

SUPPORTING OURSELVES
MAINTAINING MENTAL WELL-BEING THROUGH AN HIV+/AIDS SUPPORT GROUP IN A RURAL
SOUTH AFRICAN COMMUNITY

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Spring 2005

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Acknowledgements

In the lives of those in poor health, I have always been witness to the power of the mind in their fight against illness. I am amazed at the immense value that a support group can hold for people affected and living with HIV/AIDS. Now that I have worked so closely with such great individuals, I am most indebted to the motivated group members of St. Matthew's Clinic in Qoboqobo, South Africa, for allowing this research to take place. There is no way that I will ever forget the time that they spent with me in order to voice their concerns. In completing this research study, I have come across some very unique people who have taught me the importance of maintaining the spirit alive in the battle against HIV/AIDS.

I am especially thankful to my research advisor, Zoliswa Manzana, for arranging my meetings with the support group. I appreciate all the efforts that were made to organize a Health Awareness day in Ngobazana for HIV/AIDS with my support group, and for the English to isiXhosa translation of "11 Ways to Cope with Stress", which I presented as part of the support group's community awareness activity. It was with her actions that the group recognized me as one of their own. In retrospect of the consequent experiences, I truly believe that part of me has become South African. I finally felt a sense of belonging as I sang and danced to songs and statements of HIV disclosure in isiXhosa. In staying in the rural area of the Eastern Cape of South Africa, my values of generosity, patience, and activism have been reaffirmed. I am so grateful that in the fight against the high prevalence of HIV/AIDS among women many have shared their life stories. Yet never have these individuals failed to create a sense of welcome and encouragement. Their reception has fueled my desire to continue providing social support for people affected and living with HIV/AIDS.

To the town of Qoboqobo, a million thanks for the wonderful hospitality and friendliness! Qoboqobo was definitely rejuvenating. I would like to thank my rural home stay family for being an immense guide and support during my stay. It was the neatest thing getting to and from the St. Matthew's Clinic from the hill of my rural home. I had many interesting conversations on that winding dirt road. I have never felt so free and adventurous in my life!

Furthermore, I am most grateful to Dr. Boateng and the S.S. Gida Hospital nurses and staff. Most especially, I would like to thank Nurse Hewana and Nurse Kota for their words of empowerment and motivation. Many thanks also go towards the people at the Qoboqobo Municipality and the Constituencies' Office.

Also, I am most indebted to the SIT Public Health Team at Nelson Mandela Metropolitan University for providing me with the necessary tools for conducting my research study in Qoboqobo. I would like to thank Dr. Mthobeli Guma for allowing me to explore the use of the focus group setting as a valuable researching tool. Even more important are the wonderful lessons of isiXhosa given mostly by Titshalakazi Xoliswa Zauka. I would also like to thank my NMMU translator, Nomvuyo Jack, for working on such short notice and for allowing me to ask so many questions about the discussion that she transcribed.

All of this work would not have been possible without the financial support from Southwestern University, the Kahler Foundation, the Paideia Honors Program, and the Benjamin A. Gilman Institution of the Institute for International Education. I definitely think that coming back to South Africa is a goal of mine! I felt so tingly inside at the end of the day, but I was completely exhausted from having to deal with the situation and finding the most appropriate way to express the support group's concerns. My study abroad experience has surely been very holistic. I know that in reality I have learned to value the culture for all its beautiful customs and for its undeniable truths. No one can take those very precious experiences that I have shared with my HIV/AIDS support group in Ngxalawe where I worked daily for a month.

To all the wonderful people that I have met during and up to the period of my Independent Study Project, I give many thanks for creating many lasting memories. Thank you very much for participating in my study and I have faith that together we shall overcome our struggle against the lasting impact of HIV/AIDS!

Abstract

This paper primarily explores the importance of the support group for people infected and affected by HIV+/AIDS. At St. Matthew's Clinic in the rural area of Qoboqobo, I invited women between the ages of 25-49 to freely participate in the focus group discussions. I believe that the health care sector could benefit from these groups, both as formal outreach services and informal support networks. There is a lack of healthcare services in rural areas. Of particular interest, PLWA are continuously encouraged to join an HIV/AIDS support group. This paper aims to explore how people are dealing with stress and HIV/AIDS-related dementia and other psychological impacts. In trying to understand the high rate of unemployment in Qobo Qobo in March 2005, I found an HIV/AIDS support group that works toward self-sustenance. However, there are many HIV+ clients who are not yet in the support group. I want to know how support group members are being educated to decrease stress related to living with HIV/AIDS.

Objectives of the study include finding how support groups for HIV/AIDS aid in their mental health. The case study also had the following objectives: **a) to explore the psychosocial benefits of an HIV/AIDS support group; b) to establish rapport with the PLWA Support Group at St. Matthew's Clinic; c) to provide agency to those involved in order to address the major mental health concerns through focus group discussions and key informant interviews; and d) to identify what all involved parties are doing to address mental health problems, including nurses, HIV counsellors, provincial government and members of the community.**

These women, the social worker and all nurses interviewed at S.S. Gida Hospital and St. Matthew's Clinic noted that HIV/AIDS definitely has a negative psychological impact on the person living with HIV/AIDS, family members and society as a whole. Shock and stress-related illnesses were the most cited as affecting a person's mental well-being. Also mentioned by the group members and professionals was depression resulting from the stigma of HIV/AIDS and from the loss of a loved one. Despite the presence of dementia and the loss of motor functioning in the late stages of AIDS, few mentioned this AIDS trait as being a mental health problem.

I. INTRODUCTION

In visiting Qoboqobo and other rural communities throughout the Eastern Cape of South Africa, I noticed the strong presence of support groups aimed at maintaining the well-being of people living with HIV/AIDS (PLWA). In retrospect, I have noticed that the program's fruitful excursions created the necessary analysis of available health care facilities and access to support systems for PLWA. Many support groups were often set up at anti-retroviral (ARV) distribution sites. For example, in the area of Lusikisiki there were 15 active sites for ARV dispersal, and each site had a support group in order to aid in the adherence of the anti-retroviral drugs. In another region of the Transkei, I visited a successful gardening project that was being maintained by the healthy members of a PLWA support group. In their garden, they grew a variety of vegetables like tomatoes, beets, spinach, cabbage, and potatoes. The harvest was then collected to feed PLWA and their families. Of specific interest, the vast majority of these garden cultivators were the young family members of the people living with and affected by HIV/AIDS.

However, prior to visiting the Transkei, I had lived in the rural area of Qoboqobo, also known as Keiskammahoek. For a week in March 2005, I, along with other public health researchers, investigated the high rates of unemployment and its impact on the health of the village of Ngxalawe. In the process of doing field research in the local community clinic of St. Matthew's, I came across a PLWA support group that worked towards self-maintenance and group empowerment. Initially, I met this group at a nearby room outside the operating clinic. In the main room, I found several elderly women sitting on the cold cement floor. To the left, there was a small kitchen. A child with Down's syndrome waited with his mother, and loose potatoes laid aimlessly around three sacks by their workroom. At this point, I noticed that seven dishes of mashed potatoes had been served. I knew that this environment was definitely not an adequate meeting place for an HIV+/AIDS support group. Immediately, I thought that their food provisions were ill-prepared to provide these PLWA with the required nutrition for mental and physical well-being.

My decision to return to Qoboqobo was made when a group member commented to me in isiXhosa, “I see the value of being in a support group because I feel a sense of belonging and I know that I will live yet another day.” When the PLWA support group members talked to me at that time, the main concerns that were communicated focused on their lack of money and nutritious food. The main problem is that the sources of income are at a current standstill and too few avenues for work and employment are available in the community. Several questions arose from these preliminary observations. I wished to investigate the main initiatives in place that promote the well-being of PLWA. I wanted to know what they were doing to survive. After my initial visit in March, I was highly interested in investigating how these members were empowering themselves and creating change in their lives and communities. Furthermore, I wanted to know how this situation causes distress in people living with HIV/AIDS in a community which lacks resources. For these reasons, the central aim of the present study was to investigate the manner in which PLWA use the support group setting to cope with their mental health problems in the rural community.

From the case study findings, it can be suggested that alternative measures are available to ensure the mental well-being of PLWA in a resource-poor community. Disclosure of their HIV status through HIV/AIDS awareness activities and finding solutions to their problems within the support group improves the psychological well-being of these individuals living with HIV/AIDS. Furthermore, as their nutrition is compromised due to the lack of economic resources, the group of women work towards creating their own resources through a community garden project and by selling their beadwork. However, currently there is not enough money to buy a new supply of beads and seedlings for the garden. This poor nutrition and the absence of work for PLWA have triggered the collaboration between NGOS, which ultimately affects the

mental well-being of PLWAs. Of course, worth mentioning is the group's request for more training and education of HIV/AIDS. All PLWA and their families have the right to an appropriate and continuous education on HIV/AIDS. Adequate resources should be found through the increased collaboration of Community-based organizations, families of PLWA, support groups and other NGOs. Furthermore, the inclusion of PLWA into awareness activities within the community were not only a source of empowerment for PLWA but also makes HIV/AIDS prevention increasingly effective. Immediate action should take place on behalf of all sectors of society to implement a beneficial and creative support network for the mental health of PLWA.

II. LITERATURE REVIEW

According to the existing literature, there are many ways in which HIV/AIDS impacts the mental well being of individuals. From the roundtable discussions with the South African Human Sciences Research Council, Freeman et al. (2003) state the links between mental health and HIV/AIDS are both profound and highly neglected. In addition, Meintjes et al. (2001) suggest that mental health problems, relatively seldom taken into consideration, are equally important during conflict. Issues affecting a person's mental health can be provoked by the traumas suffered after physical or sexual violence or by economic difficulties. Olley et al. (2003) found that most prevalent psychiatric diagnosis was current depression. PTSD is more common in females with HIV/AIDS. The increasing prevalence may reflect high levels of stigmatization and stress faced by HIV/AIDS patients in South Africa. Health workers rarely recognize these mental health concerns and rarely make the mentally ill the object of psychological, material or appropriate legal assistance (Meintjes, 2001). Adjusting to the social degradation that face many PLWA has caused many community members to act. However, in establishing the mental health

care services for people living with HIV/AIDS in a resource-poor community, a myriad of factors needs to be considered.

A. Prevalence of the HIV/AIDS epidemic

After democracy was proclaimed in 1994, South Africans had to deal with the terrible repercussions of the old apartheid state along with the growing epidemic of HIV/AIDS. Present research has revealed that South Africa has one of the fastest growing epidemics in the world. In March 1998, the then Health Minister, Dr. Nkosazana Zuma said that an estimated 2.5 million South Africans were infected, and 50,000 more become infected every month (Simon-Meyer and Odallo, 2002). According to a report prepared by the governmental South African Statistics Agency, the deaths related to AIDS has risen a steep 57% from 1997, with the most deaths occurring in the ages of 15-49 years. Since the working age adults are the most sexually active, there is much risk for infection among this age group (Wines, 2005). It is young African women who are most susceptible to infection, have the highest rate of infection, get the most inadequate and inferior access to treatment, take most responsibility for caring for the sick and dying and have the shortest survival rate. Exacerbating the HIV/AIDS epidemic are the presence of malnutrition, lack of education in HIV/AIDS and ARV drugs, opportunistic infections like TB, and the social stigma of being HIV-positive (Anabwani & Nazario, 2005). Now, more than ever, a proper response to such a critical time is urgently needed to prevent further destruction on the socioeconomic developments of this nation.

B. Research Evidence for the Psychosocial Impacts of HIV/AIDS

Many research studies suggest that HIV/AIDS certainly has an effect on the individual's psychological functioning. Olley et al. (2003) found a review of the psychiatric literature of HIV infection shows that the disease is associated with substantial psychiatric morbidity,

psychological distress, and negative social impact. Furthermore, psychopathology was common in both male and female patients with newly diagnosed HIV/AIDS; male patients were more likely to abuse or depend on alcohol and to engage in risky sexual behaviors than females; and females were more likely to have PTSD and to use planning and religious activities as a means of coping. The increasing prevalence of depression may reflect high levels of stigmatization and stress faced by HIV/AIDS. Stress from work, worry, insecurity, stigma, depression, anxiety, withdrawal, aggression are major concerns among people living with HIV/AIDS (Freeman, 2003). Similarly, Freeman concluded from current research as well as the practical experience of participants, the following mental disorders were linked and relevant to HIV/AIDS: A) Mood disorders – depression, manic episodes; B) Neurocognitive disorders, including slowing of cognitive processes and memory and attention deficits; C) Impaired motor functioning; D) High degrees of hopelessness, active, and passive suicidal ideation and intent; E) Personality disorders; F) Psychosis (as a late manifestation of the disease); G) Depressive and cognitive dysfunction overlap. The true neuropsychiatric impact can often only become clear once the depression has been treated (Freeman, 2003).

C. Women's Mental Health & HIV/AIDS

In reviewing the psychiatric literature of the effects of HIV/AIDS, a general theme arose suggesting that the psychosocial impacts have unique ramifications by sex/gender. Estimates of psychopathology in patients with HIV/AIDS vary, however there's some evidence that HIV-infected women are twice as likely to be depressed as HIV-infected men (Olley et al., 2003). It is young African women who are most susceptible to infection, have the highest rate of infection, get the most inadequate and inferior access to treatment, take most responsibility for caring for the sick and dying and have the shortest survival rate (Gilbert & Walker, 2002). Given that in the

developing contexts women with HIV/AIDS may face greater stigmatization and more previous and current negative life events than men, it's possible that in these regions there's a concomitantly greater risk of psychopathology, maladaptive coping, and disability among women (Olley et. al, 2003). Yet Freeman (2003) points to the fact that women who have higher rates of HIV infection than men, may find themselves neglecting their health in carrying out their perceived social roles with devastating implications for all. A crucial factor as well, with the stigmatization associated with the diagnosis of HIV/AIDS, patients may be unwilling to disclose psychiatric symptoms unless clinicians take the initiative to address them.

D. Rural Health and Unemployment

The destruction caused by the HIV/AIDS epidemic is especially felt among the rural communities of South Africa. Pillay & Lockhart (2001) state that as a result of South Africa's apartheid history, mental health care for black Africans, especially in rural communities, has been grossly inadequate and even non-existent in many areas. Gilbert and Walker (2002) add that women predominate in rural areas. Furthermore, with the increasingly high unemployment rate, the people of the rural areas are especially exposed to conditions like wasting caused by malnutrition. Severe malnutrition impairs immune function and decreases resistance to infection. Anabwani and Nazario (2005) further illustrate, nutritional and micronutrient deficiencies are common in HIV-infected persons and play a major synergistic role in disease progression and in the retardation of growth and development of children. All persons with HIV infection should undergo nutritional assessment at the time of their first contact with health care professionals. Appropriate interventions and on-going monitoring should follow assessment. These factors need to be considered when designing a prevention program for the communities in South Africa.

Pertinently, an individual's work contributes to their mental health. In illustrating this point, Campbell (2003) argues that because the levels of social inequality in South Africa are among the highest in the world, it is unskilled and uneducated women in the rural areas of South Africa and the surrounding countries that have few opportunities for employment. Desjarlais et al. (1995) emphasize that the ability to earn income in the informal economy, in the agricultural sector, or in wage-paying jobs can help women increase their independence and maintain self-esteem. Control over financial resources enables women to manage household affairs and provide for their children without the support or cooperation of male partners, if necessary. Much of the work available to women is poorly paid and labor intensive, however. Working conditions are often dangerous and benefits nonexistent. Under these circumstances, work contributes to oppression rather than independence (Desjarlais et al., 1995). In South Africa, high levels of unemployment accompanied the dismantling of structural apartheid in an international context of globalization and economic marginalization. From at least the 1950s, South African women were at the forefront of protest and organization against apartheid. The key to their successful mobilization and sustained political action resides in two significant phenomena. The first is that, since the Second World War, the black working-class population has experienced high rates of urbanization. The second is the high level of worker, women, and youth mobilization and, reaching beyond these groups, the organization of civil society to include the establishment of professional and business organizations as well as community organizations. From at least the 1960s, in spite of repression of the apartheid state, mobilization and politicization continued within and among these groups (Meintjes, 2001).

E. Support Networks and Mental Health

Pre- and post-counseling are only the beginning of a continuum of prevention and support and not an end (Freeman, 2003). Supportive group interventions come in many group forms, labeled variously as self-help, mutual help, mutual assistance, treatment and support. Environmental resources and constraints affect the initial formation of support groups and their development over time (Galinsky, 1995). From the beginning of the AIDS epidemic, group work has been seen as a valuable modality to help PLWAs overcome social isolation and gain some measure of control over their destinies. Their continuing existence attests to participants' strong needs to universalize sometimes overwhelming emotional responses to the stresses of this devastating disease, to problem-solve around strategies for coping with its effects, and to exchange resources which can enhance the quality of an uncertain abbreviated life (Wenocur, 1993).

There is an obvious need to provide a continuum of care, encompassing not only medical but also physical and mental rehabilitation services as well. In an area of high HIV prevalence, the provision of appropriate, multi-disciplinary health care services to PLWA presents a major challenge to the health services (Hughes, 2004). There is a positive relationship between the mental well-being of people living with HIV/AIDS and the resources available to them. Support groups can be an important source of emotional support, guidance, and information for people who are dealing with common sources of stress (Galinsky, 1995). The need for vigorous health promotion programs cannot be sufficiently emphasized, especially in view of the benefits of early detection and treatment. Pillay and Lockhart (2001) argues adamantly that there also needs to be particular focus on rural women, considering the inadequate health care resources in their communities and the socio-economic hardships facing them. Women in these communities must

be empowered with knowledge about their health and illness prevention options. Thus, the collaboration between all sectors of society including NGOs, CBOs and FBOs and the family needs to be encouraged and developed. Together these groups will be able to determine a proper response to the psychosocial preventions and treatment for PLWA.

Wenocur (1993) states that the support group setting helps individuals to do the following: The universality of experience which has been identified as a therapeutic factor in groups helps to accomplish these objectives: a) identifying ways for members to reach out to families, friends and lovers for instrumental assistance and emotional support; b) expressing otherwise unacceptable feelings of rage, sadness, guilt, fear and shame occasioned by different biopsychosocial crises; c) focusing on the present, and exploring options which may enhance the daily quality of life, both physical and psychological; d) finding ways to demonstrate care for peers, family, and friends who may themselves have become estranged or overwhelmed due to their own fears and anxieties; e) exploring quality of life issues (how people want to live and ultimately to die) as they grow more dependent on others or more disabled; f) providing positive reinforcement for each member's unique experience as a person with AIDS in a society which increasingly exhibits intense AIDS-phobia.

There is a strong need to provide primary care workers with mental health skills and thus integrate mental health care into the primary care structure. Such a move could make mental health care accessible to all inhabitants, thus deviating from the policies of the past (Pillay & Lockhart, 2001). Similarly, Freeman (2003) suggests that VCT counselors need to be trained to recognize mental health problems. They should then be able to refer clients to other practitioners for medical interventions such as anti-depressants for those who needed this and/or for longer term counseling. Ideally the counselors should also be available and skilled to do more than one-

post session for a certain proportion of the users. Of particular importance, Gilbert and Walker (2002) emphasize there is a transmission of mis-information and a lack of knowledge of HIV/AIDS, particularly among women. For this reason, future research should primarily focus on empowering women, especially young adolescent women on the importance of HIV/AIDS knowledge and sex to further spread awareness in their relationships at home, at work, and in society.

While there is an emphasis on the biological aspects of the HIV/AIDS epidemic and the use of ARV drugs, much more direct action should be taken by community organizations and governmental services to provide families and individuals affected and living with HIV/AIDS with psychosocial support and education on the HIV/AIDS epidemic. It is detrimental to use community based initiatives and the family to fully address the impacts of HIV/AIDS on a person's psychosocial well-being. In reality, health programmes that only target an individual's sexual behavior do not answer the full question of how HIV/AIDS is transmitted. The health programmes should more responsibly recognize that there are socioeconomic pressures facing the often marginalized and poor women of South Africa. By doing so, the health programmes will highlight the more relevant social issue at hand – poverty is perpetuated by race and most importantly by gender. Furthermore, institutions committed to alleviating the nation of such a devastating epidemic should account for the sociodemographic information of the group that is most affected, that is women between the ages of 15 and 49. This reevaluation should be done not only to tailor to the mental and physical needs of these women, but also to further investigate the relationships between this group and men and children of South Africa. In this manner, the community with few resources can healthily rely on collective community action that targets these aspects of the HIV/AIDS epidemic.

III. METHODOLOGY

In order to collect valid responses in a more anthropological approach, I decided to conduct focus group discussions and in-depth interviews on the mental health care concerns of members in an HIV/AIDS support group in a rural community. The main objective was to understand how PLWA are handling any psychosocial stressors and mental health problems.

For the research study, a qualitative analysis was employed in order to access the appropriate content data. Interviews were held at St. Matthew's Clinic, S.S. Gida Hospital, and within the community of Qoboqobo. The focus group discussion was translated from isiXhosa. Transcribed interviews accessed the narrative data and were the major mode of data collection. The interviews were then compared and analyzed so as to validate the findings. Categories were then set and defined as themes emerged. To express the overriding themes, direct quotations from the respondents have been incorporated into the presentation of the findings.

A. Focus Group Discussions

Focus group discussions facilitated the research. The focus group setting produces a lot of information far more quickly and at less cost than individual interviews. They are excellent for obtaining information from illiterate communities. The researcher can be present at the session which allows follow-up responses if required. They are usually well accepted by the community as they make use of the group discussion which is a form of communication found naturally in most communities.¹ These guided discussions were held during the pre-scheduled support group meetings on Mondays and Wednesdays at 10 am. Matron Manzana, the nurse that works closely with this group, arranged for the first focus group discussion to take place on Monday, April 18th, 2005. This nurse invited several women and men to shape the content of my research. A translator was needed in order to facilitate the discussions. My advisor at St. Matthew's Clinic, Nurse Zoliswa Manzana, asked Sister Kota, S.S. Gida Hospital Outreach Coordinator for

HIV/AIDS, to act as a guide during the discussion. A letter of informed consent was explained in isiXhosa, agreed upon and signed before members took part in these discussions.

The focus group discussion aimed to 1) to identify the major mental health concerns, i.e. stress, depression, anxiety, and anger; and 2) to identify what is being done to ensure mental well-being among themselves and others. Furthermore, since transportation is a problem for many of the HIV+ clients, the group started doing outreach activities in the surrounding areas. These days are called HIV/AIDS Health Days. I actively participated in an HIV/AIDS Awareness Day at Primary School in Ngobazana. My attendance involved a speech in isiXhosa on “11 Ways to Deal with Stress” to the public. I believe that this involvement was a form of active participant observation which contributes to the strength of the case study. This measure was used to collect relevant data and was also valuable to the support group’s aims.

B. Participant and Key Informant Interviews

For a month, I worked alongside the St. Matthew’s Clinic Support Group for people living with and affected by HIV+/AIDS. To get more in-depth information on coping strategies for mental health concerns, I selected a woman and a man between the age of 25 and 49. Additionally, the nurse in charge of the support group, HIV counselors and one social worker were asked on their opinion of how the support group’s mental well-being is being ensured. Furthermore, I collaborated with doctors, nurses, and a social worker at S.S. Gida Hospital to gain insight on the connection between rural community health and PLWAs mental well-being. In order to further assess the social services that are provided to PLWAs and which ultimately affect their mental health, I attempted to interview a government official at the Social Welfare Department in Bisho. However, due to their non-appearance and inaccessibility through phone calls, faxes and personal visits, a meeting was not made possible. Together, the content analyses of these interview data will produce a more vivid account of the relationship between HIV/AIDS and the mental health of PLWA. For an outline of interview questions, please refer to Appendices 3 and 4.

IV. DATA

A. Background of the Case Study: A PLWA Support Group at St. Matthew's Clinic

1. *The Town of Qoboqobo*

On March 6, 2005, I had the wonderful opportunity to partake in a rural health excursion to the area of Qoboqobo. Along with the rest of my peers, I researched the rural community and its health services sector. Keiskammahoek, or Qoboqobo in isiXhosa, is a town that is situated on the Keiskammahoek River 42km Northwest of King William's Town and 32km southwest of Stutterheim. Furthermore, this area was originally a frontier post. It became a village after 1853 and attained municipality status in 1904. Pre-1994, the area belonged to what was known as "Ciskei".¹ The Ciskei and Transkei were two designated "states" for the Xhosa speaking people in the Eastern Cape.² After 1994, it fell under the Eastern Cape Province Government.³

The main languages spoken in the area of Qoboqobo are isiXhosa and Afrikaans. Ms. Madlokazi states further on the presence of foreigners, "There are usually no other languages spoken here. Maybe if there are people visiting from KwaZulu-Natal, there are constituency officers who understand the language and easily translate in order to communicate effectively." For the use of cell phones, many people do not get service in their villages, for most of the villages do not have networks. In town, there is Vodacom, M2N, and other networks. Electricity is available, but very unreliable. Madlokazi recounted her life in the townships where "a thunderstorm has the power to knock out the electricity."⁴ Adding on the standards of living, Mr. Mphulamphulam says that the biggest problems are maintaining the water purification projects in place, i.e. the water leakages and the process of the purification system.⁵

Modes of transport include traveling on backies and buses which go around on the main tar road that runs through the villages. The person must wait for the transport to arrive and take them out of town. There are transports to and from Rabula, Ngobazana, and other locations. The villages are not that far from each other. Buses are available mostly for the workers, nurses, and usually arrive in Ngxalawe around the early morning or at night. It's currently 10 Rand to get to and from King William's Town from Keiskammahoek, and is R24 to get to and from Alice from

town. To get to Mkumbizo, it is R14 each way.⁵ The clinics reach from Vaaldraai to the colored townships of Sophumelela. From town, it is about 6k to St. Matthew's Clinic. Otherwise, a person is on foot to get to wherever they need to be.

2. History of St. Matthew's Clinic HIV/AIDS Support Group

During my rural homestay in Qoboqobo, I came across a support group for HIV+ clients of St. Matthew's Clinic while investigating the resources available for the unemployed since Keiskammahoek has an incredibly high unemployment rate. St. Matthew's Clinic was previously the first community hospital of Qoboqobo. However, as the rural area of Keiskammahoek grew, now currently including over 25,000 people, this clinic was transformed at the hands of people desiring better accessibility to their healthcare services. Therefore, S.S. Gida Hospital was constructed on the other side of town in order to be more accessible to the community members.

There are 5 support groups in the area of Keiskammahoek: 1) Masivuke, 2) Luxolo, 3) Pilasande, 4) St. Matthew's Clinic, and 5) Gateway Clinic next to S.S. Gida Hospital. The group began in April 2003 with 5 people, 2 men and 3 women. The member who began the support group noticed that there had been a high incidence of HIV/AIDS in the population of Qoboqobo. From an interview with her, she states, "I was willing to be the one who would start the support group. We are here because we love our nation, and also because of HIV/AIDS. I worked closely with the social worker at S.S. Gida Hospital to prepare our registration forms for our support group. At the beginning, we struggled to find food and a place to meet. Yet, we knew we must talk in order for our stress to go down."⁶

For one month, the group met in the clinic where they bought and ate bread together, and then the same lady went to the board of S.S. Gida Hospital to seek help for the group members. At the clinic, the electricity goes out and phoning is often a problem. Furthermore, the institution is based in a house. This is not an appropriate facility to run a clinic. The clinic must not be a house. Moreover, since the hospital still manages and works together with St. Matthew's Clinic, the hospital board decided to grant the group permission to use the flat outside the Clinic. The support group at St. Matthew's Clinic now meets biweekly on Mondays and Wednesdays at 10

am in their own 2-room flat. The 21 adult members are mostly older women above the age of 25 years. The group also includes 6 children. Not all members attend every meeting. Two of the members receive a disability grant and another 2 receive child grants. In an interview with the nurse who guides the support group, Nurse Manzana states the following on the purpose of the support group,

‘The group is for those that are affected and living with HIV/AIDS. HIV/AIDS is an invisible disease. Closer observation is needed for these people. They are educated on HIV/AIDS. Therefore, advice is given on safer sex, diet, and care. Usually tips and awareness are exchanged for problem solving. For support groups, there should be continuous counselling, but all members are not yet trained in HIV/AIDS. There is no official support group for children. Thus, the group aims to include the entire community. There are not many males here, but we feel better in coming. Group sharing is special to us because we share many views.’⁷

Therefore, one can see why focus group discussions were employed in the research design. It was very convenient to have focus group discussions with the members of this HIV/AIDS support group.

B. Psychological impact of HIV/AIDS

In the first focus group discussion, 5 women between the ages of 25 and 70 years old met with an HIV/AIDS Community Outreach nurse from S.S. Gida Hospital and I, to discuss their major mental health concerns as well as any of the coping strategies they use. These women as well as the social worker and all of the nurses interviewed at S.S. Gida Hospital and St. Matthew’s Clinic noted in their interviews that HIV/AIDS definitely has a negative psychological impact on the person living with HIV/AIDS, family members and society as a whole.

1. Shock

Shock and stress-related illnesses were the most cited impacts that HIV/AIDS has on mental well-being. A HIV/AIDS community outreach nurse clarifies, “In fact, the mere fact that you have been diagnosed with HIV/AIDS is really a stress on its own. There are stages that a person would have to undergo like that of shock, stresses, and anger towards how she has

contacted this HIV/AIDS virus.”¹ Moreover, an HIV/Counsellor said, “The person, who is HIV+, especially if they are hearing it for the first time, has a shock. They are shocked the first time, and some have those bouts of crying too loud like hysteria. Furthermore, you must differentiate between the two - HIV is the virus and AIDS is the disease. Some people they don’t know the difference. If you are talking about HIV+, some people usually associate it with, ‘I’m ill. I have AIDS.’ ”² When a person becomes aware of their HIV+ status, they think, “I am going to die now.” Instead the person must think positively and not think that they are going to die. As one of the group members states, “Do not think about your status constantly because at the end of the day you are not a person dying of AIDS. You are a person living with AIDS.”³ Many people think that they are going to die once they hear of their positive status. A distinction should be drawn between full blown diagnosable mental illness, including neuropsychiatric illness, and psychological disturbance resulting from HIV/AIDS. Both are important and both need a health service response.⁴ People’s quality of life can be substantially improved, but first, more education needs to reach those people who are unaware of the treatment options and the progression of the disease.

2. Denial

Part of the process of accepting the positive status is going through denial. An HIV/AIDS Counsellor interviewed at S.S. Gida Hospital notes, “Some come here and they want to know, if they’ve tested in Cape Town or somewhere else they want to know if here they are going to be HIV again. Usually they deny it. Some people come again to say that the one that she first took was false. It was false that first one and they are unwilling to accept the truth.”² This denial is very common and yet very dangerous for the health of the PLWA. The person can continue to engage in risky sexual behaviors such as not using protection with partners. Furthermore, during this period many fail to take care of their immune system by abusing substances like alcohol and refusing to take precautionary measures that can prevent mother-to-child transmission.

3. Stigma

The lack of knowledge about HIV/AIDS in the rural area of Qoboqobo has an effect on the way that HIV/AIDS is stigmatized. “I should think that HIV/AIDS really does have an effect on mental health because of its stigma. Our people really they haven’t yet accepted it in the proper manner. Stigma takes the form of rejection [of the PLWA] by the partner, by the relatives, and by the society. We still have a challenge to let people know that HIV/AIDS is just like any of the other terminal diseases so they need to accept the peoples in order to have a longer life.”¹

4. Depression and other Stress-Related Illnesses

Also mentioned by the group members and professionals was depression and sadness resulting from the stigma of HIV/AIDS and from the loss of a loved one. Nurse Kota says, “If she doesn’t have a strong support system, it reverses back to those depressions, stresses and stress-related illnesses because she doesn’t go and pick up that well-being of accepting the disease that she has got.”¹ For instance, the nurse working closely with the St. Matthew’s Support Group comments that HIV makes someone feel guilty and it is very difficult for the person to accept the positive status. He’s stigmatized within the community. He then feels insecurity if he is neglected by those who are around him. He becomes emotionally unstable and any of the following can occur. He can become moody, angry, sad and depressed, and isolated.⁵ One of the main reasons that the support group meets is to deal with their own depression caused by the loss of a loved one or fear of dying. For instance, a member states, “My brother died with AIDS, and two other people from the community had also past away. That hurt me so much and so I came to talk about this pain with the people here. It was important for me to come and get help at this support group.”³

5. Unmentioned Dementia

Despite the presence of dementia and the loss of motor functioning in the late stages of AIDS, no one mentioned this as a mental health problem among the group or among the professionals when asked about how mental health is impacted by HIV/AIDS. In fact, the closest response to neuropsychiatric responses was a male member stating, “I would like to know about

mental health. It's said that during the steps of being HIV positive, you get to the stage where the virus affects your mind. I would like to know why and what is being done to solve the problem. I would like to know about that."⁶ Many of the responses dealt with the shock and the stigma of HIV/AIDS that PLWA face in society. This pattern probably stems from the fact that not much information is available to rural communities about how HIV/AIDS causes neuropsychiatric diseases. There's also a difficulty in distinguishing between symptoms that have a psychosocial etiology from neuropsychiatric problems. As the treatments are likely to differ, making an accurate assessment is important.⁴

C. Stressors and Problems

1. Support Group Registration

Registration of the Support Group has not yet occurred. The group has been declined for financial support from the government once after filing to be recognized as an official HIV/AIDS support group. According to the HIV/AIDS Community Outreach Nurse, people recently diagnosed with HIV/AIDS are encouraged to seek outside sources of support. Yet, she recognizes that this step also needs a backup support, one in which the results can be seen. She explains, "Clinically, maybe the HIV+ patient is still in Stage 1 and she can't get the disability grant on her own. So, on that goal you really motivate them to do a business plan, to register themselves as well with a support group that is known locally so that we can access the funds to financially support them. Like for instance because of the piece of land behind the clinic we thought of cultivating it so that they come and we can start a soup kitchen and have meals. That would make the support group attractive so that they come and have at least one meal for that day. But because of ifinances [finances] and budgetary problems we found out that there is a delay."¹ Despite the period of waiting, the group believes that once registration has come underway, there will be money to fund our project.

2. Lack of HIV/AIDS Education

The unifying theme in all of my research is that education on HIV/AIDS is necessary for all affected and infected with HIV/AIDS. Knowledge can have extremely positive effects on people's mental well-being and their sense of security. For instance, a woman from the support group stated enthusiastically, "If I had solutions to my problems, I feel stronger. Power lies in understanding and knowledge of HIV/AIDS."² Similarly, another member talks about how he worries about getting more information of HIV/AIDS. He said with much strength, "I can be less stressed if I've got all the information I need with everything that comes in my way. If I am taking the stages and I know that I have got this, I have to do this and this and this. Even if I've got the information then I would relax because there's nothing more to worry about."³ Nurse Manzana added the following comment, "Persons living with and affected by AIDS need to be empowered and trained with the knowledge of HIV/AIDS. There is no one here who does that for the people. The group started in September 2003 and we have not received any financial support. I am worried! Professional help should always be available during their meeting times at least. I think if we can train at least one of the members so that she can further educate her peers it would be good."⁴

A spirited member of the group stated, "We also want training and access to more information. There needs to be more awareness, more education and more people getting checked for their HIV status. Nurses must be trained and we need to be trained. We are advised to avoid drugs like alcohol. We have asked Nurse Manzana to send us to get training, but nothing as of yet has happened. She says we must wait and so we wait, but we must come together to do something in the meantime. Let us not sit and do nothing. We must do something. We believe that the training and the treatment should come to us because we have no money."² The members are mainly being educated by the awarenesses given by the sisters, the nurses at the clinic, communities, radio slots, and Soul City on TV. There's no specific person who can teach the members. Yet, government keeps telling them to wait for training and the support group grant.

The community outreach nurse at S.S. Gida stated, “Problems are that there is a shortage of medicine and a lack of economic resources to provide training to people in the vicinity of St. Matthew’s Clinic.”¹ It would require R6000 to deliver trainings to 21 people to cover the expenses of food and educational materials. However, it was mentioned to the community outreach nurse that the group thinks they have the right to training and they have the right to receive training on their side of town because they cannot afford to travel to the hospital site. The group also recommended a different plan for training. They said that because the trainings are taking too long that they prefer to get the information by phone and they would write it down. They are willing to do this as long as there’s information being passed. Continued counseling is so important; yet, this option is not a possibility for those individuals that need it at the moment.

3. Nutrition and Sustenance Projects

There’s a lot of malnutrition in this area. There has been an overdraft of the budget and shortage of staff. Therefore, the condition of the PLWA deteriorates. In the support group, the members usually want bread and a drink and “the majority come to clean and wash their clothes. There is no food and the group usually comes together to buy a bit of food. We take from the mealie fields and potatoes which are grown by us.”²

No medication is available either. Yet, the support group members still are strongly aware of their availability in other parts of the country. A member stated emphatically, “There are treatments that are available! We have seen those adverts on the radio and we hear them talk about it on television shows like Soul City. We really want medicines like Neverapine because we know we would become healthier. The treatment and support would make us less worried.”⁵

In addition, there is no source of income for most of these members. With a hushed tone, a member added, “We work on these crafts in order to make money, but there are no beads and

there's nothing to eat.”² At the clinic, they are given porridge and some potatoes if there's some available. Nurse Manzana continued to note on the importance of support groups:

“In the support group, we are suffering; but we share each other's problems. A member doesn't have to disclose their status, but I believe that their lives are extended through their participation. Advice is offered among these people.”⁴

The HIV/AIDS Outreach Nurse, stated further, “Meanwhile the support group at S.S. Gida Hospital started doing beadwork and selling that beadwork because at least for those who have amakhaya angenanto [Xhosa for nothing at home], meanwhile, we take from that money and we see support come in.”¹ Yet for the St. Matthew's Clinic, food shortage is very difficult to deal with. The group commented, “We have gardens but we have no money to buy seeds for planting or gardening. There are no beads for bead making. So we depend on food donations from the Keiskammahoek Youth Care Center and cloth donations from the St. Matthew's Church. The sisters help us by finding us sponsorships. Government action takes too long to get money and support.”²

D. Dealing with the Pain: Healthy Living Strategies

1. Disclosure

Disclosure was claimed by all involved members and professionals as the first step to get any help. In a case where an individual discloses, they allow for their feelings to be expressed instead of allowing for the harmful effects of suppression to lead to the ideation of suicide or revenge. The support group aids in the transition between rejection and denial of the positive status towards acceptance of a life with HIV. In the S.S. Gida support group, Sister Kota added, “We sit together and then we let these people explore themselves, make their self-awarenesses in writing because at times the people don't ventilate as much during the counseling but when we are gathering together they can even ventilate it down. Kota then displayed the wonderful quilts. So in here we did make something like quilts whereby one draws what she feels about this diagnosis. That woman who has been diagnosed said that this type of disease looks like a monster. It is a bad animal that crawls towards our children - it was a mother, this one – within

our communities taking them, and at the end resulting to graves. Some said, 'I see the sun rise. I see the world beautiful with all the type of fruits but now there come the enemy of HIV and this one related it to a bat destructing the nectar of those fruit trees and then it come to be that the life begins to come down. The fruit is falling down which means the tragedy has come.' Others said, 'I feel there is darkness when I see this HIV/AIDS because I was having children but now I am alone. Also I am left by myself with no children having loneliness, having nothing to remember.' So really to them by being in the support group they do get the strength of surviving.¹ Zea et al. (2005) suggest that disclosure is related to greater quality of social support, greater self-esteem, and lower levels of depression. Moreover, findings indicated that social support mediated the relationship between disclosure of Zero-status and both self-esteem and depression. Thus, disclosure resulted in greater social support, which in turn had positive effects on psychological well-being. The support group setting is very beneficial to do this because the members are there to offer psychological advice as well as confidentiality to those who feel unwelcome in other areas of society, such as at their home, school, church or in the workplace.

2. Health Days

One of the main initiatives being done is the HIV/AIDS Awareness Days in which the support group arranges community gatherings to educate the public. Awareness about HIV/AIDS needs to be spread within the communities. This entails health talks at every place where people gather, such as at schools, churches, youth meetings, and sport events. The group recognized me as one of their own when they invited me to speak on Freedom Right's Day at Ngobazana on Wednesday, April 27th, 2005. I finally felt a sense of belonging as I sang and danced to songs and statements of HIV disclosure in Xhosa. A male member of the support group added that it is important for the members to educate the community in order to diminish the myths of HIV/AIDS. He states in an interview, "With the group we do teach, with that much that we know. Then we try to teach what is going on, you see. We do have a nurse here that she collects a lot of information so that we understand the whole situation. Someone will be interested and ask what we are doing, and that's when I will explain the story of what I am doing and why. We

try to give the information to the people and we even go to the nearby schools and teach them about the HIV/AIDS and the surrounding areas.”² The group definitely serves as a community resource and the community seeks the members to gain information on HIV/AIDS. For example, at the awareness campaign, there was a man who was not ashamed to ask for many condoms. Although the women and the children snickered, the man made a unique step in making it acceptable to protect yourself in the act of sexual intercourse. His comment truly made me realize that if more men were to do that, it could act as a great example of protection for the younger adolescents. Furthermore, women could encourage males to use protection.

3. Support Network: Exchanging Stories & Tips

PLWA feel a sense of belonging within a support group. Many feel like they are a member of that family. Nurse Manzana said that members speak out on the value of the support group. She says, “Members state, ‘I am not alone. I am still the person I have been before.’ As a group member, you hope that you can become a citizen once again. Something new will happen and then the person in the group will begin to voice problems.”³ When asked who they talked to the most about their mental health problems, the group responded with, “Family members and children, mostly because they are the most supportive. The support group and counsellors are also there for us.”⁴ In the group, there is a sense of shared responsibility, found both in confidentiality and in being there for each other and take care of one another. When a person shares their problems, this disclosure is healthy because the problem is no longer only in the troubled person. Nurse Manzana declares, “PLWA also work towards finding a solution for that situation. I am there just to guide them. If there is a problem they feel that can’t be dealt with, then the group will ask for help from one of the nurses here. They will come to me and say, ‘Sister, someone is not well. Please help!’ ”³ The problem is not one’s own responsibility. There is more responsibility among the members to handle the problem.

4. Planning for the Future: We want a hospice!

The hospice should be run by the own members of the support group in which the HIV+ clients are nursed by their own. The retired nurses used to do this type of home-based care.

These feelings of power and hope create actions to sustain a sense of mental well-being. Networking is also very important. We have to make connections for our group to work. For example, we really want to start a hospice by using the resources that are available here, such as the houses and places that have been left behind. Here it is not compulsory to build churches and hospice. The trained nurses and doctors can work at their own invented hospice because houses can be cleaned up. Nurse Kota then emphasized that the group must communicate that vision to the nurses and plan. The group wishes to consult all the stakeholders on the HIV/AIDS like MEC and Counsellors in order to network. Acceptance, to have hope in all what you are doing, is key in order to become powerful. “My own actions which I take upon the community, nurses and other resources makes me feel secure.” The capacity-building taking place at the moment is at a stall because there are no beads for beadwork and at the moment we just talk about our problems and do awarenesses. The group must learn about home care and proper services for the hospice seeing that they are very interested in starting this home care institution in their community.

5. Poverty/Income and Its Effect on Mental Health of PLWAs

The Social Worker noted that the people that are suffering from HIV/AIDS in this area are often those who are disadvantaged to begin with.¹ If the patient is very ill, they may qualify for a disability grant. However, by the time it arrives many have died. A lot of people come here from Capetown, Johannesburg and Port Elizabeth to die. People go to work after being in the support group because they gain confidence and strength. However, because they may not find appropriate health care and support in the city, these same members may return sick after working. Therefore they might not continue to keep in check with their medication and treatment. They have returned back to their original place of birth after leaving to get jobs in this region of high unemployment.²

V. RECOMMENDATIONS FOR PSYCHOSOCIAL COPING

Education needs to continue with the collaboration of hospital organizations and other community-based organizations. The group urges people to test and seek support services if they are feeling ill, depressed, or just want to be part of the group. Nurse Hewana, the Infection

Control Nurse talked about the collaborative educational activities that she will continue this year, “Last year we had a workshop with the faith healers, the traditional healers, the stakeholders and all those things. It was role clarification and the referral system because we know that our people believe that they are being bewitched so they must go to their traditional healers. And they are helped by their traditional healer. It was a nice exercise activity. As right, after that, I had some referral letters that were from the traditional healers around and faith healers. The patient came here with that and disclosed their status to me. I took over and then we worked hand in hand. I make them understand that HIV/AIDS is not a bewitchment into [thing] disease. It’s a disease that is caused by the HIV virus. Yea, so we work hand in hand.”¹ The involvement of traditional healers in the area of Qoboqobo and the support group would benefit PLWA to ensure their mental well-being. Being that their culture can be used effectively to provide the PLWA with a sense of comfort, mental coping strategies can be developed for PLWA.

“So I am planning to have another workshop for July to continue also with these ARVs. What’s going to happen with the support group, I am arranging an in-service training. I am going to train them next week - the support groups, the traditional healers and the faith healers. Even in the hospital board, I do go there because the hospital board is a mouth for the community. When they go out they hold meetings for the whole community. I do have a slot there on quality assurance, infection control, HIV/AIDS.”¹ Collaborative efforts are encouraged to be in action between the PLWA support groups and NGOs and CBOs. The HIV/AIDS counsellors at S.S. Gida and St. Matthew’s Clinic stated, “We do work hand in hand with the NGOs (Non-Governmental Organizations, the CBOs (Community Based Organizations) and the FBOs (Faith Based Organizations) within our communities. We do make awareness so that they do know the HIV/AIDS meaning the disease on its own. Then one must not judge the person, but accept and support the person as much as possible meaning to be supported by their relatives and within the communities through the activities that they are doing right now.”¹ To further the progress of mental health care available to PLWA, there is a beneficial support network that counsellors can

shape as well. Sister Kota comments on this action, “As counsellors, we try to identify problems which we encounter here in our area. Then we try together as counsellors to tackle those problems in turn so that if one had a similar problem she will know when she comes back how to tackle it. Then it means that it’s an experience for the one who has not yet met such a problem. In turn when there’s a problem that is similar to that one she can consult the first problem for reference.”²

VI. LIMITATIONS OF THE STUDY

A. Unsuccessful Contact with the Social Development Office in Bisho

Despite numerous attempts with phone calls, faxes, and visits to their office in Bisho, I failed to reach a representative of the provincial government that could elaborate on the issue of disability grants and other sources of support available to people with and affected by HIV/AIDS. Unfortunately, I was unable to access an insider’s perspective on how the Social Development Office in Bisho functions in order to deliver social grants and services to rural areas like Qoboqobo. Instead, I sought information among the social workers at S.S. Gida Hospital and Mrs. Mbete at the Keiskammahoek Child and Youth Care Center. Accessing more of this accurate type of information would be most beneficial to a support group and newly-infected persons with HIV/AIDS, especially for the process of their future planning initiatives.

B. Focus Group Discussions

In conducting the focus group discussion, a translator was used to facilitate the discussion, I believe that sometimes the way I worded the questions required more explanation as to describe some of the terms used. For example, there are no words for certain mental health problems in isiXhosa, so I had to modify my questions in the process of translating. Although the translator did an excellent job of conducting the group discussion, I took only brief notes during the session

and she summarized many of the responses on paper to assist me. Thus, there is the possibility that anecdotal details might have been left out from the translator's summary of the group discussion. It was only after the session that I was able to translate, transcribe and restructure my focus group answer and modify the guiding questions for the nurses and the social workers. Furthermore, the results from my focus group discussion cannot be used to make statements about the wider community. They indicate a range of views and opinions, but not their distribution. In addition, the moderator who is not well trained can easily force the participants into answering the questions in a certain way. Focus groups can paint a picture of what is socially acceptable in a community rather than what is really occurring or believed, although this problem can be limited by careful participant selection and good moderating skills.¹ I found that focus groups do have limited value in exploring complex beliefs of individuals, and as a result, in-depth interviews were more appropriate in soliciting this personal information.

C. Interviews conducted in the presence of others

Like in the focus group discussion, where socially acceptable answers were at times given, one of my key informant interviews should be analyzed carefully due to the member's wish to have a friend present in the interviewing room. Furthermore, the support group nurse walked in the midst of the conversation. However, I believe that this interview was as sincere and honest as possible. The fact that the person wanted to know more about mental health and its relationship to HIV/AIDS shows that the member was both engaged and active in the participant interview.

D. Interviews conducted in English

Most of the interviews were conducted in English though many attempts were made to speak in isiXhosa for the sake of having information flow freely between the researcher and the participants of the case study. One of the nurses in Maternity/PMTCT remarked honestly after speaking to her in isiXhosa, "It is right for you to try to speak Xhosa. When counseling or doing research, it should be as if there are only two – the researcher and the participant. There should

be no language barrier.”² For this reason, much more culturally-appropriate research should be done in the diverse field of HIV/AIDS. Examples such as those shown in the rural community of Qoboqobo. Ideally, more research should be conducted in the rural areas by native speakers of Xhosa and Afrikaans. If native speakers are not available, then researchers should be invited to learn and use Xhosa and Afrikaans.

E. Stigma and Mental Health and Illness

Mental health represents one of the last frontiers in the improvement of the human condition. In the face of wide-spread stigma and inattention, mental health must now be placed on the international agenda.³ Since the stigmatization of mental illness is still a pertinent issue, my fear is that many of the group members’ mental health concerns were not voiced. Again, through personal conversations guided by the emergent design and semi-structured interviews, much valid data was gathered.

VII. CONCLUSION

In conclusion, the services that are already in place in the community can benefit the PLWA and ensure the psychological well-being of PLWA. Here where as there is no funds for professional counsellors, the community comes together to be part of this support group. Still, there are many problems facing the support group. Nurse Manzana said many have ideas to do great things, but there is no follow-up. The women from the support group get help from people in above positions in other organizations. Furthermore, the group would feel less stressed if there was acceptance by the family, greater self-acceptance, an active support group, ART Treatment, and a Living Diet if there is no support at home. These problems were presented to the community outreach nurse at S.S. Gida who in charge of communicating with the HIV/AIDS support groups in the area. Training was going to be pushed for the following week, but in the meantime, the group is left to network with NGOs like the Keiskammahoek Youth Care Center This NGO delivers food as part of a program-based grant which is primarily supported by the government and S.S. Gida hospital. Most importantly, I believe that the family of the PLWA, partners, friends and relatives should be extremely involved in the care of PLWA. This

recommendation was strongly voiced by the group members at St. Matthew's Clinic, stating, "Some of our family members are very accommodating to our needs and wants. My family asks me if I need anything such as vegetables, money, and support. They bring me to the doctors and if they can't help find a solution to my problem at home they often seek the doctor to help. My brothers took me out to dinner and a movie to make me happy and make me feel better. To those who know me, they come out and share what makes me feel like that, advise me to consult nurses and doctor. My family members once note anything that deviates my mentality – supports and share nice things with me, and allow me to ventilate my problems." ¹ Family members are the ones that know PLWA the best and certainly impact their psychosocial well-being. In addition, I strongly encourage that the involvement of the youth in the Health Awareness Days be closely explored as these individuals play a great role in shaping the social values and sexual behaviors. The involvement of Future research needs to target the family, friends, and partners of PLWA as valuable sources of support.

VIII. Endnotes

Methodology

1. The World Health Organization's "Focus Group Manual." August 21, 2003.

Data

A. Background of the Case Study

1. Letter from Dr. Mthobeli Guma, March 2005. It is proper to note that Qoboqobo is one of the educational corridors that includes: Victoria Hospital, University of Fort Hare, Lovedale, Fortcocks, and St. Matthew's College and the Federal Seminary that use to provide inter-denominational theological training for South Africans, expropriated by the apartheid Government for its intellectual challenge against the regime.
2. See HYPERLINK "<http://www.sahistory.org.za/pages/chronology/thisdday/1968-11-14.htm>" <http://www.sahistory.org.za/pages/chronology/thisdday/1968-11-14.htm>.
3. See HYPERLINK "<http://www.freeglossary.com/Bantustan>" <http://www.freeglossary.com/Bantustan>. Originally there were about 10 Bantustan homelands,

which were established under the 1951 Bantu Authorities Act and began to be given “independence” in 1976. These homelands resulting from the Apartheid doctrine were unpopular because the boundaries of the Bantustans were drawn to exclude economically valuable land. Becoming citizens of the new territories meant losing citizenship of South Africa where the majority of candidates for reassignment of citizenship lived and worked. This would cause them to lose what few rights and privileges they had as citizens of South Africa.

4. These data are from an interview with Phelisa Madlokazi, April 21st, 2005. During my stay at my house in Ngxalawe, there were a couple of days of heavy rain which caused the electricity to blow out. I was given a candle and matches for emergency lighting. Furthermore, the houses are not heavily insulated so they are rather cool inside, even on hot days.
5. Discussion with Mr. Mphulamphulam, April 21st, 2005.
6. Key Informant Interview with St. Matthew’s Support Group member. April 20th, 2005.
7. Interview with Nurse Manzana. March 10th, 2005.

B. Psychological Impacts of HIV/AIDS

1. Interview with Sister Kota, April 17th, 2005.
2. Interview with Sister Nowethu Madikane, April 21st, 2005.
3. Focus Group Discussion. April 18th, 2005.
4. Freeman, 2003.
5. Interview with Nurse Manzana, April 20th, 2005.
6. Key Informant Interview. April 17th, 2005.

C. Stressors and Mental Health Problems

1. Interview with Sister Kota, April 17th, 2005.
2. Focus Group Discussion. April 18th, 2005.
3. Key Informant Interview. April 17th, 2005.
4. Interview with Nurse Manzana, April 20th, 2005.

5. Focus Group Follow-up. April 20th, 2005.

D. Nutrition and Sustenance Projects

1. Interview with Sister Kota, April 17th, 2005.
2. Interview with Nurse Manzana, April 20th, 2005.
3. Focus Group Discussion. April 18th, 2005.

E. Dealing with the Pain: Healthy Living Strategies

1. Interview with Sister Kota, April 17th, 2005.
2. Key Informant Interview. April 17th, 2005.
3. Interview with Nurse Manzana, April 20th, 2005.
4. Focus Group Discussion. April 18th, 2005.

Limitations of the Study

1. The World Health Organization's "Focus Group Manual." August 21, 2003.
2. Interview with Sister Nowethu Madikane. April 21st, 2005.
3. Desjarlais et al., 1995.

Recommendations for Psychosocial Coping

1. Interview with Nurse Hewana. April 21st, 2005.
2. Interview with Nurse Kota. April 17th, 2005.

Conclusions

1. Focus Group Discussion. April 18th, 2005.

IX. Bibliography

A. Primary Sources

1. Interview with Nurse Manzana, HIV/AIDS Support Group Nurse at St. Matthew's Clinic. March 10th, 2005.

2. Interview with Sister Kota, HIV/AIDS Community Outreach Nurse at S.S. Gida Hospital. April 17th, 2005.
3. Key Informant Interview with member of St. Matthew's Support Group. April 17th, 2005.
4. Focus Group Discussion with St. Matthew's Clinic HIV/AIDS Support Group. April 18th, 2005.
5. Support Group follow-up meeting at St. Matthew's Clinic. April 20th, 2005.
6. Key Informant Interview with member of St. Matthew's Support Group. April 20th, 2005.
7. Interview with Nurse Manzana, HIV/AIDS Support Group Nurse at St. Matthew's Clinic. April 20th, 2005.
8. Interview with Nurse Hewana, Infection Control/Quality Assurance Nurse at S.S. Gida Hospital. April 21st, 2005.
9. Interview with Phelisa Madlokazi at the Constituencies Office in Qoboqobo. April 21st, 2005.
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X. APPENDICES

Appendix 1. Clinical Chart for Patients at St. Matthew’s Clinic (Attached)

Appendix 2. Map of Keiskammahoek (Attached)

APPENDIX 3

Interview Questions

A. Questions for the first Focus Group Discussion

1. Why did you first join the support group?
2. What are some of the main reasons you come to the support group?
3. Do you talk about feelings of apathy, depression, anxiety, and stress?
4. Has anyone come to talk about these problems?
5. Have you learned anything about how to deal with these problems?
6. If so, do you use any of these techniques for your mental well-being?
7. What do you worry about the most?
8. What do you do to cope with these problems? Be honest.
9. How do your loved ones cope with your mental health problems?
10. What do you think would make you feel less stressed as an HIV/AIDS client?
11. What more can be done?
12. In what ways are you being educated about mental health and HIV/AIDS?
13. Who do you talk to the most about your mental well-being?
14. Is there anything else you would like to add on this topic?
15. What is being done about the food shortage?
16. Do you think that this food shortage has an effect on your mental well-being?

B. Questions for the Key Informant Interviews

1. How did you join the St. Matthew’s Clinic support group?

2. How did you first feel while being at the support group?
3. How would you deal with any mental health problems like stress, anxiety, depression and anger before?
4. How do you use the support group to feel mentally healthy?
5. Can you tell me how HIV/AIDS has changed your mental health?
6. What is the most important lesson you have learned from being in the support group?
7. What are the major conflicts that you face from being in the support group?
8. Do you feel you can do anything about it?
9. If so, what are you doing?
10. What are fearful of as a result of living in this rural community with HIV/AIDS?
11. Can you tell me who is closest to you when you are trying to cope with a problem?
12. Would you like to add anything else?

C. Questions for HIV/AIDS Counsellors and Nurses

1. What effects does HIV/AIDS have on PLWAs mental well-being?
2. How do support groups help PLWAs mental well-being?
3. What things are being done to address the mental health problems of PLWAs?
4. Are people being educated on mental health problems and mental well-being?
5. How can the support group setting be improved?

D. Questions for the Social Workers

1. What is the process of getting a support group grant for people with HIV/AIDS?
2. How do you as a social worker help the HIV/AIDS support group members?
3. As a social worker, what do you think affects the mental well-being of an HIV+ client?
4. How do grants help PLWAs?

E. Questions for the Bisho Social Development/Government Representative

1. What is the process for PLWAs to receive monetary aid, like disability grants?

2. What is the process like for an HIV/AIDS support group to be registered?
3. How do food security programs work?
4. What steps are being taken by the Bisho government to ensure the mental well-being of PLWAs?
5. Is there a big push for people to be educated on support group formation and maintenance?
6. Is there any communication between members of a support group and the Bisho government?
7. Otherwise, do you know what is happening on the ground?

APPENDIX 4

Questions for Focus Group Discussion

St. Matthew's Clinic Support Group for People Living With and Affected by HIV/AIDS

In the first focus group discussion, 5 women between the ages of 28 and 64 (40,43,46, and 64) met with an HIV/AIDS outreach nurse from S.S. Gida Hospital and I to discuss their major mental health concerns, as well as any of the coping strategies for their current situation. A focus group discussion was guided by Nurse Kota and me. Then the discussion was translated from isiXhosa and transcribed in order to complete a thorough content analysis of the data collected. The following are the questions and answers both in isiXhosa and English.

Question 1a: Yintoni ekuzisa kwisupport group?

Answer: Obhuti bam baweleka ngenxa ye AIDS nabanye abantu apha ekuhlaleni bayaphela. Into eyandizise apha yintlungu yokubona ukufa kwabantu. Ngoko ndifuna ukomeleza nabanye abantu ndibanike uncedo, nemfundiso malunga neHIV/AIDS. Mna ndandizo funda, ndifuna ukomelela kuba kaloku mna ndiHIV/AIDS positive.

Question 1b: Why do you come to the support group?

Answer: Many of the members came to deal with the pain of lost loved ones, family members and for themselves too. They come to ventilate about their problems and gain more information of HIV/AIDS. One of the responses was, “I came to the doctor and found out I was HIV+. I wanted to learn about HIV/AIDS because of my positive status. After seeing that I needed help I first initiated the support group.” Another member stated that, “My brother died with AIDS, and two other people from the community had also past away. That hurt me so much and so I came to talk about this pain with the people here. It was important for me to come and get help at this support group.” Educational support is often a desire that the members wish to attain with their membership. Another member joined because she had heard about the support group at the clinic. The unfortunate loss of her cousin, who had not yet checked her status, forced her to seek answers as to why she had past away. Yet the group has come to realize that they instead have had to educate the community in order to decrease stigma about HIV/AIDS. Thus, the group has created educational outreaches within the community for the awareness of HIV/AIDS. Visits are made to schools and churches.

Question 2a. Yintoni enenza nihlale apha?

Answer: Into eyenza ukuba sihlale apha sifumana ingcebiso, siyomelezwa, kwaye sifundiswa nomsebenzi wezandla nokuzityalela ziqhamo nemifuno, kumnandi apha sonwabile kuba sonwabile kwaye into yalapha iphelela apha ayiphumeli ugaphandle

Question 2b: What makes you come here?

Answer: What makes us come and stay here is that we are advised. We support ourselves, do handwork, and try to plant veggies and fruit. It is nice here and we are happy because what we do here does not go outside. Confidentiality is extremely important to the group.

We get updates on knowledge of HIV/AIDS and related issues. Information needs to be accessed. Right now, the information that they get is very informal and not sufficient.

We get support by sharing our past experiences. With the information that we share, solutions to our problems are found.

We learn other skills like beadwork, such as the emblem of the HIV/AIDS ribbon. We teach each other handwork skills. If someone is good at beadwork or using cloth for craft making, that person will teach others making our group strong and productive.

We plant vegetables and fruits in our gardens and we prepare soil for cultivating the gardens together.

When the members are in the support group, there is a strong sense of unity of old and young members. There is acceptance of each other and there is more confidentiality of the shared interests and experiences (information revealed). Confidential discussion and the rule for disclosure to stay within the group are extremely essential to the feeling of security. A member states that equal rights are important for all. There should be a push for awareness within the community. The awareness started last year. After discussing her problems to the group members she feels much better and at ease. I observed that the whole time before this question this younger member was giving her back to the group while they sat on the only bench in the room. However, when she expressed these feelings of emotional release she changes her sitting position so that she is facing the group and me. She is attached to the group the whole time but extremely passionate about this point. She stresses that the members of the community must first get tested and support others who are HIV-positive. They must realize that it is not the end of the world and must be positive about their status.

Question 3a. Ingaba uyathetha ngemvakalelo zokungaziva ufuna ukwenza nto okanye unestress okanye idepression?

Answer: Yeyona nto esihlala sithetha ngayo ke leyo kuba sikhe sithethe ngengxaki qemizi yethu side siphume nezisombululo ngamanye amaxesha.

Xa unengxaki ikwenza uzive umzimba wakho uphantsi kwaye wenze ukuba ungafuni nokuthetha kwaye ezizinto zyayichaphazela indlela otya ngayo yiyo lonto sisithi kufuneka uphume uye kwindawo ezifana nesupport groups ufumane uncedo.

Question 3b. Do you talk about feelings of stress or depression?

Answer: The support group has a guiding nurse, but among themselves they encourage each other to share the problems that they encounter at home or whenever. There is problem solving and they come to a solution. The members find easiness afterwards. Their participation in the support group continues because they find that talking about their problems with people that are in similar situations helps them to find solutions to problems that arise.

Sister Kota depicted the psychological effects of knowing that you are HIV-positive status with the following illustration. If you have a problem, your body comes down. If you don't want to talk about your problem, your body and mind is weakened. You may not want to eat and may not sleep right. The support group helps you to voice that concern and your mind is left at ease. There is initial shock and feelings of anxiety, depression and stress overcome the person. The person must come to accept their status in order to get better. It is only then that their health will improve.

Question 4a. Ingaba ukhona umntu okhe eze azakunifundisa?

Answer: Ewe. bakhona abantu abafana nonesi apha naxa sisiya kwiawareness days siye sifumane imfundiso.

Question 4b. Does someone come to teach you about these feelings?

Answer: Ewe. Yes. There are some people like nurses. Sisters do come to direct the group and give guidance, and update information. On awareness days they get information. Nurse Boto teaches them. Awareness Days are for children at the schools and for the clinic clients.

Question 5a. Ingaba ukhona into oyifundileyo ekusombululeni ezingxaki?

Answer: Iba khona ukuba ibingekho ngesingenalo ixesha lo kuhlala apha, ininzi into esiyifundayo apho.

Question 5b. Have you learned anything about how to deal with these problems?

Answer: Yes, if not, it would depress us and not allow us to come and join the support group. We didn't come here to not cope with our mental health problems. We do get support. We need more education and awareness must increase within the community.

Question 6a. Ukuba kunjalo ingaba ukuwasebensiza lamaqhinga ukuphilisa ingqondo? Yomntu ofuna uncedo.

Answer: Ukuhlala ndawonye sincokolengexaki ezithi sizifumane kwaye yenza kubelula ukucebisa nabanye abantu. Ingakumbi abantwana besikolo bona basigcina sibusy kakhulu kuba bade baye nasezinelwini zethu? Siye sibanike nezincwadana bafunde befumene ingcebiso nedlela amabaziphathe ngayo.

Question 6b. If so, do you use any of these techniques for your mental well-being?

Answer: If we sit together and talk about our problems, it makes it easier to find solutions quicker. Everyone comes with a problem and together we figure things out. * Support Group acts as a Resource to the community*. It comes easier for the people within the community to come out and ask for more information from us until such that we refer other information to the sisters in the clinic for both the young and old. We especially keep the school kids busy.

Although the kids may not come to our support group meetings, they have come to our houses. They ask about HIV/AIDS information, books, and other related materials.

Question 7a. Yintoni izinto eziye zinihluphe?

Answer: Into esihluphayo yinto yokuba thina sithi sibanceda abantu sibaxelela ngalengozi bekuyo ufumanise ukuba abantu kungona beyifihla lento kwaye bangafuni kuva nokuba sele ecetyiswa. Into engamandla kungakathali kwebentu.

Question 7b. What things do you worry about the most?

Answer: Firstly, this disease is painful. “I am scared of dying drastically or at an early age due to a mix of infections.” Ignorance. I worry about the people that don’t care about their sexual behaviors. They see pamphlets and we even go out to the people in the community. People don’t listen. We worry about the people who don’t want to use protection. We try to proclaim that having “flesh on flesh” sexual intercourse puts you at risk for HIV/AIDS. Yet, there is still so much ignorance in the community. People continue with at-risk behaviours, and even if they have HIV they hide it. When they find out, they don’t tell anyone right away. I worry a lot about those people who are unaware of their status who are sexually active and irresponsible.

Question 8a. Nenze njani ngalengxaki? Unyaniseke.

Answer: Siye sithi xa sihleli nje singomama ndiye udincokole ndiveze imiba ethile apha encokweni nduje ndibone ukuba abanye abantu bathi cwaka bangafuni kuveze ezabo izimvo, kodwa ndibe ndiqinisekile ukuba bawufumene umyalezo.

Question 8b. How do you cope with these problems? Be honest.

Answer: When we get together with the other women, we talk about these things. Our lessons in safe sex and abstinence cannot be forced. It’s up to the people to retain and use that information. We can go and lecture to the people but only they have the power to keep that information and use it to protect themselves. Opinions and more information given to the solution.

Question 9a. Ingaba abakuthandayo bamelana njani nengxaki?

Answer: Babakhona abazamayo ukuza kuwe bazokubuza ukuba yintoni mhlwawumbi le ukutyaya, enze icebo lokuba uyekwagqirha xa kucaca ukube ingxaki le ingaphaya kwamendla akhe.

Ngamanye amaxesha baye bandithathe bandise kwindawo apho ndiye ndizive ndonwabile sincokole ngengxaki.

Question 9b. How do your loved ones cope with your mental health problems?

Answer: Some of our family members are very accomodating to our needs and wants. My family asks me if I need anything such as vegetables, money, and support. They bring me to the doctors and if they can't help find a solution to my problem at home they often seek the doctor to help. My brothers took me out to dinner and a movie to make me happy and make me feel better. To those who know me, they come out and share what makes me feel like that, advise me to consult nurses and doctor. My family members once note anything that deviates my mentality – supports and share nice things with me, and allow me to ventilate my problems.

Question 10a. Yintoni enokwenza uzive okanye onokuyenza ukuthuboza ingqondo yakho ekucingeni ngalemeko okuyo nje nge HIV/AIDS victim? Or Yintoni ocina ukuba abanye abantu bangayenza okanye bangakwenzela yano ukukuxhasa?

Answer: Eyana yonanto kukungasoloko ucinga ngokuba kanene ndiHIV-positive kwaye ndizakufa ngenye imini. Akubalu lekanga ukucinga izinto ezinjalo ezinegative.

Ukuba umntu simnika amayeza, okanye ingcebiso ingaba yonke lonto yanele na ukwenza umntu azive ethomalele apha kuye emphefulweni.

Akwanelanga kuba kuyo yonke lonto eyona ibalulekileyo kukwamkeleka ekuhlaleni ngokubanzi kunye nentshapo zethu zizamkele kwaye zisixhase. Okwesibini unyango dufana nepilisi ezi kudala kuthe thwa ngazo koonomathotholo, isupport groups nazo zinalo igalelo alikhulu, kuba kaloku za siphaya asicingi kakhulu kwaye ingcebiso zabo ziyasakha.

Unyango lona luyenza masilinde kuba kaloku ukhulumente usenza uphando, kwaye kusafuneka abantu baqeqeshwe. Kufuneka kuqeqeshwese abantu bakonga emakhaya, kuqeqeshwe abongikazi kwakunye noogqirha.

Ndinicebisa ukuba nisoloko nisiza apha kwisupport groups. Le nto yoqeqesho izakuthatha ithuba. Kuba iqale phaya eRhawutini, iyekwezinye indawo ezifano noEast London, Umthatha, and thina singabokugqebela kuba kaloku sisemaphandleni.

Question 10b. What do you think would make you feel less stressed about your HIV status?

Even if there's something you want someone to do for you, even a support thing?

Answer: 1) Acceptance by Family; 2) Self-acceptance; 3) Support group; 4) ART Treatment; 5) ARVs and Living Diet if there is no support at home.

When a person becomes aware of their HIV+ status, they think, "I am going to die now." Instead the person must think positively and not think that they are going to die. Do not think about your status constantly because at the end of the day you are not a person dying of AIDS. You are a person living with AIDS. There needs to be more awareness, more education and more people getting checked for their HIV status. Nurses must be trained and we need to be trained.

We have asked Nurse Manzana to send us to get training but nothing as of yet has happened. She says we must wait and so we wait, but we must come together to do something in the meantime. Let us not sit and do nothing. We must do something. We believe that the training and the treatment should come to us because we have no money and it is far away to visit S.S. Gida Hospital.

Question 11. Is it enough for nurses to provide the medicines and educational support?

Answer: No, it's not enough! We need our family and the community as a whole to accept and support us. There are treatments that are available. We have seen those adverts on the radio and we hear them talk about it on television shows like Soul City. We really want medicines like

Neverapine because we know we would become healthier. We also want training and access to more information. The treatment and support would make us less worried.

Sister Kota added, “The training is a long process which begins in Gauteng Province, move down to East London, Umthatha, and they are the last place to get the training. The government must train caregivers, doctors, nurses and such professionals for the dispersal of ARVs. You must be patient. The group says ok, disheartedly. That treatment is life long and there is training involved in the use of ARVs. She recommends that they must come to the support group.

Question 12a. Ungaba nawo amandla okuhlengabezana nengxaki zengqondo?

Answer: Apha akanyanzelekanga ukuba kude kwakhiwe isakhiwo seHospice, singazisebenzisa izakhiwo zecawa, nezindlu ezingahlali bantu. Sisebenzise aba bantu besihe sabaqeqesha babe nngame volontiya bancede lamaxhoba eHIV/AIDS xa athe agula kakhulu ada amkelwa nazingqondo.

Question 12b. Do you feel that you have the power to do something about your mental health concerns?

Answer: To consult all the stakeholders on the HIV/AIDS like MEC and Counsellors. We want a hospice! “If I had solutions to my problems, I feel stronger. Power lies in understanding.”

Acceptance, to have hope in all what you are doing. These feelings of power and hope create actions to sustain a sense of mental well-being. Networking is also very important. We have to make connections for our group to work. For example, we really want to start a hospice by using the resources that are available here, such as the houses and places that have been left behind. Here it is not compulsory to build churches and hospice. The trained nurses and doctors can work at their own invented hospice because houses can be cleaned up. Nurse Kota then emphasized that the group must communicate that vision to the nurses and plan. We work on these crafts in order to make money, but there are no beads and there’s nothing to eat. “My own

actions which I take upon the community, nurses and other resources makes me feel secure.” The capacity-building taking place at the moment is at a stall because there are no beads for beadwork and at the moment we just talk about our problems and do awarenesses. The group must learn about home care and proper services for the hospice seeing that they are very interested in starting his home care institution in their community.

Question 13a. Ingaba apha kwezihospice nithatha abantu aba ngakana ni na? Ingaba nithatha omama abadala okanye amantombazana amancinci?

Answer: Hayi, sithatha wonke umntu. Ingakumbi kulutsha du kuba kaloku lentsholongwane ihlasela bona ikakhulu.

Question 13b. Will you be taking just older women for the hospice or younger girls too?

Answer: No, we will be taking in all people who need to be in hospice care. We want the hospice for especially the younger ones because they are the ones who suffer the most.

Question 14a. Ziziphi indlela eniye nifundiswe malunga ngezigulo zengqondo noGawulayo lo?

Group Response: Oko kuqala sifundiswa ngokuba ungacingi ngokusebe nzisa iziyobisi ezinjengo ngotywala, necuba?

Clarification for group: Nizifuma naphi kwaye nizifumana njani?

Answer: Siye sizifumane apha xa sincokola nomongikazi okanye kwimihlangano ye HIV/AIDS. Akukabikho uqaqesho olumandla nje ngokuba besesitshilo ezizinto zithatha ixesha ukuza apha ezilalini kwaye zuyafumaneka ingcebiso phaya konomathotholo neTV.

Question 14b. In what ways are you being educated about mental health and HIV/AIDS?

From awarenesses given by sisters, nurses at the clinic, communities, radio slots, and SoulCity on TV. There’s no specific person who can teach them. Government keeps telling them to wait. We are advised to avoid drugs like alcohol.

Question 15a. Ngubani oyenamntu othi uthethe naye ngendlela ovakalelwa ngayo?

Answer: Siye sithethe nabazali bethu okanye abayeni bethu. Thina ke bantu banabantwana siye sithethe nabo siphalaze imbilini yethu kubo kuba sibathembile.

Question 15b. Who do you talk to the most about your mental well-being?

Answer: Family members and children, mostly because they are the most supportive. The support group and counsellors are also there for us.

Question 16a. Ingaba ikho enye into engenye ofuna ukuye ngeza apha kwesisihloko?

Answer: Ingabakho nokuba ayidibani nesihloko, ndingathi mna mayibekho into efana noqeqesho kuthi thina bantu baHIV/AIDS positive ukwenzela sikwazi ukunceda abanye abantu apha ekuhlaleni.

Question 16b. Is there anything else you would like to add on this topic?

Answer: We need more training to gain more information about HIV/AIDS! We want training for those people who are HIV+ so that they can in turn help others.

Question 17a. Kwenziwani ngoku nqongophalo kokutya?

Answer: Anzima ke leyo kuba kaloku sinazo izitiya asinawo amandla akufumana imbewu yokulima, baye bathi ke osister aba basincede ngamanye amaxesha basifunele izisponsor kuba uRhulumente lo, uthi masime kwelela silindile ke. Ngoku umntu uzipathela into yokutya endlini yakhe.

Question 17b. What is being done about the food shortage?

Answer: Food shortage is very difficult. We have gardens but we have no money to buy seeds for planting or gardening. There are no beads for beadmaking. So we depend on food donations from the Keiskammahoek Youth Care Centre and cloth donations from the St. Matthew's

Church. The sisters help us by finding us sponsorships. Government action takes too long to get money and support.

Question 18a. Ingaba iyani chaphazela agokwasengqondweni?

Answer: Kakhulu kuba kaloku umntu usoloko ecinga ukuba uza kutya ntoni wa kuba asiphangeli kwaye esinabantu basincedayo ngokwasezimalini.

Question 18b. How much does this situation affect your mental health?

Answer: Yes, this does affect us very much because we are always thinking and worrying about what we are going to eat because there is no money for food. We worry too much about this issue. Where can we get food? We are not working and there is no financial support! We are very depressed about our situation.