who are from Siyaphila. We learned to make rings and necklaces but soon found that no-one in Richmond was buying them. We then tried sending the beadwork to Ixopo where people would sometimes buy it.”

Like any other organisation, the Thokozani Support Group relies on income, no matter how small, to undertake its work in the community. Much of the money raised would be used for funeral expenses for members who had died, while the group’s efforts at providing home-based care swallowed up the rest.

Before I could ask Zanele about home-based care, she surprised me and asked me a question. “Have you been to houses where someone is dying of the disease?” she asked.

“Not really,” I replied, adding that I visited Nozipho* at her house in Ndaleni and that she had pointed out the homes of some people living with AIDS.

“People are sick and dying in their houses. The mothers are very sick. They cannot walk or do any housework or cook food for the children. Their bodies are covered with sores. It’s like their bodies are rotting. They have nothing. Sometimes they don’t even have food to eat.

“We would visit them and take vegetables so that they could have some healthy food. We also took washing powder and soap to give them a bath and wash their clothes. If we could afford it, we would also buy Savlon to help clean the patient’s sores, and hopefully make them feel a little bit better.”

I complimented her on the sterling job that the group was doing, but she shook her head ruefully at me, and I knew that something dramatic had happened at the organisation.

“This was only happening at a few houses about two years ago. That was all we managed to do because we didn’t have much money. The church was giving us some money and with that we were able to do some home-based care, but we couldn’t go to areas like Patheni and Inhlazuka. But then there were some problems with the money. I think some members stole from the group’s bank account and the church stopped helping us ... it was a big problem and since then we have stopped home-based care.”

I asked her what training she had received in order to undertake home-based care and she replied that members would train each other, and that by talking, members gained the information required.

“No, not really. You see, we have Greta and she knows everything because she works with the community health care workers and the volunteers and does the training with them on home-based care. But our main job was to try to make the person comfortable, like give them a bath, wash their clothes and clean their house and I don’t think we needed training for that. We would also just sit with them, give them company and read from the Bible. We try to talk happy things to them. They will also ask us questions about what is happening about the disease and we also learn a lot from spending time with these sick people.” *(Speaking confidently.)*

“What do you learn from these people, Zanele?” I asked.

“You see, we learn more about the sickness. We can actually see what is happening to them, you know, like when they have AIDS. We see the sores, I mean big, big sores on them, the shingles that cover their body, the glands on the neck are so big. Shame, some can’t even eat food, they can’t swallow the food. But we give them porridge. We see the suffering and also the children suffer because the mother is so sick. They even cry because of the pain.

“Ooh, ooh, but I feel very disappointed that the group doesn’t do any home-based care now. We love to do that but we don’t have the money. But that doesn’t stop us. Some of the members will still go and visit people and talk to them or help them with the cleaning of the house or to cook some mealie meal or cook some vegetables from our garden for them. Even if we don’t have the money we are still part of our community and the people there. We love them and we like to be there for them, especially if they have small children who need attention and support.”

(Expression of sadness fills Zanele’s face.)

Two children that are orphans



Photograph by Zanele Zuma

I took this photograph because I wanted to show the children here. Their mother died of AIDS. They are staying with their grandmother and aunt. They also get food parcels from the Drop-in Centre. The thing that made me take the photograph is that these children need help because the grandmother is not getting any pension. They also applied for a grant for these children. They don't live too far away from my home so I always visit them so see how they are doing. I love these children. Sometimes when I ask Greta to give me something from the garden to cook for supper, I take some for these children too. I try to help this family by arranging their grants and birth certificates because I go to the village often. I also have a list of other children that need social welfare support. Some people feel that because I am a member of the Thokozani Support Group, I can get things done quicker, but it takes a long, long time.

At one of the homes, which the group visited to provide home-based care, they found a man, perhaps 50 years old, lying asleep on the cold mud floor. It was raining and the floor was wet. He had no food and no blankets and there was no-one to look after him. The group visited the man

every day until he died, feeding him, clothing him and trying to make his last days as comfortable as possible.

At present, Zanele is the Thokozani Support Group's secretary, a position which she evidently relishes and is proud to hold.

"I take down notes of the meetings we have, I record the dates when we have the meetings and I also have to inform other members when the next meetings will be held. My other job is to go to the community and do community awareness around HIV/AIDS, even at the clinic. If there is an AIDS day we also try to make that day special by making people in the communities aware of the disease...

"Occasionally white people from the village help by donating old blankets and food. Several NGOs have also visited the Thokozani Support Group, but, apart from Siyaphela, all have made hollow promises and have not returned."

Orphans from Botha's Hill



Photograph by Zanele Zuma

The mother of these children died of AIDS. These orphans are staying with the grandmother and she gets a pension. The grandmother has also applied for a grant for these three children. They are all at school.

These children do not stay in Richmond. They stay in Botha's Hill. During the time I had to keep the camera, I had to look after my very sick cousin in Botha's Hill who is also HIV-positive and is dying. I hope you don't mind. I just wanted you to see that these children and a whole lot of other children staying here are supported by the organisation Valley Trust working there. The organisation buys the school uniforms for them and does many other things for lots of children there because there are lots of orphans there too. See how nice and happy these children look. They even look healthy. I always ask this group when they are going to come to Richmond to see how our children are living. These children know me very well and I look after them when I am in Botha's Hill. They were very excited to have their photograph taken and they said that I am a very important lady.

But Zanele and the other members soldier on. The Thokozani Support Group has gained both the trust and confidence of the community. Consisting of members who are themselves infected with the HI virus, people find it easier to ask them for help.

“Others, they come to us and explain their problems, like headaches, running stomachs and coughing. We advise them to go to the clinic first so that they can speak to Sister Mtungwa. If that person decides to take a HIV test, it must come from the clinic. If the person is found positive, then it is Sister Mtungwa who will tell the person about the Thokozani Support Group. We are not allowed to just let people become members. We will find that some people are afraid to join the group because they are not prepared to expose their status.

“Like with this one man. I looked at him and saw that he was sick. I approached him one day at the clinic because he is my friend. I asked him what was wrong and he said that he didn't really know. ‘I think there are people who bewitched me at work’, was his reply. He did go for a blood test and he revealed to me that he was positive. He also told me that Sister Mtungwa and Greta informed him of the support group and gave him the dates that the group met. He is very happy to come to our meetings because he says that he can see many other positive people. He used to

stay in Inhlazuka but after he joined the group, he moved to Ndaleni because then he could be closer to the support group.”

Being a member of the Thokozani Support Group has also impacted on the personal decisions Zanele makes. Practising what she preaches, Zanele stresses that she practises safe sex and at all times tries to stay confident.

“I don’t have a problem because I accept that I am positive and I am prepared for anything to happen to my life.”

As I sat there listening to Zanele and trying to comprehend how she so bravely deals with all the sadness in her life, I decided to brighten the conversation by asking her about the happier moments in her life. But, as it turned out, very little of Zanele’s life has been happy.

“I cannot really remember some of the happy moments in my life. But I know that I was very happy when I got married and stayed in my own house. That’s all and there are not many happy things that happened in my life or I can talk about.”

Looking back on her life, Zanele remembers her childhood as an orphan living in Botha’s Hill where she was forced to wake up “extra early” to herd the goats before school.

“Again in the afternoon, I had to take the goats and the cows to the river to drink water. It was so terrible but there was nothing that I could do because I was staying there with these people and I had no other place to go to. So that is how I remember spending my childhood until I became older. After that, I went away to Durban to look for a job. I had a domestic worker’s job. I was doing washing and the cleaning of the house but I left because the money was too little.”

The one factor that seemed to have punctuated the lives of all living in Richmond was the political violence. For Zanele, not only was the turbulent period traumatic, but also signaled the time that “the soldiers brought the disease to Richmond”.

I asked her about that, and after a long silence with her head raised to the ceiling, she looked back at me with tears in her eyes. I told her not to worry and that perhaps we could speak about it some other time, but Zanele clearly wanted to get it off her chest.

“Oh no! The university must know what happened to the people. I was affected by the violence. I lost a lot. My house was burnt down. They burnt down many houses and we had to sleep in the forest. Many of our things were stolen from inside our houses. They would even steal the meat from the fridges of the people. They would take anything and everything. Some people I know, they burnt down their houses, killed their children and their father. There is another family I knew, they killed the whole family, the father, mother and four children. There are many families where there are only children left. Their parents were killed. These children have no one. Some children were lost but they don't know where their parents are or what happened to them.” *(As if trying to get through the episode as quickly as possible.)*

Aunty looking after orphaned nephews



Photograph by Zanele Zuma

These children are staying with their aunt. She is the one at the back in the white T-shirt. She is like a mother to these children. She supports these children by getting temporary jobs. Their mother died of AIDS and the father was involved in the violence. These children go to school. Their grandmother used to pay their school fees, but she too passed away. She used her pension money to pay the school fees. Now I don't know how they are paying school fees. These children are doing so well at school. I had to go to their schools and explain to the principal the situation at home so that these children too don't get chased away for not paying their school fees.

“What is your opinion of the soldiers that were here during that time?” I dared to ask the woman.

“Some soldiers were fine but other soldiers, you could not understand if they were on our side or the other side. The soldiers were abusing the youth and also members of our families. The other thing is that the girls were falling in love with these soldiers. It was so sad for me because these soldiers were not going to stay in Richmond forever. Some girls were too young to know that they were being used. Other parents allowed this and liked the idea because they got free groceries or money for their daughters being with the soldiers. But there were those people who didn't like the idea and were angry.” (*Speaks helplessly.*)

“Some people that I spoke to in Richmond say that the ‘soldiers brought the disease’. Do you agree with this?” I asked.

“We only started hearing about the disease after the soldiers left. More and more people started dying only after the soldiers left. So I think that the soldiers did help to bring the disease. The girls were very happy with the attention they were getting from the soldiers. The soldiers were spending time with more than one girl at a time. And suddenly, all the soldiers were gone. I don't think even one soldier came back because he ever loved a girl.” (*Speaks out angrily.*)

“We need to tell the people that AIDS can kill and we are people also living with AIDS and that it is important to go for testing so that you know your status. It is dangerous to stay at home without knowing your status. We also tell them to stop saying that it is the neighbours who are bewitching the children and adults and that is why they are dying. People, they need to know that there is AIDS all around. If you are HIV-positive, you need to accept it although it is difficult. We, as a group, we are trying to encourage people to go for testing and to stop saying that it is witchcraft. We also give them pamphlets so that they can read about HIV/AIDS.”

“I will not lose hope. I see myself as a strong person and with that I will continue with life because I know I have the power of God by my side and the help and support from the members of the Thokozani Support Group.”

Chapter Five - Discussion of Findings

5.1 Introduction

Despite my intentions to map the genesis of a community-based organisation in Richmond and its contribution to community learning, if anything, my journey into the soul of Richmond has given me a unique perspective on the realities and dualities of South African life for which I am grateful. Having borne witness to some of the most extreme cases of abject poverty and sorrow, I leave Richmond filled with hope because I have also witnessed the immense courage, bravery and determination of a handful of individuals who are making a difference against the greatest of odds.

It is here that I try to make sense of all that I have heard and seen in Richmond and this section provides not just a summary of the facts and findings that have emerged from my data collection but also perspectives and patterns that have emerged from the intimate relationships and friendships that I shared with five members of the Thokozani Support Group.

5.1.1 Purpose of Study

Overall, the purpose of my undertaking was to excavate and thereafter illuminate the contribution that the Thokozani Support Group was making with regard to community learning in Richmond. It is a simple research question, yet the complexities of the Richmond society created realms and dimensions to my research that were unexpected yet, in retrospect, provide a richness and fullness to the data.

In order to achieve the objectives inherent in the research challenge, one needs to deconstruct the research question: How has the Thokozani Support Group contributed to community learning?

From the above question, several concepts, themes and challenges emerge. Before one attempts to evaluate the “how” with respect to the group, one has to unpack the concept of community within the context of Richmond. Through this understanding I was able to

bring into focus the lens required to peer into the depths and recesses of the Thokozani Support Group.

Unlike NGOs and other more formal organisations, the Thokozani Support Group as a CBO consists entirely of individuals who are intricately attached to their community and to the challenges they hope to address. More importantly, these are not arms-length challenges: members of the Thokozani Support Group, the majority being PLWAs, are directly affected by events and circumstances unfolding, and this “*potjiekos*” of complexities and experiences contribute daily to the functioning of the group and its impact within the community.

I cannot over-emphasise the importance of the concept of community contained within the research question. My understanding of community within the context of my urban upbringing, proved frustratingly inadequate to absorb the texture of society in Richmond.

Notwithstanding the fact that Richmond has a deeply fractured and turbulent history, the township communities I came face-to-face, with provided rich evidence of a community culture very different to what I experience living within urban communities.

Urban communities, to which I am accustomed, are defined primarily as residents sharing similar cultural and economic circumstances. Apart from local government elections, the work of religious institutions and perhaps the establishment of community watch forums, which incidentally would qualify as a CBO, residents participate in very little collective action.

Township communities in Richmond appear to be distinctly different from suburban communities in that there are a significant number of individuals who actively engage in activities that address the welfare of others in the community. The Thokozani Support Group is one such manifestation. During the time spent with members of the organisation it became clear that apart from the emergence of CBOs such as the Thokozani Support Group, the local ward committees and Sakisizwe (which at the time was a township youth-based CBO) residents actively engaged in other community-based activities, including stokvels.

All of the participants voiced their concern about the prevailing socio-economic challenges facing Richmond and indicated their individual determination to try to make a difference. The proliferation of CBOs, in this case the Thokozani Support Group, is a prime example of social interdependence in which a common challenge gives rise to a structured community response. However, in the case of Richmond, it also appears that the community has several other anchor points that assist in creating the cohesion required for the community to function as a collective.

Paramount to this is the embedded set of values and traditions associated with the concept of traditional governance. Apart from the local ward councillor and the associated municipal leadership, the community has re-instated and embraced its traditional leadership consisting of local *Indunas* and *Amakhosi*. This institution was banished from ANC-controlled townships during the nineties because of its links with the Inkatha Freedom Party.

These institutions now work within a carefully structured framework developed and administered jointly by the Royal Household and the Department of Traditional and Local Government Affairs. The re-emergence of a fully functional traditional leadership dimension has re-inforced traditional collective social norms and values within particular communities. Within this context, issues of community importance are often discussed communally and decisions taken thereafter.

It also appears that the local clinic is another anchor for community unity. Apart from merely supplying medical services, it is also a place for gathering and discussion. Sister Mtungwa at times finds herself overwhelmed by the number of people coming to the Richmond Clinic, this despite the fact that there are already mobile clinics servicing some of the townships further away. She and Aunty Greta use the clinic platform to disseminate information on HIV/AIDS as well as to encourage PLWAs to join the Thokozani Support Group.

Barab and Duffy (2000: 197) propose that a community has “a significant history, shared cosmology, a common cultural and historical heritage, social interdependence and reproduction cycle”. South African urban communities fall substantially short of the above definition with respect to the required characteristics of having a destiny and social

interdependence. While I have already touched on the lack of social interdependence in urban communities, the achievement of “shared destiny” is impaired by the high degree of urban mobility and mixture of classes within urban communities. By this I mean that urban communities are not characterised by a single class structure. Within these communities you have a mix of merchant, working and unemployed classes, which, although sharing the same community, do not share the same destiny.

Townships in Richmond, however, display all the characteristics to qualify for Barab and Duffy’s definition. They have a significant history defined not only by the prevailing socio-economic climate, but also by the indelible impact of recent political violence; apart from some exceptional instances, families within the community share a common destiny shaped more by macro influences given the levels of disempowerment; the community shares a common cultural and historical heritage that has a tangible manifestation in systems such as traditional leaders and traditional healers; survival and relative prosperity are largely linked to social interdependence as well as to adherence to community norms and values.

The high degree of social interaction, social interdependence and subscription among the community to a similar set of social norms, values and practices, therefore, lays the foundation for Wenger’s social theory of learning to be realised. He says the concept of community learning is a social theory of learning in which the primary focus is on learning as social participation through active participation, thus creating communities of practice. The Thokozani Support Group, therefore, is a realisation or manifestation of a community of practice. It draws from a pool of interconnected people who share similar circumstances and supports them in deepening their knowledge and by facilitating interaction on an ongoing basis.

Lending further support to the concept of community learning contained within the research question, Barab, MaKinster and Scheckler (2003: 23) advance the view that the community is a “persistent, sustained network of individuals who share and develop an overlapping knowledge base, set of beliefs, values and experiences.”

5.2 Conceptual Framework

As I said earlier, my journey of research revealed realms and dimensions that I was not expecting to encounter. Nonetheless, I have striven to present and interpret my findings within the parameters set out in the chapter.

My leaning towards qualitative methodologies and specifically a bimodal form of both life history and photo voice appears to have been vindicated and I fully appreciate Dunpath's (2003) view that to fully understand an institutional structure and its behaviour requires that we see organisations as collectives of individuals who are constrained and shaped by their context.

5.2.1 Research Participants

A sample group of five individuals belonging to the Thokozani Support Group were identified. They were asked to participate in a research process that would involve semi-structured open-ended in-depth interviews. All ethical and consensual considerations were taken into account during the sample selection and subsequent interviewing phases. However, despite permission from the subjects for their identities to be revealed within this discourse, given the sensitive nature of the data emerging, I have opted to conceal the identities of some of the participants.

5.2.2 Analysis of Data

Data collected from the open-ended interviews was converted into narratives, which as I noted earlier, are stories distinctly capable not only of transferring factual information but also of capturing subtle emotion and mood which enhances the reader's understanding.

The use of the life history methodology did, however, provide me with a unique opportunity of developing intimate relationships with the people with whom I came into contact. Whether this proximity to the research participants clouded my objectivity, I cannot tell. However, I make no apology for any emotional attachments I have developed with members of the Thokozani Support Group. Their life stories have had a profound impact not only on my outlook on life, but also on my understanding of our society.

However, a word of caution: Given that narratives are by their nature subjective and that their focus is not necessarily on historical accuracy, other scholars may derive conclusions and opinions that differ from my interpretations. These I would welcome, so long as it enriches and broadens our pool of knowledge and contributes to the further empowerment of organisations such as the Thokozani Support Group.

Using a bimodal data collection strategy by incorporating the photo voice research tool, I have hoped not merely to add on to the research but to provide an additional dimension, by allowing the participants themselves to provide us with a glimpse of their world through their own eyes.

5.3 Findings

Conceptual and Environmental Overview

5.3.1 Richmond

Nothing can really prepare you for Richmond. As a visitor passing through, Richmond is a picturesque town nestled among the green rolling hills of the KwaZulu-Natal Midlands. With a bustling and noisy central business district, it resembles one of any number of other smaller towns scattered throughout the area. Yet below its surface and Richmond reveals itself to be a deeply disturbing place.

Much has been documented about the violence that simmered for years among the town's politically divided communities. It is also well known that much of its rural population lives in poverty and that HIV/AIDS is also rampant, and Chapter Two outlines much of this. However, none of this prior knowledge prepares you for the depth of the tragedy that is unfolding in this town, 30 minutes away from the province's capital.

Referring to Dunpath (2003) I noted earlier that organisations, particularly CBOs, need to be seen as collectives of individuals who are both shaped and constrained by their contexts.

Perhaps the most striking feature of all the participants in the research process is their proximity and attachment to the Richmond environment. All of them live in Richmond and all of them are in some way directly affected by the town's past and its present.

Relatively speaking, the violence that engulfed the region occurred fairly late on the timeline of events that contributed to the shaping of the contemporary socio-economic issues affecting the town. Undoubtedly, violence played a fundamental role in the destabilisation of Richmond, but the seeds of today's despair were sown much earlier.

5.3.2 Economy and Poverty

The economy of Richmond and its surrounds is largely agriculturally based, involving primarily farming and forestry. While providing the bulk of employment opportunities, the sector is largely characterised by labour exploitation and is seemingly unable to meet the job demands of the area's growing population. Given the high poverty levels, coupled with the high unemployment rate, it comes as no surprise that there are those willing to exploit the desperateness of those in need of work. Lucas recalls his experiences cutting grass at the timber plantation:

It was a job for HIV-positive people and I got paid about R25 a day. It was very hard. You see we had to work for 15 days and could only collect our wages after about three months. Maybe they hoped we would die before being paid or maybe they wanted to make sure we kept returning to work.

Given the lack of job opportunities and rampant labour exploitation it is a small wonder that the majority of families in the area seem to live below the poverty line. Apart from Sister Mtungwa and Aunty Greta, all of the participants, and as I am led to believe, all of the other members of the Thokozani Support Group, are largely unemployed and live from hand to mouth.

As in the case of Nozipho Langa, poverty, hunger and the frequent inability to provide her children with a plate of food often leads to anger, resentment and bitterness:

Why are all you people coming here saying that you want to help us? We have no food; we are hungry and our children are hungry.

Emotions aside, the stark reality of not being able to feed herself and her young children has meant that she, like other young, single mothers in the area, has been forced by circumstances, and notwithstanding the fact that she is HIV-positive, to resort to prostitution as a means of surviving. As she says:

Sometimes I was so desperate for money to feed my children that I often worked as a sex worker. So my friends and I used to get paid for doing that, you know, selling our bodies.

Unsurprisingly, the vicious cycle of poverty breeds other negative social consequences. Against the backdrop of a “catastrophic” AIDS epidemic (SAHRC, 1999), and in the absence of a sustained, well managed and participatory programme, the outlook for particularly the poor and unemployed in Richmond remains bleak.

5.3.3 HIV/AIDS

The sheer scale of the epidemic and its consequences in Richmond leave one bewildered in attempting to find an entry point that would adequately quantify the impact of the disease in the area.

All five of the research participants are directly affected, and some infected, by the virus. Sister Mtungwa who runs the local clinic and who was instrumental in forming the Thokozani Support Group has this to say:

The disease came suddenly and spread rapidly. More and more people started to die. We nurses were very much aware of the disease. The chest hospital had a steady flow of patients and tests confirmed they were positive

Death, however, is but one of the consequences arising out of the HIV/AIDS epidemic in Richmond. The emerging data reflects a plethora of issues such as orphans, child-headed households, denial, fear, helplessness, ignorance, sickness and superstition, each of which has its own trajectory.

Constraints of both time and space, frustratingly, prevented me from delving deeply into these issues. However, given their importance in relation to the Thokozani Support Group's impact on community learning, the following is a brief overview of the emerging themes related to HIV/AIDS. Some of these issues will be expanded upon as the discourse unfolds.

5.3.4 Information

Among the many challenges created by the epidemic and one that is central to the Thokozani Support Group's purpose is that of information – its dissemination and the barriers to its proper dissemination.

In the context of information one finds within the data a clear pattern of ignorance, denial and superstition that, apart from constraining the efforts of the Thokozani Support Group, contributes to the entrenchment of HIV/AIDS within the Richmond community.

Upon learning of their HIV status, many of those infected refuse to accept the outcome. All of the Thokozani Support Group members interviewed, at some point or other, express frustration and, at times, outrage that despite the evidence, people stubbornly refuse to come to terms with the disease:

"People keep saying there is no such thing... "

"You know, its like playing a big game here, everything for them is fun."

"She told me she would rather die than be tested for AIDS."

The denial, however, is not baseless. In fact many of the members of the Thokozani Support Group understand first-hand the fears and anxieties and stigmatisation associated with the disease.

Take Lucas Ndlovu for instance. Despite an inherent fear of death, rejection and stigmatisation, he found the courage within himself to undertake the test. Perhaps he found encouragement and support in the fact that as a member of the Thokozani Support Group, there were other members who had disclosed their status and who understood what he was going through.

The ramifications for those who, because of their fears, anxieties and superstitions, deny themselves access to information and support are very severe. The disease is ruthless and takes a frightening toll not only on the infected person, but also their families.

5.3.5 Manifestations of HIV/AIDS

The disease manifests itself in many ways. Those infected develop severe headaches and Flu-like symptoms, black spots all over the body and sores in the mouth and throat which make eating almost unbearable. They become weak and cannot walk, sores begin to fester, they develop diarrhoea. The body becomes susceptible to tuberculosis (TB), rashes develop and the skin begins to peel, particularly on the hands and feet. Sometimes the onset is slow and lingering, but for some the disease progresses rapidly.

The mother was very sick. She could not walk or do any housework or even cook food for the children. Her body was covered in sores. It is like her body was rotting. She had nothing.

The consequence of HIV/AIDS is the further breakdown of families, resulting in an additional financial burden of caring for income earners who are now too debilitated to retain employment. Ultimately, the disease kills, leaving in its wake a dramatic increase in orphans and child-headed households. Nozipho Langa explains the emotional turmoil she sometimes experiences:

Sometimes I get fed up with life. Look at the people in Richmond. People are crying for food, people are sick and they are dying. There are children looking after children. I have such a big family and I have three babies too. What will happen to them if something happens to me?

Sister Mtungwa paints an equally bleak picture about the impact of HIV/AIDS on the community. She even wonders whether residents have a distorted sense of what is normal and what is not:

We used to just say that Richmond is bewitched. Nothing ever goes right in Richmond. Its always one thing after the other. You heard of the violence here, so many people were killed. So many children don't have parents. Children walk around aimlessly. You don't know where they are supposed to be, whether they are in school or if they even have a family. But here in Richmond we see this so often that we don't see it as a problem anymore. People and children are trying to fend for themselves...

5.4 Understanding the Thokozani Support Group

The data emerging from the narratives has provided a variety of perspectives and insights into the Thokozani Support Group and the role it is playing in community learning within Richmond. This diversity of individual perceptions, together with more formal data gathered from documentary sources, must now be converged into a singular, admittedly subjective, understanding of the organisation, how it operates and succeeds or falls short in its quest to further community learning.

To extract this understanding the narratives have had to be filtered to extract data and themes reflective of issues such as organisational capacity, skills development, planning, the generation, reproduction and expression of knowledge, the impact of the broader environment on individual contribution, among others.

5.4.1 Organisational Overview

In the literature review in Chapter Two, it was noted that very little documented information existed on the Thokozani Support Group. This research exercise has, however, revealed the following facts about the organisation that will provide a basic understanding as we approach the core focus of this study.

The organisation was established in June 2001 as a first-line community response to the unfolding challenges created by the HIV/AIDS epidemic in the area. Thokozani Support Group is a CBO and receives no formal funding or sponsorship. Meetings are convened at the local clinic.

The majority of the membership is recruited from PWAs in the area. Members receive no remuneration for their efforts and interventions.

Initially, the group's primary intervention strategy was to provide desperately needed home-based care as well as information dissemination. However, the total absence of funding put an end to the former. The organisation now focuses on recruitment of PWAs, education and information dissemination, and conducting workshops.

5.4.2 Resources

5.4.2.1 Access to Funding

All of the research participants cite funding, or rather the lack of it, as the organisation's single most important barrier to implementing successful intervention strategies in Richmond.

Quite apart from outside programmes and projects, such as the provision of home-based-care, the lack of funding also impacts negatively on the organisational capacity in that the group recruits and sustains membership only from those areas in walking distance of the clinic.

Outlying areas that are, as Sister Mtungwa explains, in dire need of assistance and support are therefore marginalised to the extent that residents from those areas are economically prevented from becoming members, attending meetings and thereafter from informally transferring knowledge and skills back to their communities.

At a formal project implementation level, the provision of home-based care, which not only provided households affected by HIV/AIDS with material and

medical support, but also with the opportunity of direct knowledge transfer, had to be abandoned by the Thokozani Support Group. The project proved too expensive for the group, both in terms of providing supplies such as Savlon, detergents, fresh fruit and vegetables etc, as well as in terms of the cost of transporting the Thokozani Support Group members to these areas.

As dismal as the present funding outlook may now appear, two years ago, the organisation received a limited yet steady inflow of funds, namely from the Catholic Church and the local municipality. Both these funding streams were terminated, however, when certain members of the group gained access to the organisation's bank account and plundered its contents. To what extent the incident damaged the group's credibility has not been tested. However it is clear that the occurrence points to a significant structural deficiency.

5.4.2.2 Organisational Resources

Apart from two long thin wooden benches, a rusty and broken filing cabinet, two broken office chairs, a broom and a bucket, the Thokozani Support Group has little else. The organisation does not have a fixed venue and meetings are either held at the agricultural hall across the road from the clinic or under a nearby tree. The organisation has no stationery, apart from some chart paper and the occasional marker pen which means that neither minutes nor notes are taken during meetings. Knowledge transfer is primarily verbal.

Last year the members initiated a vegetable garden that was intended to provide families affected with HIV/AIDS with a source of nourishment. This initiative came to an end when construction work started for the expansion of the clinic in 2005. Although disappointed at the failed outcome of their garden project, none of the research participants indicated that they would seek an alternative piece of land to continue with the project.

Despondency, it appears, is a common thread among the participants, especially the PLWAs. Throughout the narratives, participants lament over projects that have failed and support they have not received. However, given the challenges facing

the organisation and the personal difficulties of daily life for the members, it is perhaps both understandable and expected that despondency and other negative emotions such as sadness, anger and frustration would be found in such abundance. What is of importance is that as powerful as the barrier of despondency may be, the Thokozani Support Group members often overcome it, finding hope, courage and the determination to carry on.

The lack of basic resources makes it very difficult for the organisation to function properly, let alone deal with strategic issues such as lobbying and making applications for funding.

5.4.3 Organisational Capacity

Organisational capacity generally refers to an institution's ability to pursue its objectives, taking into account human and non-human resources. Having dealt with the issue of funding resources, this section probes the organisational capacity of the membership, looking at issues such as accessibility, skills development and training, and the ability of the organisation to function as a repository of local knowledge.

In evaluating capacity development interventions within their CBO network, Acord (2002) cites three levels of capacity needs:

- *Individual – technical skills, knowledge and the awareness and ability to think critically which will help people challenge the social structures and processes which may be impoverishing, marginalising or oppressing them.*
- *Group capacities – including administrative skills, such as record keeping, organisational abilities such as planning, and interpersonal dynamics such as mutual respect.*
- *External relations - analytical capacities such as identifying market trends, and political capacities such as building alliances, as well as building the organisation's legitimacy both among the people whose interests it may be seeking to represent and among outsiders it is relating to.*

It is important to also note that an organisation has both a practical and strategic capacity with the former pertaining to meeting the objectives of the organisation and the latter to meeting the mission of the organisation. Thokozani Support Group, as I have said earlier, is positioned to respond to the immediate challenges of HIV/AIDS in the community.

Organisational capacity and the concept of capacity building are increasingly being associated with the concept of sustainable projects (Acord, 2002). In a study of sub-Saharan CBOs, Acord researchers claim to have found very little documentation about capacity building with CBOs, but highlight the need for recognising that “any given community has a variety of forms of organisation, and that any given individual or group within the community, however poor or marginalised they are, will have many existing capacities” (Acord, 2002:6).

The membership of the Thokozani Support Group, apart from Sister Mtungwa and Aunty Greta, consists entirely of PLWAs drawn from the Richmond area. Given the health status of the membership, the Thokozani Support Group has a very high membership turnover rate. During the research process only one of the founding members of the organisation was still alive, despite the fact that the Thokozani Support Group was under five years old at the time.

Apart from the high membership turnover rate, members often find it difficult to attend meetings regularly. Factors responsible for this, according to the research participants, include: environmental factors such as the weather; health issues such as conditions arising from HIV infection; and personal issues, primarily matters pertaining to unemployment. The lack of funds even impacts on the group’s ability to attract membership from areas other than Ndaleni which is within walking distance of Richmond town where meetings are held. A case in point is Lucas Ndlovu. He claims that he relocated from Inhlazuka to Ndaleni in order to be able to attend the Thokozani Support Group meetings. Whether this points to an urgency to fill certain vacuums in his own life, or a dependency on the support that the Thokozani Support Group provides, or even perhaps his relationship with fellow member and resident of Ndaleni, Zanele Zuma, cannot really be established. The fact remains, however, that he could not maintain his

association with the Thokozani Support Group while living in Inhlazuka. It was too expensive for him.

Naturally, the above scenario impacts negatively on the organisational capacity of the CBO and therefore limits the ability of the group to impact positively on community learning. On the other hand the high membership turnover inadvertently yet continually introduces new outlooks and fresh perspectives and experiences, which, in turn, generate knowledge. What is of particular concern, however, is the Thokozani Support Group's ability to retain and thereafter transfer that knowledge to the community. The high membership turnover, coupled with the inability to record data inadvertently results in a loss of knowledge, which Sister Mtungwa herself has described as knowledge "vacuum".

The inability to hold regular meetings due to the high absenteeism rate also introduces a degree of disorder or entropy into the organisation which impacts on the group's ability to plan, implement and evaluate the interventions they put into place. Sister Mtungwa is particularly mindful of the fact that the organisation lacks the capacity to properly plan and thereafter successfully implement and sustain projects and plans:

Sometimes I feel that they (the support group members) don't know what they want or what they need. Sometimes they have all these ideas and plans, but they don't know how to carry out these plans. The members have the motivation, but I don't know.

Perhaps one of the key reasons for the lack of organisational capacity is the organisation's weakness when it comes to structure. The data reflects that the Thokozani Support Group consists of one central committee comprising the entire membership at any given time.

The organisation's chairman is a Mr Hlatshwayo who, in terms of the organisational structure, is not a member of the Thokozani Support Group as he is not a PWA. Rather, the organisation co-opted him because of his seniority within the community. However, his age and deteriorating health minimises the role he plays within the organisation and apparently he only meets with the group once every three months.

Despite his limited presence, Mr Hlatshwayo did introduce the policy that bars non-PLWAs from participating in the organisation's decision-making process. While the reason for the introduction of this policy has not been researched, the decision itself has created room for organisational tension, particularly because Sister Mtungwa and Aunty Greta who, although not PWAs, are the organisational backbone of the Thokozani Support Group.

Zanele Zuma is the secretary and although quite proud of her title, the frequent absence of resources such as pens and paper makes her role relatively meaningless at times.

Nozipho Langa is the group's organiser. She schedules meetings by checking the availability of members and liaising with Sister Mtungwa and Aunty Greta who, more often than not, also deploy her to attend workshops or awareness events. However, it appears that Nozipho's "popularity" is also a source of organisational conflict that occasionally reduces the organisation's capacity, as Sister Mtungwa explains:

You see the Thokozani Support Group as an organisation experiences many problems. The members are generally very happy but there are many problems that cause tensions and fights.

Sister Mtungwa says there is fierce rivalry between Lucas and Nozipho. The former often tries to assert his dominance on the organisation and does not take kindly to Nozipho being selected to attend workshops. The outcome of these feuds is that either Nozipho or Lucas, depending on the circumstance, would "boycott" meetings and community work until their damaged ego healed.

Not being able to participate at a decision-making level has, to an extent reduced Sister Mtungwa's enthusiasm and increased her frustration, particularly as she was the catalyst for the formation of the organisation. Despite this pessimism, she acknowledges that such an arm's length approach does contribute to the empowerment of the group and a degree of self-sustainability. Yet, given her vast knowledge pertaining to community health and specifically HIV/AIDS, her absence diminishes her capacity to direct and influence the organisation or to mediate among the members during periods of conflict and tension.

Furthermore, her absence despite her expertise, means that discussions and interpretations of events and experiences, by the group may generate inaccurate and harmful knowledge.

5.4.3.1 Capacity Development

Given the acknowledged lack of organisational capacity within the Thokozani Support Group, it is surprising that the group has made very little attempt to address the issue. At the time of writing this report, the organisation was not registered with the Richmond Municipality, the Department of Health or the Department of Social Welfare.

While this was a source of concern for both Sister Mtungwa and Aunty Greta, the rest of the sample group seemed unbothered by this fact. The reason for this may lie in the fact that among the members, frustration seems to easily set in, particularly when processes become tedious and the benefits to be derived from such efforts seem obscure. Take, for example, the group's approach to the municipality to request accommodation. The municipality took over a year to respond and then only gave permission for the group to use a room next to the Agricultural Hall for meetings, prompting one of the participants to declare:

The municipality has been one of our greatest disappointments.

Despite the frustration and feelings of hostility towards the municipality by members of the organisation, this study has found that the municipality has in fact provided the Thokozani Support Group with some support.

Initially the municipality awarded the Thokozani Support Group a monthly grant of R800, which was later revoked when it emerged that members had stolen money from the group's bank account. Despite this serious blow to the organisation's credibility, the municipality continues to provide ad hoc support in the form of lending the group a television set to watch HIV educational material when available.

Despite the difficulties in accessing support from government sector departments and agencies, Sister Mtungwa does draw from the resources at her disposal to help empower the Thokozani Support Group. However, sometimes even these attempts end in disappointment. In an attempt to inject skills and support into the organisation, Sister Mtungwa suggested to the district health office that a representative task team sit in on the meetings to provide technical assistance. The district office rejected the idea, however, responding that CBOs must learn to do things on their own.

Another source of frustration among the Thokozani Support Group members is the regular stream of NGOs who make their appearance and thereafter “disappear”. In fact, when this researcher initially approached the Thokozani Support Group for permission to undertake the study, Nozipho, one of the PWLA Thokozani members, reacted with cold anger:

Why are all you people coming here saying that you want to help us? We have no food, we are hungry and our children are hungry. Many people come to the Thokozani Support Group saying they want to help, but we never see them again.

You think people care about what is happening here in Richmond ... We are still waiting. Our people are desperate ...

Engagements with organisations such as Paau and Napwa have left behind a particularly bitter taste for the support group. Sister Mtungwa says that many of the NGOs that interact with the organisation merely attempt to provide educational material, but that this support is not nearly sufficient, particularly as members have first-hand knowledge of the disease. Furthermore, she says that the support programmes generally have a short duration “with little or no follow-through”.

The lack of formal NGO interventions and the provision of support to the Thokozani Support Group, being the only CBO operational in Richmond, corroborates the assertion that NGOs are “rarely found in any significant numbers in the deepest and most rural parts of our country” (Ntsime, 2001: 115).

The only exception to the above experiences with the NGO sector is the group's relationship with Pietermaritzburg-based NGO Siyaphila. Seemingly, the Thokozani Support Group and Siyaphila have a relationship spanning just over two years. Although the NGO does not provide any direct material support, it has developed workshops dealing with, among other issues, transmission, nutrition, positive living and planning which encompasses the drafting of wills.

On an individual basis, members, through their affiliation and exposure to the Thokozani Support Group, seem to have an adequate degree of skill and knowledge to implement and conduct community learning programmes. Apart from access to formal knowledge from Sister Mtungwa, Aunty Greta and occasional workshops they may attend, members have first-hand exposure to the issue of HIV/AIDS. Access to these skills and knowledge does result in them challenging social structures and processes that contribute to the problems the community is facing. The data illustrates a clear pattern among the participants of enhanced wariness towards superstitions and back door concoctions prepared by traditional healers. In fact, the Thokozani Support Group members feel empowered enough to even challenge other residents on their dependence on traditional healers, promoting the clinic instead as a source of reliable and effective treatment.

At a group capacity level it appears that the Thokozani Support Group is extremely weak. In the absence of both resources and regular and well-attended meetings, the organisation struggles administratively. There is virtually no record-keeping and accountability. At the very worst, this lack of organisational capacity was brought into sharp focus when funds from the organisation's bank account went missing. Furthermore, there is no organisational planning. Besides the occasional meeting in which Sister Mtungwa requests members to develop plans, apart from ideas, very little materialises thereafter.

Politically, the lacks of administrative and organisational capacities have hampered the organisation in building alliances. Apart from Siyaphila, all other NGO interventions were short lived. Its relationship with the municipality is also

strained, partly as a result of the bank account fiasco and partly because of the organisation's failure to produce a constitution that is a pre-requisite to registering for any support.

It appears that a dichotomy of expectations is beginning to surface regarding CBOs. The data suggests that external sources of support such as the Department of Health, municipality and even NGOs, do not want to get intimately involved with CBOs for fear of creating dependency. Even the Thokozani Support Group's chairman was adamant that non-PLWAs not be allowed any executive powers. He said the Thokozani Support Group members must learn to do things on their own. Thokozani Support Group members, however, have a different perspective. They are willing, capable and have access to first-hand local knowledge with which they can assist their community. Their efforts, however, fail because they have few resources, no funding and limited access to capacity-building interventions to assist the organisation to grow.

It is also a matter of the perceived benefits to be gained from any expenditure on capacity development. First and foremost members want to be out in the community providing home-based care. When confronted with abandoned and starving children, child-headed households and breadwinners lying rotting in their beds, it is here that Thokozani Support Group members believe they can make the biggest impact. It is also here that they have the ability to transfer knowledge through implementation. All they need to sustain this activity is funding for travelling costs and access to food and hygiene provisions. Further training and skills acquisition, they believe, can come later. The community needs help now. As Zanele Zuma explains:

Ooh, ooh, but I feel very disappointed that the group doesn't do any home-based care now. We love to do that but we don't have the money. But that doesn't stop us. Some of us will still go and visit people and talk to them or help them with the cleaning of the house or cook some mealie meal or vegetables from our garden for them. Even if we don't have the money we are still part of our community and the people there. We love them and we like to be there for them.

Aunty Greta adds that the Thokozani Support Group, although in need of help, does not wait for handouts.

Our members are doing their best. They don't expect anything in return, just the solace from knowing they have made a difference ... We operate like a community-based organisation. We do not wait for any handouts or money because we know we will end up waiting forever ...

We try to make a difference now, not tomorrow ...

5.5 Community Learning

5.5.1 Definition

Community learning, according to Wenger (1998), is a social theory of learning, the primary focus of which is on learning as a social practice. This description is supplemented by various pieces of literature. Pointedly, the *AIDS Bulletin (1999)* goes further to challenge the idea of viewing bureaucrats, health workers and researchers as experts, thereby alienating the community sector by limiting our expectations of this sector's abilities.

5.5.2 Relevance to Definition

Pointedly, this theory holds water when tested against the context of the Thokozani Support Group. A summary of all data obtained from the participants supports the notion that learning occurs via the transfer of knowledge into social practice. (*See diagram at the end of this chapter.*)

5.5.3 Understanding Social Learning and Factors that Shape its Form

Foley, cited in Smith, (2003), suggests that “the most significant learning occurs informally and incidentally”, and in his exploration, thereafter recommends several pertinent questions to evaluate learning as a social theory. Three of these questions remain integrally relevant to this discourse. They are:

- What are the crucial elements of the political and economic context and how do these shape education and learning?
- What forms do education and learning take?
- What does all this mean for education?

The answer to the first part of question one has been covered in detail in previous chapters. However, Richmond is a deeply impoverished and isolated rural community. Unemployment and poverty impacts significantly on formal education and training with many children being forced to leave school in order to find jobs that will assist in feeding households.

HIV/AIDS is rampant, and although this study has not provided any quantitative data to substantiate this assertion, empirical data and data collected from interviews, primarily with Sister Mtungwa from the local clinic, provide sufficient authentication.

On the political front, it has been well documented that Richmond has been the centre of a political battle that manifested itself in intense violence that claimed the lives of hundreds of residents and left in its wake a deeply divided society, perhaps still suffering the effects of post-war trauma. Auntie Greta’s recollection of one particular incident is chilling. The day after the massacre she speaks about, President Nelson Mandela visited the scene.

Ndalení was a bad, bad place to stay. People were killing people daily and I was afraid for my children ... it was around 4 am. My son was knocking on my

*window and he said 'Ma, did you hear that they killed the whole Nxumalo family'.
The husband, wife and a friend were killed. They lived close by to us.*

Within the present political dispensation, residents and community-based organisations such as the Thokozani Support Group have to tread carefully to avoid offending the existing leadership structures, which, although providing relatively little support, have the power to hinder the Thokozani Support Group.

5.5.4. Forms of Learning -- Formal, Informal and Non-formal

“The most significant forms of learning occur informally and incidentally”. (Foley, 1999: 2.) While I agree that much of the Thokozani Support Group’s contribution to community learning is informal, there is a significant degree of learning taking place which can be characterised as “non-formal” as the bulk of community learning takes place via a transfer of skills and knowledge non-formally through house visits and casual encounters with other PWAs.

Internally, the organisation functions similarly to a support group with members sharing information and providing each other with comfort, understanding and encouragement. Externally, through its programmes, the group transfers and assists the community to deal with some of the challenges of HIV/AIDS.

It is perhaps useful at this point to differentiate between the terms formal and non-formal, as well as informal. Coombs (1968), cited in Rule, P. (2003), defines non-formal education as:

Any organised, systematic educational activity carried out outside the framework of the formal system to provide selected types of learning to particular sub groups in the population, adults as well as children.

The Human Sciences Research Council (HSRC), writes Rule (2003), provides the following definitions for formal, informal and non-formal learning:

- **Informal education** – spontaneous, as that which occurs within families and in neighbourhoods;
- **Formal** – that which takes place in a planned way at recognised institutions such as schools;
- **Non-formal** – planned but adaptable and takes place in organisations, institutions and situations outside the spheres of formal and informal education.

Most of the Thokozani Support Group's contribution to community learning is located in the sphere of non-formal education.

Returning to the forms of learning undertaken by the Thokozani Support Group, its interventions consist largely of non-formal experiential information sharing.

As was noted earlier, the Thokozani Support Group members consist primarily of PLWAs. At their regular meetings members share their experiences with each other and provide support and encouragement. Within the context of these discussions, knowledge is generated, allowing it to be reproduced, shared and expressed.

The sharing of experiences allows members to subject their views and interpretations to the scrutiny of others and, in this way, misconceptions and fallacies are soon highlighted. Further to this, the occasional presence of both Sister Mtungwa and Aunty Greta, serve as a constant checkpoint, ensuring that the knowledge generated contributes to the goals of the organisation and, importantly, is medically sound.

However, not all knowledge generated and transferred to members is experiential. Sister Mtungwa holds regular workshops with the group sharing information and knowledge she draws from her profession and from the resources available to her from government. Furthermore, the Thokozani Support Group is in regular contact with Siyaphila, a Pietermaritzburg-based NGO that provides occasional workshops and training. Members of the group are often encouraged to attend workshops. Upon their return information is shared and discussed in their meetings.

Community learning outside the confines of the organisation takes place in various forms. Given the high rate of infection within the community, members are in daily contact with friends, family and neighbours who are in some way affected by the disease.

However, the process of knowledge transfer is often fraught with difficulties and obstacles. Apart from resistance, mistrust and denial, the Thokozani Support Group members often expose themselves to ridicule and even anger.

Nozipho, who was once a prostitute and who has now freely disclosed her status to the community, says she is at times confused about how people refuse to accept the disease:

Once, as a member of the Thokozani Support Group I tried to help those girls and encouraged them to stop selling their bodies, but I almost got hit. It is very hard for people to listen.

Incidents such as the one above have now left Nozipho questioning whether she in fact has the right “to tell other people how to live”.

Sometimes I feel I have no right to tell other people how to live. I can only tell myself because I know the truth about myself ... and the truth is that if I had stayed a sex worker I would have killed other people.

For people like Lucas however, the disclosure of his HIV-positive status has contributed positively to him being able to share information with others infected with the disease. Against the backdrop of mistrust and resistance, his disclosure of his status has assisted in sidestepping some of the barriers that exists. As he so often points out, disclosure creates a relationship of trust and respect.

People like you to admit that you are positive, and then they don't stop asking you questions. Sometimes, if you don't tell them you're positive, they will think that you are playing games with them and they will get angry.

But if there is someone who will stand up and say 'I am positive' then people will believe in this disease.

Apart from casual interactions, workshops and attending awareness related events, the provision of home-based care by the Thokozani Support Group members was, perhaps, the group's single most important intervention. Given the scale of the epidemic and the general absence of any social welfare net capable of extending the required support directly into the homes of families affected by the disease, the provision of this service not only offered a critically needed service, but also provided the organisation with an ideal platform to share knowledge and help empower members of the community.

5.5.5 Levels of learning

5.5.5.1 Personal Development

At its most basic level, the Thokozani Support Group provides the platform for members themselves to learn and develop through a process of information assimilation via informal relationships that develop, and through more structured discussions that take place within the group. Members regularly share experiential information at meetings and it is within the context of these discussions that knowledge is generated and shared. This enables members to come to terms with the disease and the impact it is having on their lives. For instance, based on her involvement with the Thokozani Support Group, Nozipho took the decision to quit prostitution. This was a significant milestone in her personal development. On an emotional level members are exposed to people who are experiencing very similar circumstances, thus creating an atmosphere of trust, understanding and empathy, all of which allow members to express themselves openly. For Lucas, exposure to this environment enabled him to accept his HIV status and to disclose the fact to his family and friends.

There is so much they can learn by joining. We all have something in common. It's just so nice when we come together. We feel stronger and happier. We don't feel lonely. We give advice and we take advice.

Thokozani Support Group means 'to be happy', and when we leave in the afternoon we actually feel happier.

5.5.5.2 Skills Acquisition – Non-formal

Apart from the occasional workshop conducted by Sister Mtungwa and Aunty Greta, the group has very limited access to skills development resources. Over the years NGOs have made brief appearances with little or no follow-through prompting growing frustration and mistrust among members. The exception, however, has been Siyaphila, a Pietermaritzburg-based NGO that has maintained and nurtured a lasting relationship with the Thokozani Support Group. Apart from conducting workshops Siyaphila also arranges for the Thokozani Support Group members to attend events that will enable members to gather information. Topics covered in the workshops include basic knowledge and transmission, nutrition, positive living, and planning.

5.5.5.3 Organisational Development

Perhaps the reason for so many of the problems plaguing the organisation is the virtual absence of training towards organisational development. Sister Mtungwa did suggest that people with technical expertise join the group but the chairman rejected this.

The lack of systems and accountability ultimately resulted in donor funding being plundered by certain members. This resulted in the funding being terminated.

The lack of organisational skills has also contributed to the fact that the group remains an unregistered organisation.

5.5.5.4 Community learning - Informal

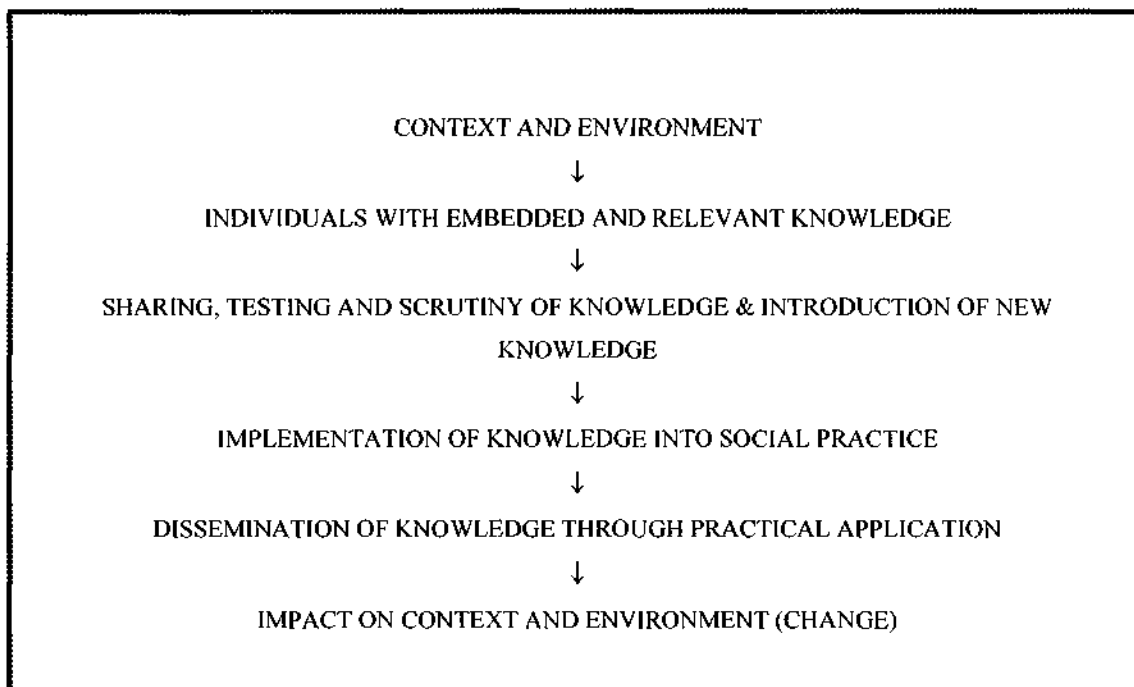
The expression and reproduction of knowledge in the community occurs on several levels, the most immediate being the transmission of information into the social realm of each member, that is, family and friends.

On a secondary and broader level, some members are sufficiently empowered to openly acknowledge their HIV status and share information about their experiences at community meetings.

Finally, and perhaps most importantly, the Thokozani Support Group members directly inject knowledge into households directly affected by HIV/AIDS through home-based care. Apart from addressing the health and nutritional needs of affected families, members spend much of their time educating these families on various HIV-related issues.

5.6 Diagrammatical Process of Community Learning

Below I have constructed a flow chart to illustrate the process of community learning that occurs among members of the Thokozani Support Group and which is later transferred into the community. This process is a key factor in relation to my key research question “How has the Thokozani Support Group contributed to community learning?” I have provided notes on the chart on page 170, and these provide a direct reference to the issues of context, form, responses and challenges to how the organization contributes to community learning.



Location-socio-economic factors such as poverty, employment. Historical context, particularly political violence. Environmental factors, particularly HIV/AIDS.

Individuals with embedded knowledge – shaping of contextual and environmental factors on the individual, first-hand experience of relevant issues, as well as cultural and community-value embeddedness. The Thokozani Support Group members.

Sharing of knowledge – the Thokozani Support Group meetings in which members share experiences and derive support. Information is tested and knowledge generated. This platform allows the introduction of new knowledge from formal sources such as the clinic, etc.

Implementation – First level. The members translate knowledge into social practice. The ability to translate knowledge into practice internally before disseminating it broadly into the community provides the organisation with an invaluable buffer zone wherein potential knowledge is subjected to further scrutiny.

Dissemination -- Social learning and the dissemination of knowledge into the community takes place at a practical level. Home-based care in particular enables the organisation to provide practical interventions that can be replicated.

Impact -- The environmental and contextual circumstances initially influenced and shaped the knowledge that was generated. Within the context of these discussions, within the community of practice, new knowledge is generated, implemented through social practice, which is further replicated. This sequence ultimately impacts on the environment and context, which initially gave rise to the community of practice, and, in effect, change, either positive or negative, is stimulated.

Chapter Six - Conclusion

6.1 The Broader Environment

It is hardly likely that the prevailing macro-economic factors in the greater Richmond area will change sufficiently to impact on the town's socio-economic environment. Until such a change occurs, poverty, unemployment and illiteracy will remain significant.

The HIV/AIDS epidemic will also continue on its devastating trajectory, fuelled by the prevailing socio-economic climate. The on-going elimination of income earners and the rise in numbers of orphans and child-headed households will deepen the crisis.

In the absence of a government-initiated or supported turnaround strategy the epidemic will provide the community with an ever-increasing burden of dealing with the consequences of the disease. Apart from treatment responses, these consequences will manifest in learning and educational challenges.

As is presently the case, the prevailing climate and associated challenges will stimulate the need for greater social action learning in which people get together, motivated, to achieve a common purpose.

In Richmond the Thokozani Support Group is a manifestation of situated social action learning. However several fundamental barriers limit the organisation's ability to contribute effectively to community learning.

Environmentally, these include, among others, poverty, unemployment, illiteracy and the impact of HIV/AIDS.

6.2 An Overview of the Organisation

Organisationally, the Thokozani Support Group's ability to contribute to community learning within the sphere of it being defined as a community of practice, is compromised severely due to several and significant deficiencies such as: organisational and administrative lack of capacity; the lack of resources both for internal and external requirements; and the specific lack of skills and knowledge to support properly managed and sustainable interventions. Apart from these shortcomings, the diverse membership and the frequent absence of any tangible benefit create internal stresses and tensions that also impede the organisation's ability.

Most importantly, the organisation does not have access to funding, which is a contributing factor to many of the abovementioned organisational deficiencies. The lack of money also put an end to the home-based care programme, which has effectively reduced the CBO to a PLWA's support group and impeded its ability to impact on the broader environment.

The organisation's ability to contribute to community learning is also greatly constrained by these challenges. The Thokozani Support Group is a manifestation of what Wenger calls a community of practice – a mutual development process between communities and individuals. However, the high membership mortality rate coupled with the absence of any knowledge management protocols often result in the loss of knowledge or the ineffective reproduction and transfer of such knowledge.

Externally as well, the Thokozani Support Group's ability to contribute to knowledge transfer is also compromised. Superstition, mistrust, denial and even resentment and anger constitute powerful barriers that the Thokozani Support Group members are faced with daily.

6.3 Reflections on the Thokozani Support Group and suggestions on some of the challenges they face

6.3.1 Dysfunctional May Soon Become Non-functionality

Objectively I must concede that the Thokozani Support Group is dysfunctional and on the brink of becoming non-functional. This is a tragedy for several reasons. While the organisation lacks several skills and resources that are vital to its viability and sustainability, it is certainly not short of devoted, enthusiastic and caring volunteers.

The Thokozani Support Group's proximity to the centre of the epidemic positions it ideally to be the first and perhaps even the last-line response to the consequences left in the epidemic's wake. In the near absence of any NGO HIV/AIDS intervention in the deep, depressed and rural communities of Richmond, the Thokozani Support Group exists and is prepared to do the "dirty" work that neither the NGO community nor government seem capable of or willing to do.

Apart from the organisation's physical proximity to the effects of the epidemic, members of the CBO are inherently better equipped than outsiders to implement community-based interventions as they have situated knowledge of the environment, culture and prevailing societal norms and values.

Being an organisation consisting of PLWAs provides the organisational advantage of having first-hand awareness and experience of the disease and its impacts. PLWAs contain and can generate experiential knowledge. Furthermore, their PLWA status establishes a bona fide that enables members to gain and maintain trust in the community, as well as assist other PLWAs to overcome the fears and anxiety associated with voluntary counselling and testing as well as disclosure.

Notwithstanding these interventional advantages, it is the organisational capacity that ultimately determines the organisation's potential to contribute to community learning.

6.3.2 The Funding Paradox

As fundamental as funding is, the Thokozani Support Group is faced with an unfortunate paradox. Funds can unlock and support the organisation's efforts to build the organisational capacity, resources and skills that it needs. However, it needs organisational capacity, resources and skills to generate and manage funding.

What comes first? Neither. The Thokozani Support Group needs a well-managed intervention that includes the upfront provision of funding and resources as well as a concurrent organisational empowerment model.

As this research process has illustrated, frustration is a common and serious barrier among the Thokozani Support Group members who are reluctant to expend organisational energy on capacity development. Skills acquisition and training are a secondary priority. The immediate priority for them is to deal with their own infection and improve their own quality of life through the support and knowledge provided by the Thokozani Support Group and thereafter extend their support and information into the broader community. Organisational empowerment initiatives independent of any tangible outcomes or benefits stand a limited chance of success.

6.3.2.1 The Research Paradox – to Reward or not to Reward?

The same scenario faces potential research initiatives. This endeavour encountered initial suspicion and resentment from some members of the organisation. This reaction was based on several previous encounters with research initiatives that left the participants feeling betrayed in that their association and participation produced no tangible benefit.

One has to accept that participants may not necessarily benefit directly from the outcomes of the research, but perhaps the wariness and resentment that has surfaced points us to a possible flaw in our approach to research design.

Whatever form the incentive may take, it is important that both research initiatives and capacity building and training interventions provide the Thokozani Support Group members with a tangible benefit to their participation. Unlike employees of NGOs, the Thokozani Support Group members are all volunteers.

We also need to be considerate of the fact that the Thokozani Support Group members themselves face severe personal challenges arising from unemployment, poverty, hunger, the consequences of HIV/AIDS as well as many of the other social ills affecting their communities. The sincere desire to make a difference and rise to the challenges facing their communities cannot be disputed. However, we have to concede that their involvement in the Thokozani Support Group is not entirely driven by benevolence, and there is a certain degree of reliance on the organisation for material support such as the occasional stipend for attending HIV/AIDS related community meetings, and access to home-based care materials.

This is an important issue when it comes to funding because invariably the transfer of funds into the organisation will create stress, tension and even perhaps division among the membership, many of whom feel entitled, and perhaps even justifiably so, to derive some benefit for their involvement. From a risk management perspective, the provision of a stipend to the membership may reduce the risk of funding being used for purposes other than those intended. More importantly, however, the ability to provide the Thokozani Support Group members with any sort of remuneration will provide several positive spin-offs for the organisation as a whole.

6.3.2.2 The Benefits of Remunerating the Thokozani Support Group Members

Remuneration to all the members who earn virtually no income at all will:

- Assist in alleviating poverty among the members;
- Improve the health status of the PLWA members;
- Lengthen and enhance their participation in the Thokozani Support Group;
- Reduce the risk of members “abusing” project funding;
- Mitigate the members’ resistance to non-tangible capacity development.

Thus the foundation phase for any sustainable capacity development process must begin, firstly, with providing members with a direct tangible benefit for themselves. There is *nothing intrinsically illogical about this*. From companies to corporations and from NGOs to government departments, the basis for securing human capacity is the exchange of resources.

6.3.4 Building Sustainable Capacity

I suggested earlier that the Thokozani Support Group is presently dysfunctional and, in the absence of a turn-around strategy, may soon become non-functional. Apart from the lack of funding there are several other reasons for this:

- The organisation has virtually no infrastructural resources such as secure premises, stationery and information storing and retrieving facilities.
- The organisation has very limited administrative capacity partially because of the lack of resources but primarily because of a lack of the necessary skills.
- There is a general absence of organisational and planning skills, which reduces the members' ability to properly plan, execute and evaluate interventions.
- The organisation has a dysfunctional structure that fuels internal stress and conflict and prohibits organisational growth and development.

6.3.5 The Need for a Turn-around Strategy!

The future viability and sustainability of the Thokozani Support Group lies in the ability of the organisation to attract a sustained and comprehensive empowerment intervention. Given the current policy of government to remain at arms length from CBOs to “reduce the risk of dependence”, the only sector that offers a glimmer of hope is the NGO sector.

In fact the discourse within the NGO sector on expanding community access to HIV treatment, care and information is beginning to shift towards examining the role CBOs can play in the provision of these essential services. The Southern African Regional Poverty Network (SARPN, July 2005), in a joint publication with the World Health

Organisation (WHO), the Joint United Nations Programme on HIV/AIDS and Sidaction, titled *Expanding access to HIV treatment through community-based organizations*, calls for funding agencies and national authorities to support and strengthen the work of CBOs as “these organisations have emerged to provide essential services in HIV-related prevention, care and treatment”.

The SARPN report further cites a 2004 Sidaction research survey into community-based responses to HIV/AIDS in Africa. Sidaction confirmed the existence of an extensive community response to HIV care and treatment that is run by people living with HIV/AIDS. The report states that these programmes are driven by the needs of the community and are increasingly focusing their activities on treatment.

The Agency for Co-operation and Research Development (Acord) has also confirmed the existence of a widespread community-based response to HIV/AIDS in Southern Africa. Within the context of the organisation’s Botswana-based activities, the NGO has identified capacity building as a central component in developing strategic partnerships between NGOs and CBOs.

While an NGO intervention may hold the key to the Thokozani Support Group’s viability and sustainability, it is more importantly the nature of the intervention that will ultimately count. Given the complexity of the challenges facing the Thokozani Support Group, earlier on, I drew attention to the need for a comprehensive and sustained intervention. A quick overview of the challenges facing the organisation illustrates that these challenges are very much inter-related. You cannot provide funding without putting into place administrative capacity to properly manage and dispense the funding, you cannot dispense funding without having the appropriate strategic and operational capacity to develop, implement and thereafter evaluate interventions and programmes, and you cannot develop and implement programmes without the necessary information and education support and tools. In fact, all of the above become far more difficult to achieve in the absence of an organisational structure that supports rather than inhibits organisational growth.

6.3.6 NGO Partnership

Despite the use of the word earlier, the term intervention is entirely inappropriate as it suggests a forceful and imposed action to “change what is happening in somebody else’s affairs, especially prevent something undesirable” (*Encarta World Dictionary*).

Furthermore, the term intervention suggests that the required action will be of primary benefit to the party on the receiving end of the intervention. This is not necessarily the case, and there appears to be sufficient literature to suggest that NGOs themselves are beginning to reposition themselves to act as bridging agencies between grassroots delivery and programme implementation and the more formal, yet equally important, role of advocacy, networking, research and funding solicitation.

This points to the need for a partnership that will assist the Thokozani Support Group overcome the barriers that presently stand in the way of the organisation achieving its objectives. The Centre for HIV/AIDS Networking (Hivan) has already realised that partnerships and community involvement “is the way to bridge the gap between theory and reality”. In 2005 the NGO launched a pilot three-year project in Mtunzini, which is a rural, poverty-stricken and isolated area in Northern KwaZulu-Natal. The NGO is hoping to derive a model of best practice that can be exported to rural areas around the country.

Young (1999) adds to the mounting call for meaningful community partnerships, and provides several strategies for increasing NGO/CBO participation in the partnership against AIDS.

First and foremost, Young calls for greater understanding and respect for the NGO/CBO sector that will contribute to stakeholders redefining or, perhaps, broadening the concept of what constitutes an “expert”. She argues that people closest to the epidemic must be factored into responses, given the exposure of people at grassroots to the effects of the epidemic and their experience in mobilising and educating their communities. These people hold valuable skills, knowledge and experience.

There is also a dire need to catalogue experiences and draw lessons and models of best practice from these experiences. Young suggests there is insufficient assessment of intervention impact, and that this absence of information disempowers NGOs and CBOs by impeding their ability to demonstrate their value.

In terms of sustainability, the “state of emergency” created by the spread of the disease, argues Young, means that certain, particularly grassroots organisations cannot afford to be constrained or prevented from accessing funding and resources because of red tape barriers. In the case of partnerships with grassroots organisations she also highlights the need for the respective roles and responsibilities of the partners to be clarified through well-defined structures for communication, consultation and collaboration. These partnerships must also support ongoing capacity building mechanisms that will enable the recipient partner to carry out its roles and responsibilities even if the partnership terminates. Young advocates that funding must contain an allocation for capacity building.

However, hand in hand with capacity building, NGOs and CBOs must commit to good governance and in doing so be able to fully articulate their mission, guiding principles, values, core business and mechanisms for community participation. Central to the issue of community participation, NGOs and CBOs must also ensure that PWAs are placed in key positions to drive the respective responses and are given the skills and resources to do so. Young (1999) adds that funding agencies in turn must be cognisant of the fact that PLWA-driven organisations need special consideration and that the funding must reflect this, particularly as, over time, these organisations may become less and less functional and, therefore, less able to attract funding and conduct their work.

6.4 The Potential for Community-based Learning

If we are to accept the premise that the Thokozani Support Group members, given their proximity to the epidemic as PLWAs, are in their own right experts on the disease, it stands to reason they have a valuable role to play in the containment and management of the disease in their community, particularly in the sphere of education and the dissemination of information.

Outside interventions often face a plethora of barriers spanning culture, language, suspicion and mistrust. Thokozani Support Group members, however, possess an inherent understanding and respect for communal norms, values and cultural subtleties that allow them to navigate, overcome and sidestep many of these barriers.

The challenge, however, is to provide the Thokozani Support Group members with the confidence and means to articulate and transfer this knowledge back into the community. It is at this level that the Thokozani Support Group members face the greatest challenges, both at an institutional level and at an individual level. Earlier paragraphs addressed the need for partnership programmes to re-examine their approach to programme funding in order to address the specific needs of PLWAs. At an institutional level, knowledge transfer needs to be viewed within the conceptual framework of both Foley's and Wenger's theories of community learning, both of which have been explained in previous chapters.

6.4.1 Internal and External Challenges

In the context of the Thokozani Support Group, learning that emerges from social practice takes place at two distinct levels:

- Internally and non-formally within the membership whereby knowledge is generated, transferred and put into practice; and
- Externally, when members transfer knowledge into their communities through non-formal, informal and incidental transfer, the latter through a process of self-implementation that is observed and thereafter replicated by other members of the community, who in turn, through social practice, expose those around them to these ideas.

Therefore, to enhance the Thokozani Support Group's contribution to community learning at both levels we need to examine the resources, practices and skills available to the organisation.

6.4.1.1 The Knowledge Incubator

Another way of looking at level one is that of a knowledge incubator. Knowledge enters the organisation in different ways. Members, through their environmental experiences and exposure to the disease and its consequences, introduce information. This information is shaped against the experiences of other members as well as the organisation's access to formally generated knowledge gathered from Sister Mtungwa at the local clinic, support materials received from NGOs such as Siyaphila as well as material from the Department of Health.

At its most basic level the Thokozani Support Group provides a source of learning for its members. The narratives suggest that the organisation provides the platform for members to come to terms with the disease by talking to each other, voicing concerns and anxieties and learning to cope with the disease. Take Lucas, for instance. He relocated from an outlying township to Ndaleni, just to be close to the group and attend meetings. Nozipho put into personal practice the values and advice she was exposed to at the Thokozani Support Group and turned her back on prostitution.

6.4.1.2 Perspective Transformation

This process of learning within the community of practice is related to what Mezirow (1991) terms "perspective transformation". Essentially, the Community of Practice exerts, in this instance, a positive influence that, perhaps over time, contributes to a perspective transformation (the theory of how adults learn by making meaning of their experiences).

To process the information in a manner that generates knowledge, members themselves need assistance and capacity development that will enhance their ability and confidence to articulate and share information. Furthermore, the group needs to find ways of expanding its membership so that the diversity of views is broadened and that potential knowledge is subjected to a greater diversity of challenges. The confidence of individual members to challenge prevailing thoughts needs particular attention, specifically as the data reflects the emergence of dominance and jealousy among some of the key members.

Thokozani Support Group also requires greater exposure and interaction with sources of formal knowledge. It is a known source of frustration among members when outside agencies make brief appearances and thereafter disappear. This fuels suspicion and mistrust and paradoxically creates a barrier to the open and transparent sharing of knowledge from one source to another.

At an organisational level it is also critical to preserve knowledge that has been generated. At the time of writing this report 50% of the group's original membership had died, all within a period of five years.

6.4.1.3 Nurturing the Organisation's Learning Memory

Clearly, much of what members absorb from each other over time becomes part of the organisation's learning memory as information is continually handed down to new members and shaped and adapted by the inflow of new experiences. Thus, community learning and the lessons and experiences gained from the activity still remain part of the learning memory of the organisation. Nearly all of the interviewees highlighted their memories of the practice as being an integral component of the organisation's history.

As a PLWA-driven organisation, membership mortality is going to be an on-going challenge to the organisation, both in terms of capacity and knowledge loss. Furthermore, membership loss will result in the organisation becoming, as Young (1999) states, less functional. It is critical, therefore, that the Thokozani Support Group confronts this issue and puts into place mechanisms to limit these losses. Ideally, it is in the Thokozani Support Group's interests to try to increase the lifespan of its member by providing them with access to medical support as well as access to nutritional food. The organisation must also be cognisant of other factors that contribute to capacity and knowledge loss and these include environmental factors such as unemployment and poverty. An example of this is the fact that many members fall along the wayside simply because they cannot afford the taxi fare to attend meetings.

Nevertheless, until a life-saving cure for the disease is found, membership loss will continue to characterise the future of the Thokozani Support Group. The organisation requires the ability, besides memory and storytelling, to preserve experiential knowledge

that it has acquired. Unfortunately, the Thokozani Support Group has virtually no resources to enable it to store information. In fact, many of the members are either illiterate or semi-literate due to the fact that factors such as poverty removed them from school at a very early age. Thokozani Support Group, if it is to preserve knowledge, requires not only the physical infrastructure to do so but access to adult basic education and training for its members.

6.4.2 Knowledge Transfer into the Community

Having dealt with internal issues that influence the organisation's ability to impact on community learning, we now need to widen our lens to examine ways of enhancing the transfer of knowledge into the broader community. Rule (2003) and Foley (1999), both cited earlier, describe community learning as that which occurs at formal, non-formal and incidental levels. In the case of the Thokozani Support Group, community learning primarily occurs non-formally and incidentally.

6.4.2.1 Home-based Care

All of the research participants agree that the provision of home-based care formed the basis of the organisation's mission and core business and was in direct response to the unfolding consequences of the HIV epidemic in the Richmond townships. However, apart from the provision of these desperately needed services, home-based care as recounted by the research participants, has emerged as a powerful practical and experiential knowledge transfer tool. Located within the non-formal learning paradigm the Thokozani Support Group gained unobstructed access to affected families, enabling members to impart knowledge through practical application and explanation. Furthermore, having access to people within their homes allowed the Thokozani Support Group members to freely communicate with families, shielded from outside influences such as ridicule, superstition and reliance on traditional advice and medication. Furthermore, home-based care visits were not one-off interventions. Members conducted follow-up visits to ensure that skills and knowledge imparted were being properly replicated and that the desired results were being achieved.

For the Thokozani Support Group to play any meaningful role in the contribution to community learning, it is vital that the organisation is empowered to re-introduce the provision of home-based care. It is also important that that dignity and respect for the Thokozani Support Group members is enhanced within the community. As emerging role models, the community must be far more receptive and trusting of them. Presently, the Thokozani Support Group members expose themselves not only to ridicule but also to potential harm, as was the case of Nozipho Langa who attempted to convince young prostitutes to use condoms with their clients. The way in which the community views the Thokozani Support Group members is also important in terms of encouraging people to go for voluntary counselling and testing, as well as to approach local health structures for support after testing positive.

6.4.3 The Final Word

On a final note, as role models, the Thokozani Support Group members also have the ability to promote Foley's concept of informal and incidental learning, which he describes as "most significant" in that they will be confident and willing to share their knowledge and skills with the community. Given their status as role models within the community, the community in turn will also have confidence to replicate and share, both informally and incidentally, the acquired knowledge with friends and other family members. Ultimately, should such knowledge replication occur in significant frequency, it would have a positive impact on the prevailing socio-environment and hopefully help in turning the tide against HIV/AIDS in the townships of Richmond.

Bibliography

ACORD (Agency for Co-operation and Research Development) (2002). *Capacity Building for Community Based Organizations*. (Online) Retrieved November 2005. Available: www.acord.org.za

Ala, J. (2001). The Role of International Community in Combatting HIV/Aids in Sub-Saharan Africa. *Aids Bulletin*, 10(2), 8 -12.

Babbie, E. & Mouton, J. (2001). *The Practice of Social Research*. Cape Town: Oxford University Press.

Barab, SA, (2003). An Introduction to the Special Issue: Designing for Virtual Communities in the Service of Learning, *Information Society*, 19(3), 197-201.

Barab, S.A, MaKinster ,J & Scheckler, R. (2003). Designing System Dualities: Characterizing a Web-Supported teacher Professional Development Community. *Information Society*, 19(3), 237-256.

Barab, S.A. & Duffy, T. (2000). From Practice Fields to Communities of Practice. In D. Jonassen and S. Land (eds) *Theoretical Foundation of Learning Environment*. (pp25-56). Erlbaum Associates: University of Indiana, Bloomington.

Baxen J. & Briedlid A. (2004a). HIV/Aids and Educational Contexts: Beyond the Content to Understanding the Context. Paper Presented at the 12th World Congress on Comparative Education Societies, Havana, Cuba, 25-29 October 2004.

Baxen, J. and Breidlid, A. (2004b). Researching HIV/AIDS and Education in Sub-Saharan Africa: Examining the Gaps and Challenges. *Journal of Education*, 34, 9-29.

Bell, J. (1999). *Doing your Research Project: A Guide for First-time Researchers in Education and Social Science*. Buckingham, Philadelphia: Open University Press.

Bellah, R., Madson, N., Sullivan W.M., Snider, A., Tipton, S.A. (1985). Habits of the Heart: Individualism and Commitment in American Life. *Journal of Sociology*, 92(1), 183-186.

Boettiger, M. (2004). *A Critical Reflection on the Use of Participatory Techniques*. Honours Research Project. University of KwaZulu-Natal: Pietermaritzburg.

Brewerton, P. & Millaward, L. (2002). *Organizational Research Methods. A Guide for Students and Researchers*. London: Sage.

Bymugisha, G. (2001). 'Afterword' by Gideon Mendel. *A Broken Landscape: HIV and Aids in Africa*. London: Network Photographers.

Cortazzi, M. (1993). *Narrative Analysis*. London: The Falmer Press.

Cawthra, H.C., Helman-Smith, D. & Moloi, D. (2001). The Voluntary Sector and Development in South Africa, *Development Update* Vol 3 (3). 113 – 129.

Campbell, C. & Williams, B. (1999). Beyond the Biomedical and Behavioral Towards an Integrated Approach to HIV Prevention in Southern African Mining Industry. *Social Science Medicine*, 48, (11), 1625-1639.

Chamberlayne, P., Bornat, J. & Wengraf T. (2000). *The Turn to Biographical Methods in Social Science : Comparative Issues and Examples*. London: Routledge.

Christiansen, P. & James A. (2000). (Eds). *Research with Children. Perspectives and Practices*. London: Falmer Press.

CINDI (Children in Distress). Pietermaritzburg, KwaZulu-Natal. Regional Orphans Report (December 2001). Richmond Community Profile (2003). (Online) Retrieved September 2005. Available: www.cindi.org.za

Cohen, L. Manion L. & Morrison, K. (2000). *Research Methods in Education*. 5th Edition. London: Routledge.

Coombe, C. (2000). Mapping the Impact of HIV/Aids on Education: Asking the Right Questions. *HIV/Aids Impact on Education. Clearinghouse*. (Online). Retrieved 25 November 2005.

Available: www.harare.unesco.org/hivaids

Crewe, M. (1992). *Aids in South Africa: The Myth and the Reality*. Cape Town: Penguin Books.

Dejong, J. (2003). *Making an Impact in HIV/Aids: NGO Experiences of Scaling Up*. London: Southampton Row.

De Lange, N., Mitchell, C., Moletshane, L., Stuart, J. & Buthelezi, T. (2004). Seeing with the Body: Educators' Representations of HIV and Aids. Faculty of Education, University of KwaZulu-Natal.

Du Plessis, K. (2002). Of Strategy and Action. *Perspective*, 3(2), 67-68.

Dunpath, R. (2003). Archaeology of A Language Development in a Non-Governmental Organisation: A Doctoral Thesis in Faculty of Humanities. University of KwaZulu-Natal, Durban.

Durrheim, K. (1999). Research Design. In M. Terre Blanche & K. Durrheim. (Eds) *Research in Practice: Applied Methods for the Social Sciences*. (379 – 397). Cape Town: UCT Press.

Durrheim, K. & Wassenaar, D. (1999). Putting Design into Practice: Writing and Evaluating Research Proposals. In M. Terre Blanche & K. Durrheim (Eds.), *Research in Practice: Applied Methods for the Social Sciences*. (54 - 71). Cape Town: UCT Press.

Emmanuel, J., Wendler, D. & Grady, C. (2000). What Makes Clinical Research Ethical? *JAMA*, 283(20), 2701 – 2711.

Everatt, D. (ed.) (2001). A Review of Government and the Voluntary Sector Delivery from 1994, *Development Update*, 3(4).

- Everatt, D, & Jennings, R. (2001). Poverty Alleviation in Rural South Africa Evaluating the Community Based Public Works Programme. Pretoria: Department of Public Works.
- Fahamu (2004). Community-Based Organization: The Emerging Force from within the Third Sector.(Online) Retrieved: 07 June 2005. Available: www.fahamu.org/downloads/CBOsSurveyReport.pdf
- Fattal, A. (2004). Children's Lives-in their Own Images. *Children FIRST*, 56, July/August, 35 – 38.
- Fetterman, D.M. (1999). Reflections on Empowerment Evaluation: Learning from Experience. *Canadian Journal of Programme Evaluation*, Special Issue, (5 – 37).
- Foley, G. (1999). *Learning in Social Action. A Contribution to Understanding Informal Education*. London: Zed Books.
- French, W.L. & Bell, C.H. (2001). *Organisation Development. Behavioural Science Interventions for Organisation Improvement*. New Jersey: Prentice Hall.
- Goodson, I. & Sikes, P. (2001). *Doing Qualitative Research in Educational Settings: Learning from Lives*. Buckingham: Open University Press.
- Gouws, E. & Karim, Q. A., (2005). HIV Infection in South Africa: The Evolving Epidemic. In S. Karim, & Q. Karim (eds). *HIV AIDS in South Africa*. (pp.51 – 61). Cape Town: Cambridge University Press.
- Gow, J. & Desmond, C. (Eds). (2002). *Impacts and Interventions. The HIV/Aids Epidemic and the Children of South Africa*. Pietermaritzburg: UKZN Press.
- Grant, A.K. (2004). Understanding the Institutional Dynamics of South Africa's Response to the HIV/Aids Pandemic. Cape Town: Institute for Democracy in South Africa.
- Gray, J.N., Lyons, P.M. & Melton, G.B. (1995). *Ethical and Legal Issues in AIDS Research*. Baltimore: The John Hopkins University Press.

Higson-Smith, C. & Killian, B.J. (2000). Caring for Children in Fragmented Communities. In D. Donald, A. Dawes, & J. Louw. (eds.) *Addressing Childhood Adversity*. (202-224). Cape Town: David Philip.

Jamil, I. & Murisa, R. (2004). Building Social Capital in Uganda: The Role of NGOs in Mitigating HIV/Aids challenges. Paper presented at the International Conferences organized by the International Society for Third Sector Research in Toronto, 11 -14 July, 2004.

Jennings, G. & Solomon, S. (2002) Zeroing in on Kwazulu-Natal. *Perspective*, 3(2), 68 - 70.

Jesson, J., & Newman, M. (2004). Radical Adult Education and Learning. In G. Foley (ed). *Dimensions of Adult Learning, Adult Education and Training in a Global Era*. Maidenhead, Berkshire: Open University Press.

Kauffman, K.D. Kyle, D. (2003). *Aids and South Africa: The Social Expression of a Pandemic*. Hamshire: Palgrave Macmillan.

Kelly, K. (1999c). Calling it a Day: Reaching Conclusions in Qualitative Research. In M. Terre Blanche & C. Durrheim (Eds), *Research in Practice: Applied for the Social Sciences*. (pp.379-397). Cape Town: UCT Press,.

Kotze, H. (2001). Responding to the Growing Socio-economic Crisis. A Review of Civil Society in South Africa. *Interfund*, Vol 3 (4) 2 -7.

Kraak, G. (2001). The South African Voluntary Sector in 2001: A Great Variety of 'Morbid Symptoms'. *Development Update Annual Review*, 3 (3), 129 – 150.

Kraak, G. (2001). *Development Update: A Review of Government Delivery from 1994*. *Quarterly Journal of South African National NGO Coalition and Interfund*, 3(4), 129-186.

Macmillan, J. & Schumacher, S. (1997). *Research in Education. A Conceptual Framework*. 4th Edition. New York: Longman.

- MAP (Monitoring the Aids Pandemic). (2000). *The Status and Trends of HIV/Aids Epidemic in the World*. XIII International Aids Conference. Durban, South Africa, July 2000, 9 -14.
- Mason, J. (2004). The Legal Context. In S. Fraser, V. Lewis, S. Ding, M. Kellett & L. Robinson. (Eds). *Doing Research with Children and Young People*. (pp. 43 – 58). London: SAGE Publications,.
- Mezirow, J. (1991). *Transformative Dimensions of Adult Learning*. San Francisco: Jossey-Bass.
- Miles, M.B. & Huberman, A.M. (1994). *An Expanded Source book: Qualitative Data Analysis*. Thousand Oaks: Sage.
- Motala, S. & Husy, D. (2001). NGOs do it better: An Efficiency Analysis of NGOs in Development Delivery. *Development Update*. Annual Review, 3(3), 71 - 111.
- Muthukrishna, N. (2002). Research proposal: Mapping HIV/AIDS as a Barrier to Learning and Participation in Basic Education: A Case Study of the Experience of Adult and Child Learners in the Richmond Area of KwaZulu-Natal. Pietermaritzburg, University of KwaZulu-Natal.
- Neuman, W. (2000). *Social Research Methods*. (Fourth edition.) Boston: Allyn and Bacon.
- Ntsaluba, A. (2003). Challenges to the Implementation of an HIV/Aids Programme in South Africa. *Aids Analysis Africa*, 14(4), 4 -5.
- Ntsime, M. (2001). Partnership with Civil Society in the Community-based Public Works Programme. *Development Update - Annual Review*, 3(3), 113 - 127.
- Ntsime M. (1999). *Partnerships with Civil Society in the Community Based Public Works Programme*. Research Report for Masters degree in Management, University of the Witwatersrand, Johannesburg, South Africa.
- Patton, M.Q. (1991). *Qualitative Evaluation and Research Methods*. (Second edition.) Thousand Oaks: Sage Publishers.

Ramsoorooj, J. (2002). *An Investigation to Examine the Construction of Meanings, Attitudes and Perceptions of HIV/Aids among Lay and Professional Counsellors in KwaZulu-Natal*. Unpublished Master's Thesis. Pietermaritzburg, University of KwaZulu-Natal.

Richer, M. & Heyward, M. (2002). Is South Africa's HIV/Aids Programme the 'largest and most comprehensive in the world?' *Aids Analysis Africa*, 13(1), 14 - 16.

Rule, P. N. (2003). "*A Nest of Communities*": *Historical Case Studies of the Projects of the Interchurch Education Programme, 1978 – 1999*, a thesis submitted for the degree of Doctor of Philosophy in Education: Univeristy of Witwatersrand, Johannesburg.

Schneider, H. and Stein, J. (2000) Implementing Aids Policy in Post-Apartheid South Africa. *Women's Health News and Views*. 34, 11-14.

Schatz, M. (ed.). (1993). *Qualitative Voices in Educational Research*. London: Falmer Press.

Schatz, M. & Walker, R. (1995). *Research and Social Change: New Opportunities for Qualitative Research*. London: Routledge.

Seidman, I.E. (1998). *Interviewing As Qualitative Research: A Guide for Researchers in Education and the Social Science*. New York and London: Teachers College.

Shaeffer, S. (1994). *The Impact of HIV/Aids on Education: A Review of Literature and Experience*. Paris: UNESCO.

Simon, H. & Usher, R. (2000). *Situated Ethics in Educational Research*. London: Routledge Falmer.

Smith, M. (2003). *Learning Democracy*. A case study of learning democracy in a peri-urban community development project. A thesis submitted for the degree of Master of Education. University of KwaZulu-Natal, Pietermaritzburg.

Strode, A & Grant, K.B. (2004). *Understanding the Institutional Dynamics of South Africa's Response to the HIV/Aids Pandemic*. Pretoria: Institute for Democracy in South Africa.

Swanepoel, H. (1997). *Community Development: Putting Plans into Action*. 3rd Edition. Cape Town: Juta

Taylor, S.J. & Bogdan, R. (1984). *Introduction to Qualitative Research Methods: The Search for Meanings*. (Second edition). New York: John Wiley and Sons.

Taylor, R. (2002). Justice Denied: Political Violence in KwaZulu-Natal after 1994. *Violence in Transition series*. Vol 6. (Online) Retrieved: January 2006. Available: www.csvr.org.za/papers/papvtp6.htm

Terre Blanche, M. and Durrheim, K. (1999). *Research in Practice: Applied Methods for the Social Science*. Cape Town: University of Cape Town Press.

UNAIDS. (2002). A Conceptual framework and Basis for Action: HIV/AIDS Stigma and Discrimination. Geneva: UNAIDS.

Van der Riet, M. Hough, A and Killian, B. (2005). Mapping HIV/Aids as a Barrier to Education: A Reflection on the Methodological and Ethical Challenges to Child Participation. *Journal of Education*, 35, 74-97.

Van der Riet, M. (2004). Mapping barriers to Learning. Unpublished workshop Presentation, University of KwaZulu-Natal, Pietermaritzburg.

Walker, R. (1993). Finding a Silent Voice for the Researcher: Using Photographs in Evaluation and Research. In M. Schratz (ed). *Qualitative Voices in Educational Research*. (pp.72 – 92). London: Falmer Press.

Wang, C. (1999). Photovoice: A Participatory Action Research Strategy Applied to Women's Health. *Journal of Women's Health*, 8(2), 185-192.

Wenger, E. (1998). *Communities of Practice. Learning, Meaning and Identity*. Cambridge: Cambridge University Press.

Wenger, E., McDermott, R. & Snyder, W.M. (2002). *Cultivating Communities of Practice*. Boston, MA: Harvard Business School Press.

Whiteside, A. & Sunter, C. (2000). *Aids: The Challenge for South Africa*. Cape Town: Human, Rousseau & Tafelberg.

Willherall, C. & Noddings, N. (1991). *Stories Lives Tell: Narratives and Dialogue in Education*. New York: Teachers College Press.

World Book Inc. (2003) World Book Multimedia Encyclopedia. 2004 edition. Software Resource. Accessed: January 2006.

Young, F. (1999). Eight Strategies for Increasing NGO/CBO Participation in the Partnership against Aids. *Aids Bulletin*, 8(4), 12-14.

Appendices

APPENDIX 1

INTERVIEW SCHEDULE: LIFE HISTORY: NARRATIVES

1. Biographical Details

1.1. Biological Details:

- Name:
- Age:
- Gender:
- Marital status:.....
- Occupation:
- Main source of income:

1.2. Family Structure:

- Number of people in household:
- Number of children that you have:
- Children's' schooling/education

1.3. Other Life History Experiences:

- Place of birth
- Why are you living in Richmond now?
- Your schooling/academic career :.....

1.4. Childhood Experiences:

- Happy moments:
- Sad moments:
- Difficulties/hardships experienced during growing up years to present.....

1.5 Your experiences and other peoples' experiences regarding Richmond's political violence.....

2: Organisation and Community Learning

2.1 Members of the Thokozani Support Group:

- What was your interest in becoming a member of the support group?
- How long have you been in the group for?
- Why are you a member of the support group?
- Who can or cannot be part of the group?

2.2 When was the first time you heard about the group?

- How did you react/respond after you heard about the group?
- What did you think about the group after hearing about it?

2.3 What is your knowledge around the birth of the group?

- Do you know who started the organisation?
- Why do you think there was a need to form such a group?
- The people who started the group, are they still members of the group? Where are they?

2.4 Your role in the Organisation:

- Do you play any specific role in the organisation?
- In what ways do you contribute to the support group?
- How does the support group benefit from you or your input?
- Would you like to share any specific experiences here around your involvement within the organisation?

2.5 Recruiting Members:

- One of the main functions of the organisation is to recruit members. Who does the recruitment of members?
- Were you recruited? What process did you follow?
- What support do you or the group offer to new members?
- How is the identification of new members carried out?
- Have you seen some members leave the organisation and for what reasons?
- Why are all members of the support group from Ndaleni?

2.6 Creating Community Awareness:

- How does the organisation carry out this awareness?
- What are some of the ways that members create community awareness?
- How do people in your community respond/react to this awareness?

2.7 Other Types/Forms of Support:

- What other types of support do you offer to members of the community?
- Are there any specific forms of support that you offered to community members?
- How did they respond to this type of support?
- What motivates you and/or other members to carry out these programmes in the communities?
- Has the organisation received (in turn) any particular types of support from the community?

2.8 Difficulties in Delivering Programmes?

- What are some of the difficulties that you or other members may experience when trying to deliver programmes and/or information?
- Being an organisation that has no source of funding, surely you must experience difficulties in reaching people in various communities?
- Can you explain or describe some of those difficulties, for example, transport costs?

2.9 Other Difficulties:

- Any political barriers that influences your work?
- What are the attitudes of traditional leaders? Do they welcome you to their communities?
- What is your opinion of the traditional healers?

2.10 Skills and Knowledge:

- Where did you acquire the skills and knowledge to share information with community members?
- Did you know much about the knowledge you share with people before you joined the group?

- Were there any other organisations, government or non-government that offered your organisation support? If so, when and what type of support?

2.11 Organisational Limitations:

- Is the organisation a registered organisation? If not, why?
- Has the organisation formed a network of support with other organisations like other NGOs, CBOs, the local municipality, etc? Expand?
- Where would you like to see the organisation go to from here?
- What hopes do you have for the organisation and for other members of the group?
- What are some of the obstacles that may prevent the organisation from attaining certain goals?

3. Personal health & support from the Thokozani Support Group

1. How did you first find out that you were HIV-positive? (If status revealed)
2. What prompted you to go for a test?
3. What other type of support other than that from the support group did you receive when you learnt your status?
4. What do you think may have led you to contract the disease?
5. Are members in your family aware of your HIV status? What are their attitudes towards you?
6. Mention the skills and knowledge you were able to acquire after becoming a member of the support group.
7. What do you think is the most important advice that you always share with people in communities that are infected and affected by the disease?

APPENDIX 2

INTERVIEW SCHEDULE: VISUAL METHODOLOGY: PHOTO INTERVIEW

1. In terms of community learning, what was your main reason for taking this photograph?
2. How did you best offer help, support or advice to the participant/s in the photograph?
3. Why is this photograph special to you?
4. What important information would you like to share with the researcher about the participant/s?
5. How does this photograph help the researcher with the study that she is doing?
6. If children are photographed, do they go to school and/do they receive any type of social grant?
7. Did any of the participant(s) object to being photographed?
8. Did you enjoy using this method? What did you enjoy most about using this method?
9. What did you not like about using this method? Why?

APPENDIX 3

CONSENT LETTER ONE



Dear Thokozani Support Group Participants

RE: RESEARCH STUDY ON THE THOKOZANI SUPPORT GROUP

I am a Masters student from the School of Education at the University of KwaZulu Natal. I am also part of a broader research team that is examining the extent to which barriers make it difficult for children to take part in learning. These barriers may include crime, violence, illnesses and distance to schools. The mayor of Richmond and other stakeholders have expressed their support for this project.

A large part of the research will also include collecting data from a wide range of government departments, non-governmental organisations, and faith-based and community-based organisations. The Thokozani Support Group has been identified as one of the organisations that can assist us in finding out the contribution you have made in your respective communities with regard to the research topic. My task, therefore, is to assist the project team in obtaining this information, both for the larger project as well as for my thesis.

A meeting will be held in due course where you will be briefed more on the project. I would like to concentrate on what contributions you have made in your community with regard to helping and supporting community members infected with and affected by HIV/AIDS. I would obtain this information using the life history method, by engaging selected members in a one-to-one in depth interview where I will be given an opportunity to listen to your stories. The interview could take up to two-and-a-half hours with a break in-between where refreshments will be served.

The second part of the research will involve the photo voice method. Here, each selected participant would be provided with a disposable camera, which the participant may take back to the community and photograph issues of concern so that we may obtain a deeper understanding of the social realities the underpin these communities.

It is therefore important that in terms of the study undertaken you, the selected participants, understand that:

1. All information will remain totally confidential.
2. Your identity will remain anonymous.
3. To ensure that no important information is lost, the interview will be tape-recorded and the tapes will remain in a safe place and be made accessible only to the task team.
4. If you do not wish to participate in this research project, you may withdraw at any time.
5. You are not obligated to answer any question that you do not wish to.
6. A translator/facilitator will be present due to language barriers.

With regard to the photo voice method, it is important that you note the following:

1. Obtain permission first from a parent, or caregiver or the individual you wish to photograph or the individuals themselves if over the age of 18.
2. You may not take a photograph of individuals should they not wish to be photographed.
3. Participants to be photographed must be briefed on the project and the purpose of having the photograph taken.
4. Ensure that you follow a set theme on taking photographs, i.e., social realities underpinning communities with respect to HIV/AIDS and your assistance or contribution as a member of The Thokozani Support Group thereof.
5. A full demonstration will be given on how to use and manage the camera.
6. A period of four weeks will be allocated to you where the disposable cameras will be in your possession and thereafter it must be returned to me.
7. You will be shown the photographs once they have been developed and printed.
8. During a presentation of the photographs, you will be allowed to choose the photographs you wish to present.
9. Participants must place a cross at the back of the photographs that they do not wish to present during the photo voice discussion or do not want to form part of the thesis.

Furthermore, participants selected to participate in the project must be aware that any articles that may be published from this research or the public display of photographs will ensure anonymity

of the participant/s and the respective community by avoiding the use of any identifying information.

If you have understood the above and wish to participate in this research study, please read and complete the consent form below.

Yours sincerely

Suhana Jacobs

I, (Please write your name in full)

I will take part in this project :

I will not take part in this project:

I also fully understand the contents of the above letter and agree to participate in the research process.

SIGNATURE: _____ DATE: _____

APPENDIX 4

CONSENT LETTER TWO



Dear Thokozani Support Group Participants

This letter serves to confirm the understanding reached between the researcher and the selected Thokozani Support Group participants whereby the said participants have agreed they do NOT wish to remain anonymous and that their true identities may be used in the compilation of the researcher's thesis.

This letter further confirms that you have briefed the community participants on the project and should the participants choose to be photographed, their photograph will be used in the research project.

SIGNATURE:

DATE:

APPENDIX 5

CONSENT LETTER THREE

This consent form serves to confirm the following in respect of you as a research participant



1. You are fully informed about the research process, how it is being conducted and what it hopes to achieve;

2. You understand the expectations of the researcher and agree to participate in the study, and that at any time during the process you may choose to withdraw your involvement;

3. As an active extension of the research process, you will explain to and seek permission from the people you photograph;

4. In the instance of children being the subject of the photographs you take, particular consent is sought from the child’s parent, guardian or care-giver;

5. You have been given the opportunity of viewing the photographs that have emerged from the study and have thereafter chosen images to be used in the study;

6. The research data may be reproduced in educational articles and journals but in a way that would safeguard the privacy and dignity of the participants.

Name of participant

Signature of participant

Date: _____

Place: _____

APPENDIX SIX

CONSENT LETTER FOUR

15 September 2005



TO WHOM IT MAY CONCERN

This form serves to confirm that I (**name in full**) have seen the photographs taken by the research participants of the Thokozani Support Group and **consent / don't consent** that the researcher, Suhana Jacobs, using the picture/s in her project.

All the details pertaining to the contents of the picture were thoroughly explained to me and therefore I **give / I do not give** permission to the researcher, Suhana Jacobs, to use them in her project.

My relationship with the person/s in the photograph/s is

In conclusion, what is contained in the project **can / cannot** be used again in other educational programmes (except with the protection of the identities of the participants.)

.....
Community Participant

.....
Date

.....
Place

Ethical Clearance

18 April 2007



To Whom It May Concern:

Ethical Clearance Certificate: S. Jacobs 204518428

This is to confirm that at the time of binding this dissertation the final Ethical Clearance Certificate had not been issued yet. This certificate will be stored in the Faculty of Education office on the Pietermaritzburg Campus of the University of KwaZulu Natal and will be available for inspection.

The Ethical Clearance Certificate approved by the Faculty of Education Research Committee is attached.

Yours Sincerely

Dr. P. Rule

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