

**AN ASSESSMENT OF THE BHAMBAYI COMMUNITY WITH THE VIEW TO
PLANNING AN IMPROVED HOME-BASED CARE PROGRAMME FOR
PEOPLE LIVING WITH AIDS**

BY

MATHEEVATHINEE BENJAMIN

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SUPERVISOR: Professor Linda Grainger (R.N., R.M., C.H.N., B.Soc.Sci.)

DEDICATION

THIS STUDY IS DEDICATED TO THE BHAMBAYI COMMUNITY.

**I THANK GOD FOR THE OPPORTUNITY TO SERVE AND STUDY THIS
COMMUNITY.**

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ABSTRACT

The study was a cross sectional descriptive approach using individual interviews and a focus group. The study took place in Inanda, KwaZulu Natal. The purpose of the study was to assess the Bhambayi community at the individual, family and community levels in terms of the provision of home-based care for people living with, and affected by AIDS; and to develop an action plan for an appropriate intervention.

The Mc Donnell et al. (1994) framework formed the theoretical framework for the study. The methodology advocated in the Mc Donnell et al. (1994) framework, uses an assessment matrix for a systematic evaluation of the problems and resources with current home care for people living with AIDS (PWA's). The indicators for this study were developed from the appropriate literature and these formed the conceptual framework.

As the research setting was the Bhambayi community, the population included the following groups of people in the Bhambayi community, in accordance with the Mc Donnell et al. (1994) framework: individuals living with AIDS, the principal family caregiver of the person living with AIDS (PWA's), key community leaders and a focus group of community health volunteers.

Non-probability, convenience and purposive sampling were used. In terms of purposive sampling, the sample included a selection of typical cases and extreme cases in order to maximise information richness.

A total of at least 28 participants from a population of 88 were selected to represent the different levels of the assessment matrix. This was considered manageable, given that the researcher personally conducted all the interviews and the focus group discussion.

Four separate instruments consisting of comprehensive interview schedules using semi-structured, open-ended questions were developed. A checklist for each question was developed and this served as a guide for the researcher.

As this study was on a relatively new area of research, and was important to capture the experience of the people living it, the qualitative data was collected using the self-report method. This method yielded information that would have been difficult to gather by any other means. Furthermore, this approach allowed the researcher to ascertain what the basic issues were, how individuals conceptualised and talked about the phenomenon, and what the range of opinions were, relevant to the topic.

The pilot study that was conducted in a similar neighbouring community demonstrated that items in the tool were appropriate and that the participants showed no hesitation in their response, indicating their acceptability of the sensitivity of the enquiry.

Each objective was analyzed at the three levels of the community in relation to the assessment matrix and categories were developed based on the examination of the raw data. Important themes that emerged were given a label to clearly reflect the nature of the material. All of the data was reviewed for content and coded for correspondence.

The quantitative assessment indicated a high prevalence of HIV/AIDS in the community. The manner in which the community had identified that AIDS is a serious problem indicated a very good understanding of the disease, its causes and its impact. This mirrors what appears in scientific literature. Therefore they had an accurate understanding of the picture although they could not furnish a prevalence figure. The findings showed that there was concordance between the quantitative and qualitative data and it can therefore be concluded that the community concern and interest matched the actual situation as Bhambayi had a high prevalence of HIV infection.

The community's perception of need included material, physical and psychological support for home-based care. The community appreciated the value of the current program although they felt that their high expectations were unmet in certain areas.

This community study has clearly shown that a community development approach to AIDS home-based care can work, despite this community being poorly resourced.

Based on the findings of this study, recommendations were made, which, if implemented could enable other communities to provide more effective and sustainable home care for people living with AIDS.

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CHAPTER ONE

1.1 BACKGROUND TO THE STUDY

South Africa has the largest number of people living with HIV and one of the fastest growing epidemics in the world and the number of people living with HIV at the end of 2003, was estimated at 5.3 million people, of which 2.9 million were reported to be women. (UNAIDS, 2004).

Projections made using the ASSA600 (Actuarial Society of South Africa) model estimated that a total of 6.5 million people will be infected with HIV/AIDS in 2002. (Dorrington, Bradshaw and Budlender, 2002). According to the population-based survey by the Medical Research Council of South Africa, South Africa had an overall prevalence rate of 27.3% among pregnant women in 2003, compared with 26.5% in 2002. A UNAIDS (2004) study established that Kwa Zulu Natal accounts for 37.5% of HIV prevalence among pregnant women in 2003. This is an increase, compared with 36.5% in 2002 (Department of Health, 2003). In 1998, more than half (54%) of the admissions to medical wards at King Edward VIII Hospital in Durban were HIV related (Russell and Schneider, 2000). This situation is exacerbated by the fact that South Africa is a developing nation with limited resources. Therefore health services are not able to cope with providing adequate public health care for people living with AIDS (Department of Health, 2001).

AIDS care is increasingly becoming the responsibility of families and communities (Russell et al. 2000). In many parts of this country there is evidence of some form of community based home-care (CBHC) for people living with AIDS. Amongst these are some programs that are based on successful home-based care models such as the Zimbabwean 'FACT' model and the Ugandan 'TASO' model (Russell et al. 2000). However, CBHC models are not suited to all communities in a given country (Mc Donnell et al. 1994). The FACT model has a strong spiritual base and has its foundations firmly in the church. Although many religious groups do exist in Bhambayi they appeared to have difficulty in agreeing on fundamental principles and

practices. Therefore the FACT model would be unsuitable for this community. The TASO model requires a strong political leadership in the AIDS national program and its success is based on behaviour change through well-organised education and prevention strategies from national government. This model is broad-based, including all sectors of society. (American Foundation for AIDS Research, 2000). Although a Strategic Plan 2000-2005 for AIDS Care in South Africa did exist at the time of the study, the implementation of this plan had not reached the Bhambayi community. Therefore in the absence of suitable support systems, the TASO model would have been unsuitable for this community.

It is often incorrectly assumed that communities are alike. Each community has its own unique dynamics, such as the availability of resources, which will influence its ability to be self-reliant and self-sufficient, which are key elements to a successful program (Mc Donnell; Brennan; Burnham and Tarantola, 1994). Mc Donnell et al. (1994) have developed an assessment matrix that was specifically designed to facilitate a systematic community evaluation of the problems with and resources for current home care for people with AIDS in any given community. The information obtained from this can be used to then guide the planning of a home-based care program for that community.

A baseline study was conducted in Bhambayi by the researcher as part of a community development project (Benjamin, 2000). The survey found that Bhambayi was a relatively young, traumatised community with a strong socio-political history and a developing social organisation. Health issues including care of the chronically ill, were a major concern. The study found that 28.5% of the sample could possibly be HIV infected. The assessment was determined by applying WHO (2000) guidelines for making a diagnosis of AIDS in adults when HIV testing is not available.

Some rudimentary home-based care was being provided by the community, who were concerned about the number of younger people dying of treatable communicable conditions such as TB and other debilitating conditions associated with AIDS. In one initiative, community volunteers were trained by St John's Ambulance in basic first aid and sent out into the community to provide care to the ill and dying. This program lacked support and resources and high community expectations frustrated the

volunteer's efforts. Sinosizo Home Based Care, a non-governmental organisation (NGO) engaged in a second initiative of providing home-based care for the chronically ill in Bhambayi. Knowledge of home-based care was limited to a few volunteers who were trained and supported by the NGO. Coverage of the community was therefore limited to a few households and was unable to meet the needs of the Bhambayi community. This initiative has subsequently ceased. The community development project is described in 1.5 in greater detail.

Given the high prevalence of HIV/AIDS, the inability of the health system to care for PWA's and the problems in Bhambayi, there was a need to assess the community in order to develop an action plan to deal with the problem.

1.2 AIM OF THE STUDY

The purpose of the study is to assess the Bhambayi community at the individual, family and community levels in terms of the provision of home-based care for people living with and affected by AIDS and develop an action plan for an appropriate intervention.

1.3 OBJECTIVES OF THE STUDY

1. To determine the concordance between the prevalence of HIV/AIDS in the Bhambayi community and the community's awareness of their susceptibility to HIV infection.
2. To examine the perceived needs of individuals, households and the community in Bhambayi to identify the needs to provide care to people with AIDS in the home.
3. To examine the Bhambayi community's organisational ability and capacity to care for people living with AIDS in the home.
4. To examine the ability of health and social system to provide support and services to people with AIDS in Bhambayi.

5. To determine the strengths, weaknesses and barriers in AIDS home-based care provision in Bhambayi and develop to an action plan for appropriate intervention.

1.4 ASSUMPTIONS

The study was undertaken on the premise that:

- some form of well structured HBC was necessary in the community;
- the community had demonstrated a valid perception of need during the project process; and
- the growing concerns expressed by the community for the loss of life due to AIDS related diseases and its multi-faceted impact on the community, warranted further investigation.

1.5 DESCRIPTION OF THE STUDY SETTING

1.5.1 INTRODUCTION

The ML Sultan Technikon recently merged with Technikon Natal in 2002, and the merged institution became the Durban Institute of Technology (DIT). The ML Sultan Technikon (MLST) was established as a community based higher education institution and was founded in 1942 by its principle benefactor, Hajee Malukmohammed Lappa Sultan, a philanthropist and businessman. This was necessary to meet the educational needs of the less privileged communities (Africans and Indians) at the time, who were disadvantaged by the Government's segregationist education policies. The institution's mission statement included community outreach education and training to previously historically disadvantaged communities.

Phoenix Settlement (also known as Bhambayi) was the place where the late Mahatma Gandhi, one of the foremost Indian spiritual and political leaders of the 1900's, lived

and worked, after arriving in South Africa on a law assignment in 1893 (Fischer, 1983). He stayed in South Africa for 21 years to work for Indian rights, having, shortly after his arrival, personally suffered from discrimination. His life was guided by a search of truth. He believed in nonviolence and taught others that to be truly nonviolent required courage. Hence, he developed a method of direct social action, based on the principle of courage, nonviolence and truth which he called *Satyagraha* (Richards, 1982).

The Phoenix Settlement is presently a South African Heritage site. The Phoenix Settlement Trust (PST) is the organization that administers the affairs of the settlement. By virtue of its political orientation, Phoenix Settlement became a haven for political dissidents involved in the freedom struggle in South Africa. Furthermore, population demographics were rapidly changing as movement of people from the rural areas to the urban areas became commonplace. Bhambayi, which is 27 kilometers north of Durban, in the District of Inanda in the Province of Kwa Zulu Natal, has grown around the Phoenix Settlement as an informal settlement over the last 20 years, and now has a population of approximately 13, 000 people. Bhambayi had a history of inter-racial conflict in 1985 and party political conflict until 1999, which had deterred any form of significant development of the area. The consequences of this conflict had manifested in innumerable socio-political, socio-economic, psychosocial and health problems as cited by key community informants (Benjamin, 2000).

Bhambayi, which was of historical importance to the new South African democratic process, was of interest to MLST, and was seen as an opportunity to make a significant contribution to the development of the Bhambayi community. Consequently, in 2000, a Memorandum of Understanding (MOU) between the ML Sultan Technikon (MLST) and the Phoenix Settlement Trust (PST) was signed. The objective of this MOU was to promote co-operation and joint training of students, skills and development, exchange of information and expertise and joint projects primarily but not limited to the fields of Education and Training as well as Research and development primarily but not limited to Journalism, Public Relations and Health Services.

Work by the ML Sultan Technikon on the Bhambayi site was started in October, 2000. A community profile of Bhambayi was developed by the researcher, in the absence of an existing one, following an initial meeting with the Bhambayi Reconstruction and Development Committee (BRDC) which was essential to establish a working relationship, and the MLST role in the field of Community Development. This process of consultation was maintained throughout the project process. A comprehensive Health Assessment was done by the researcher to determine the baseline health status of this community. The researcher, who is a professional nurse, was appointed to facilitate the community development project, under the auspices of the MLST Departments of Health Care Services, Co-operative Education and Research and Development. The community development project and the research project ran concurrently for some of the time. The findings of the community profile, the health assessment survey and the description of the project process are discussed in sections 1.5.2, 1.5.3 and 1.5.4.

1.5.2. BHAMBAYI COMMUNITY PROFILE

1.5.2.1 Population composition

The population composition of Bhambayi is predominantly Black, with less than one percent being Indian. This was of significance as the researcher was of Indian origin and the assumption that language and culture would be a problem was unfounded. These barriers were overcome with appropriate responses learned over time.

1.5.2.2 Population distribution

Bhambayi is divided into eight sections with between 250-300 households per section. The settlement of people was predominantly based on political and ethnic affiliation (Benjamin, 2000). The political parties included mainly the Inkhatha Freedom Party (IFP) and the African National Congress (ANC). Ethnic groupings included Zulu and Xhosa, each with their different practices and belief systems. Some sections of Bhambayi were owned by the residents, some being third generation owners.

1.5.2.3 Community organization

The Bhambayi Reconstructive and Development Committee (BRDC) was the only recognized political body in Bhambayi. It was formed in 1992 as part of the

reconciliation process to establish political peace in Bhambayi. This process was a joint initiative led by the Kwa Zulu Natal Peace Secretariat, a non-governmental organization (NGO), and the Bhambayi community. Members of the community, who participated in the peace negotiations, were automatically appointed as members of the BRDC (Benjamin, 2000). The BRDC has been instrumental in all community development decision making in Bhambayi, including conflict resolution activities, interaction with other service providers in Bhambayi, housing development and skills development projects.

1.5.2.3 Leadership styles

Leadership styles such as in conflict resolution differed according to ethnic groupings and political affiliation across the sections. In the Xhosa-speaking ANC led sections, leadership appeared to be based on well tested tradition and the residents appeared to live in greater harmony despite the actual living conditions being similar to the rest of the community. These differences in community dynamics had a significant impact on the project process and the research study, which will later become apparent.

1.5.2.4 Infrastructure and housing

Infrastructure and essential services was in its early development. The greater part of Bhambayi did not have road access to all the homes. This prevented emergency services, such as ambulance services, from reaching its residents, sometimes resulting in loss of lives. Water was supplied by the Durban Municipality and reached the households through standpipes that served 200-300 households. Water supply had not yet reached individual households. Electricity was available in some sections of Bhambayi. Most households utilized paraffin, gas, and candles for fuel.

Housing was mainly of the informal type, of poor construction with limited living space. Temperature control, ventilation and dampness were a serious cause for concern, impacting on the health and wellbeing of its occupants. The sick, elderly, infants and young children appeared to be most affected by these conditions. Sanitation was of the pit privy system, poorly constructed in most instances, with as many as ten households sharing one toilet. Inadequate space was cited as the reason for having to share toilets, as informal dwellings were built in clusters to maximize land usage. In the ANC led sections of Bhambayi, people lived in poorly constructed

informal dwellings, built in clusters whilst in the IFP led section the housing was of better construction, and were mainly small brick and tile houses that were previously occupied by farm workers before 1985, at the Gandhi Settlement (Benjamin,2000).

Government low cost housing development had commenced in 2001, with the first phase completed by 2003. The first house was constructed after a period of nine years of negotiation. The impact of this development has been two-fold: some families have sent their children elsewhere to be raised due to the shortage of space in the government houses. The spirit of community has also been affected where older residents have been resettled. Sanitation was planned to be water-borne, but was awaiting connection to the sewage system. Meanwhile chemical toilets were being shared by households. Water supply to individual households was also awaited. The people living in the new development felt that their standard of living had not improved as they had expected. (Benjamin, 2000)

1.5.3 FINDINGS OF THE HEALTH ASSESSMENT SURVEY

In the study conducted by the ML Sultan Technikon Department of Health Care Services, the profile statistics indicated that 28.5% of the sample population was possibly HIV/AIDS sufferers (Benjamin, 2000). The assessment was determined by applying WHO (2000) guidelines for making a diagnosis when HIV testing is not available.

HIV infected people identified in the survey, were found to be in a state of neglect, often without food and too ill, making it physically impossible to access the local health facilities for treatment. They were dependant on the charity of their neighbors for essential basic needs such as food (Benjamin, 2000).

The survey further indicated that 37.1% of the sample was known Tuberculosis (TB) cases, of which 59% were not on treatment. As TB is often closely associated with HIV/AIDS, family and friends of known TB cases were afraid of the disease, thus many people were reported to have died of TB due to fear of stigmatization and a lack of care.

The community's perceived needs were determined from interviews with key informants. The community concerns included:

- apparently unsatisfactory public health care service delivery;
- inadequate health information;
- lack of skills training;
- an unprecedented number of deaths from TB and HIV/AIDS; and
- the high unemployment rate and the consequent ills of living in abject poverty.

In 2001, after consultation with the community, a decision to facilitate a home based care program for PWA's was undertaken by MLST. This was based on the survey findings and the community's request for some form of intervention to address the need for home based care.

1.5.4. THE PROJECT PROCESS

1.5.4.1 Establishing mutual respect and trust

The perception of the Bhambayi community of the proposed project was initially one of skepticism. Their past experiences with other service providers and organizations had a negative impact on the morale of the community. Furthermore, promises of development had failed. The community believed that this failure was due to lack of consultation with the community on their needs. Hence a culture of resistance to development was an important factor to consider in understanding the community dynamics.

A history of political unrest and criminal activity was also cited as a cause for concern by the community. People from many ethnic groupings and political affiliations had settled in Bhambayi over time. They consequently harbored unresolved issues that surfaced when change and development was imminent.

These factors were carefully considered during interaction with the community. Early in the project, community members attempted to resolve serious long-standing

conflicts through the project process. The researcher made every effort to maintain objectivity in these situations. This approach earned the respect of the community.

1.5.4.2. Transparency

The BRDC and the researcher agreed at the outset that communication needed to be honest and open: all proposed project activities were to be discussed with the committee; to be informed of all MLST student and other visitors to the site; to present written reports on the project process; to be available for consultation on project issues unconditionally; to attend community mass meetings on request and that the researcher be advised not to venture into the settlement alone, but to be accompanied by a community member at all times. The committee introduced the researcher at the first mass meeting in November, 2000, where personal safety and the safety of property and the Institute's students and staff was guaranteed, on condition that the proper protocol as described above was followed. Observing this protocol at all times enabled the researcher to work with confidence in the area, as the community was well informed of the project process and its activities.

1.5.4.3. Project planning and existing services

The entry point to the planning phase was determined by the committee, where it was agreed that the existing community human resources and skills be utilized. Key informants were sought, who provided guidance in sourcing community caregivers who were previously engaged in home-based care in Bhambayi.

Based on this information, volunteers were recruited to initially gather data for the community baseline survey in 2001 to facilitate a needs analysis process. They were trained by the researcher, and under the guidance of the Department of Health Care Services and the Department of Research and Development (MLST), a comprehensive study was completed in 2001. The home-based care project was planned on the premise that all chronically ill people including those with AIDS would be cared for. This decision was taken, given the fact that the AIDS carried stigma and the programme would not have met its objectives.

Some rudimentary home-based care was being provided by the community. In one initiative, community volunteers were trained by St John's Ambulance in Basic First

Aid in 1998, and sent out into the community to provide care and support to the ill and dying. This programme lacked the support and resources and the high community expectations frustrated the volunteers' efforts. A non-Governmental Organization (NGO), Sinosizo home-based care, engaged in a second initiative of providing home-based care for the chronically ill in Bhambayi in 1998. Knowledge of Home-based care was limited to a few volunteers who were trained and supported by the NGO. Coverage of the community was therefore limited to a few households and was unable to meet the needs of the Bhambayi community. This initiative had subsequently ceased.

1.5.4.4 Project activities

Training of Volunteers

Based on these findings, the researcher proceeded to train a group of 22 volunteers guided by the literature (Department of Health, 2001) in basic assessment, communication and home nursing skills. The programme was started as a comprehensive home-based care program that assisted patients with all types of conditions including HIV/ AIDS. This strategy was essential to avoid the stigma associated with AIDS specific programs. The volunteers themselves identified the need for information and training in AIDS care as they were increasingly identifying very ill patients in the community. The program gradually became an AIDS program.

The group was divided into teams for adequate coverage of the area. The volunteers had already identified households requiring further visits for assessment of an ill family member, during the initial survey.

The drop-in centre

The Gandhi Clinic building on the Bhambayi site was used as a drop- in centre for any community members needing assistance from the program. The centre was used as a soup distribution centre and a counseling facility. The researcher conducted this service on a weekly basis with the assistance of the volunteers.

Home visits by the researcher

The researcher, guided by the volunteers, engaged in regular home visits of at least six homes three times a week, to assess and plan a course of intervention and care management for the patient. The researcher was always accompanied by the volunteer providing care and support to a patient on home visits. An introduction by the volunteer was essential protocol according to community practice. The initial visit was to establish trust with the patient and the family. A detailed personal and family history was taken. A history of any medical or traditional treatment was also determined. The researcher found that all patients visited were willing to discuss their health and social problems. These problems were evaluated and a course of action was discussed with the patient and the volunteer. Provision to meet the most urgent needs was then arranged with the patient. Confidential issues were discussed in private with the patient. Social issues were also addressed on a regular basis, and these patients were referred to the social welfare agency. Patients requiring medical intervention were referred to the health facility. Arrangements to have the volunteer accompany the patient were also discussed. Many patients on chronic medication required explanation of their treatment regimen. The volunteers were constantly learning about patient management and care on home visits. Home visits by the researcher subsequently became a regular, accepted activity to the community.

Accessing material resources

Basic homecare equipment such as protective equipment and surgical sundries was initially sourced from the designated Primary Health Clinic (PHC) for the Bhambayi area. The quantity received on a monthly basis was insufficient, given the number of people that required assistance. The tertiary institution (MLST) purchased equipment as a once-off gesture. This was sufficient for six months. Equipment was also donated to the project by private individuals and religious groups on an infrequent basis. These were valuable resources that helped sustain the program.

Fund raising

The researcher was constantly engaged in fund raising activities for the project. The project was presented to the academic staff at its inception to elicit support and student participation. The objective of the Bhambayi project was to establish a site for student experiential learning. The project was also presented to groups of students

from the various faculties and departments under the auspices of the Department of Co-operative Education. This was followed by a site visit conducted by the researcher. The groups were guided by their respective lecturers in their involvement with the project. Students from the Department of Public Relations immediately identified areas of need and proceeded to skillfully raise funds for the Bhambayi Project Soup Kitchen. A substantial amount of money was raised that helped to sustain the soup kitchen for several months. The researcher also engaged in presenting the project to religious organizations. The project was adopted by one church in particular that regularly raised funds for the soup kitchen. Members of the MLST staff also donated funds in their private capacity.

1.5.4.5 AIDS related activities by other role players

The National Integrated Programme (NIP), a government initiative, was a programme intended to identify and care of children in distress, that is children orphaned by AIDS, and potential orphans. The core activity was a day-care facility that was designed to provide nutrition and care to children under the age of 5 years, and to scholars. The programme addressed all AIDS related social problems. This programme was managed by the Department of Health in collaboration with the Department of Social Development. Families of children in the programme were to receive regular food parcels. Although the programme was well resourced, it was not well received by the community as the community was not consulted. Stringent qualification criteria were a further deterrent to the programme's success. Most families in need of assistance did not have the necessary documentation, that is, a death certificate and identity documents.

The AIDS project was invited to work in collaboration with the programme. The agreement was that the programme database be shared with NIP in exchange for material support. A conflict of interest arose when the NIP management failed to commit to a Memorandum of Understanding of proposed terms and conditions for the programme.

The Highway Hospice had set up a satellite day care facility at the local PHC. The program included counseling and income generating activities for AIDS patients. The facility was managed by a professional nurse and 2 caregivers. Patients visiting the

facility said that they benefited from the activities. However, as the facility was specifically for AIDS patients, not many PWA's from the Bhambayi community were willing to attend as all AIDS programme carried a strong element of stigmatization.

1.5.4.6. Creating a database of the home-based care program

In order to monitor the programme, a database was created. This included personal details, the known diagnosis, treatment being received and current problems including social support. It became apparent that the majority of patients on the program were TB sufferers, several of whom were not improving despite being on treatment and others with a previous history of TB infection. These individuals were found to have failed in drug compliance, citing a lack of nutrition as the primary reason. It became necessary to provide nutritional support for these TB cases. A weekly supply of fortified Soya Soup powder and Soya Mince was provided to each patient. These supplies were distributed from the clinic site. Each visit created an opportunity for counseling and education.

It was through this process that patients, with increasing confidence, began to disclose their HIV sero-status. This safe environment further provided the researcher an opportunity to initiate pre-test HIV counseling and refer patients to the local health centre for voluntary testing. They would return to the researcher with the results and were provided with support and care appropriate to their needs. Hence a comprehensive database was created, with only the researcher having access to this information. Confidentiality was maintained at all times. Working with these HIV positive people and meeting as many of their needs as possible, further enhanced a trusting relationship with the researcher.

The researcher, over a period of three years, had established entry into the Bhambayi community as part of the Bhambayi project, and field work included home visits, client assessment, counseling and referral. Therefore access to the community for the research study was an acceptable process. The Bhambayi community leader, Mr. S. Zulu, who is the chairperson of the Bhambayi Reconstruction and Development Committee, was consulted, the proposed study was explained, its potential value, and the procedures involved. Mr. Zulu was in agreement that this study could possibly

assist to market the area and encourage future development and consent to conduct the study was granted.

The motivation and significance of the study will be discussed in section 1.6 below.

1.6 MOTIVATION FOR AND SIGNIFICANCE OF THE STUDY

There are several reasons for difficulty in implementing home-care programs, according to Mc Donnell et al. (1994):

- The request by a community for assistance in the care of PWA's may be met with prefabricated solutions that are unsuitable for local conditions and overestimate existing community services.
- Implementing agencies may be pressured by donors to undertake activities which have little relevance to a local situation.
- Communities may have programs imposed on them from the outside which may conflict with their interests or undermine their exiting initiatives.

This mismatching of communities with ready made solutions from the outside often results in a waste of scarce resources and goodwill. Therefore, Mc Donnell et al. (1994) recommend that the aims of a program should be to strengthen the capacity of the family and community to care for its members with AIDS by building on the traditional family structures that support all chronically ill people. This could lessen the impact of the disease on the health system and, and address a need for ongoing care of persons with AIDS and their families who may not want, or cannot afford to spend long periods in hospital.

This study has involved an assessment of the individuals' ability for self-care, the family's ability to care for their relatives and the community's capacity to sustain supportive care for community members living with AIDS in the Bhambayi community.

This study should ultimately facilitate planning of realistic interventions, so that the family and community can be empowered and supported to provide care for community members with AIDS in the home environment.

The South African scenario of rapid urbanisation has resulted in thousands of previously rural people settling in peri-urban areas, similar to Bhambayi. The assessment matrix that was adopted and developed in this study could largely be used in other similar communities for planning community-based homecare programs for people living with AIDS.

1.7 OPERATIONAL DEFINITIONS

Operational definitions used within the context of the study are provided below.

1. **Home-based care** is the care provided in the home of an individual by family members, friends and community caregivers.
2. **The individual** is the person living with AIDS.
3. The **family** refers to the kith and kin of the individual living with AIDS.
4. **Community** refers to the people living in the Bhambayi area.
5. **Perceived needs** refer to the requirements as identified by the people themselves.
6. **Organizational ability and capacity** refers to the management skills and competence of the community.
7. **The health system** in this study refers to the care provided to people with AIDS by the formal health facilities such as the hospitals and clinics.

8. **The social system** refers to the individuals and organizations that play a supportive role from outside the community such as social service agencies and other organizations.

1.8 CONCLUSION

HIV/AIDS can be described as a global health problem with serious social issues that are of relevance to the health community. Therefore a thorough understanding of the background to the problem formed the foundation to this chapter.

It was through the process of listening to the people's needs and concerns on a daily basis as the project facilitator, that the researcher was able to appreciate the impact of AIDS in this community. The people were not coping as the social ills of extreme poverty and loss of lives to disease were taking its toll. The community had recognized the need for intervention at the very outset of the community development project. Therefore they were willing to participate in the initial survey and they were forthcoming with important information in the planning phase. Many problems were dealt with during the entire course of the project.

It can therefore be concluded that the critical point of entry was a long process of establishing trust by working with the community using the principles of community development.

CHAPTER TWO

LITERATURE REVIEW

2.1 INTRODUCTION

The purpose and objectives of the study provides the framework for the literature review. Given the plethora of research concerning HIV/AIDS and the extensiveness of the McDonnell et al. (1994) assessment matrix, an in-depth review of the literature has not been provided. Instead this chapter provides an overview of the literature related to the different facets of the study. The sections contained in the review are outlined below.

The discussion of HIV prevalence in South Africa describes the extent and the determinants of the epidemic. A brief description of the phases of HIV infection and its diagnosis is provided.

A community development approach to AIDS care, prevention and control is discussed, whereby the literature will show that all action, in principle, should emanate at grassroots level with community participation and this could culminate in the people taking ownership thereby making such programs sustainable.

Central to this study is the role of the health system, both the formal and the non-formal or traditional health systems in the delivery of AIDS care and support of communities. Its role and functions are discussed. This section further describes the significance of community-based health care that is founded on principles of community development.

Models of community-based HIV/AIDS care in South Africa including those for funding, technical and support; advocacy and community mobilization; drop-in centres; home visiting and comprehensive home based care programs are described.

The critical issues of home care for the person with AIDS related to the nutritional status and psychosocial factors to be considered assessing the physical environment and the importance of meeting the informational needs of PWA's and their caregivers is discussed.

Factors related to community care of the PWA including the role of the community and the increasingly important role of the community volunteer and voluntarism in South Africa is described.

The role of the health system in the delivery of AIDS care and support within the continuum of care is then examined. These aspects include assessing the level and type of need the importance of the respect for human dignity integrating HIV prevention and care and utilizing existing community-based programs.

Integral to AIDS care is social services and support. Critical issues including difficulties in accessing social service benefits in South Africa and the need for co-ordinated referral systems within the continuum of care is then discussed.

The theoretical framework that guided this study is described in section 2.6.

2.2 HIV PREVALENCE IN SOUTH AFRICA

South Africa has the largest number of people living with HIV and one of the fastest growing epidemics in the world (UNAIDS/WHO, 2004). Projections made using the ASSA600 (Actuarial Society of South Africa) model estimated that a total of 6.5 million people will be infected with HIV/AIDS in 2002. (Dorrington, Bradshaw and Budlender, 2002) According to the population-based survey by the Medical Research Council of South Africa, South Africa had an overall prevalence rate of 27.3% among pregnant women in 2003, compared with 26.5% in 2002. A UNAIDS/WHO 2004 study established that KwaZulu-Natal accounts for 37.5% of HIV prevalence among pregnant women in 2003. This is an increase, compared with 36.5% in 2002 (Department of Health, 2003).

2.2.1. TOTAL NUMBER OF PEOPLE INFECTED WITH AIDS

According to a report by UNAIDS/WHO (2004), the number of people living with HIV at the end of 2003 was estimated at 5.3 million in South Africa, of which, 2.9 million were reported to be women.

2.2.2 RESPONSE TO THE EPIDEMIC

Although South Africa was initially slow in its response to the AIDS epidemic, a five year National HIV/AIDS/STD Strategic Plan was developed and formulated in 2000, that was intended to guide the country's response as a whole, to the epidemic. The priority areas included: prevention; treatment care and support; legal and human rights; and monitoring, research and evaluation. This plan was intended to include several sectors of society such as traditional healers, faith-based organizations, and business as their participation is deemed valuable in addressing the AIDS epidemic (Department of Health, 2000).

2.2.3 DETERMINANTS OF THE EPIDEMIC

According to the Department of Health (2000), the immediate determinants of the South African epidemic were multi-dimensional. These included behavioural factors such as unprotected sexual intercourse and multiple sex partners; and biological factors such as the high prevalence of sexually transmitted diseases. The underlying causes include socio-economic factors such as poverty and unemployment, migrant labour, commercial sex workers, the low status of women illiteracy, the lack of formal education, stigma and discrimination.

2.2.4 MATERNAL ORPHANS

Dorrington et al. (2002), estimate that by 2005, KwaZulu-Natal will have a total number of 202 277 children orphaned by AIDS.

2.2.5 CONCLUSION

In view of the increasing prevalence of HIV infections and the number of people living with AIDS in South Africa, the social impact of the epidemic will also escalate bringing untold hardship to already struggling communities. Therefore it is imperative that a collective effort is made by government and the private sector alike, to address the problem. Although the determinants of the epidemic have been identified as being multi-faceted and these have been well documented by the Department of Health, the response to the epidemic in South Africa has been slow.

2.3 DIAGNOSING HIV INFECTION

2.3.1 THE ASYMPTOMATIC PHASE

HIV infection in adults is often 'silent'; the patient usually remains symptom-free for 3-10 years. In many patients the only evidence of HIV infection is a positive HIV serology test. For other patients signs and symptoms of AIDS or immune deficiency make the chances of HIV more probable. Therefore it may not be necessary to confirm a positive HIV test antibody result if the patient has obvious signs and symptoms of immune deficiency/AIDS (Evian, 2000).

According to Moodley (2003), HIV related opportunistic infections, laboratory evidence of immune deficiency and a low CD4 cell count (less than 500mm³) could indicate moderate to very severe immune deficiency with varying degrees of opportunistic infections. The CD4 cell count is the best indicator for the risk of developing opportunistic disease or infections and the likely severity of such infections.

The interpretation of the CD4 cell count in relation to the degree of immune deficiency according to Evian (2000) is listed below.

- A CD4 cell count of 500-600cells/mm³ indicates a mild immune deficiency and opportunistic infections are unlikely to develop.
- A CD4 cell count of 300-500cells/mm³ indicates a moderate immune deficiency. Opportunistic infections such as TB, oral and vaginal Candida, herpes and folliculitis.

- A CD4 cell count of 100-300cells/mm³ indicates an advanced or a more severe immune deficiency. Opportunistic infections and some cancers such as Kaposi's sarcoma can be expected.
- A CD4 cell count of 0-100cells/mm³ indicates very severe immune deficiency. Severe and frequent opportunistic infections such as cytomegaloviral disease, atypical mycobacterium and oesophageal candidiasis.

2.3.2 THE SYMPTOMATIC PHASE OF HIV-RELATED DISEASE

After a period of 5-8 years following HIV infection, the viral load increases progressively and the immune system continues to deteriorate and become immune deficient. The signs and symptoms of more severe HIV related diseases begin to appear and this is due to overgrowth of the body's natural flora with fungal infection and the reactivation of old infections such as TB and herpes. They are also due to the multiplication of the HIV itself. The onset of oral/vaginal candidiasis (thrush) and recurrent herpes simplex (cold sores) or Herpes zoster (shingles), are commonly the first clinical signs of advanced immune-deficiency. (Evian, 2000)

2.3.3 AIDS, THE SEVERE SYMPTOMATIC PHASE OF HIV-RELATED DISEASE

The symptomatic phase usually progresses over the next 12-18 months into the fully developed AIDS phase of the disease. AIDS is associated with a high HIV viral load and severe immune-deficiency. This usually corresponds to CD4 cell counts below 200 cell/mm³ and to a low lymphocyte count (less than 1 500 cells/mm³). This allows the development of severe opportunistic infections and HIV-related organ damage. These conditions are referred to as AIDS defining illnesses and are listed in the WHO Staging System for HIV Infection and Disease. (Evian, 2000)

2.3.4 ASSESSING THE IMMUNE STATUS AND STAGE OF HIV DISEASE

The CD4 cell count is a very valuable and useful indicator of immune capacity in people with HIV. It is the most reliable predictor for the risk of developing opportunistic

infection and symptomatic disease. The testing of CD4 cell counts are costly and need sophisticated laboratory technology. In many health services, especially in rural and low socio-economic areas, these tests may not be available or affordable. The primary health care personnel will need to be guided by the clinical condition and by being alert to signs and symptoms of opportunistic infections that develop if there is immune deficiency (Evian, 2000).

According to WHO (2000), the following conditions are considered to be very suggestive of Immune-Deficiency and advanced HIV disease in an HIV positive adult person:

- recurrent or persistent *Candida albicans* (thrush) in the mouth and vagina;
- hairy leukoplakia on the tongue;
- herpes zoster (shingles) and herpes simplex (cold sores);
- skin rashes, for example, itchy maculo-papular rashes, seborrhoeic dermatitis, fungal infections, and wart;
- weight loss for no obvious reason (usually more than 10% of body weight);
- fever or night sweats;
- diarrhoea (ongoing for many days or weeks);
- dyspnoea, tachypnoea and cough (ongoing for more than a month);
- peri-anal conditions, for example, abscess, fistula and fistula;
- genital ulcers which do not heal with treatment;
- neurological problems, such as memory loss, personality changes, severe weakness, fits and peripheral neuropathy; and
- anaemia (pallor) for no obvious reason.

2.3.5 CONCLUSION

As immune deficiency often presents with a range of signs and symptoms as indicated above, it may not be necessary to confirm a positive HIV test antibody result if the patient has obvious signs and symptoms of immune deficiency or AIDS. However obtaining a definite clinical diagnosis is significant in the early stages of the disease as

this would facilitate a care plan for the infected individual and a support plan for the affected family.

2.4 A COMMUNITY DEVELOPMENT APPROACH TO AIDS CARE, PREVENTION AND CONTROL

2.4.1 INTRODUCTION

Community development is an essential part of human development that is borne out of a need identified by a community (Swanepoel and de Beer, 1996). According to Monaheng (2000), the most fundamental principle of community development is that it follows an integrated approach to problem solving. The problems are considered to be multi-faceted and it is recommended that these problems need to be addressed in a co-ordinated manner by all role players involved in development initiatives. The concept of community development when utilized in community based health care, such as in planning an AIDS program, can contribute to its sustainability (Campbell and Rader, 2000).

2.4.2 ACTION EMANATES AT GRASSROOTS

It is essential that all action emanates at grassroots level at the outset whereby the community is actively involved in the first survey of AIDS related needs and resources. These findings would form the foundation of all plans for community-based care (Campbell et al., 2000). This would provide an insight into the areas of need and stimulate the community to set concrete objectives to meet these needs (Swanepoel et al., 1996).

2.4.3 A LEARNING PROCESS

Community development is a learning process, according to Swanepoel et al., (1996) and Monaheng (2000). The learning process is made viable through three vital components, which are participation, initiative and evaluation. With participation, the community will improve in its ability to do each step in meeting its set objectives and thereby gain in self-sufficiency. Therefore reliance on external resources to reach an objective will also diminish and when they become self reliant, they also gain in human dignity (Swanepoel et al., 1996). According to Russell et al., (2000), communities have been engaged in caring for its ill members for many generations. Campbell et al. (2000) believe that as

most communities are dependant on health services and may feel that they will not be able to manage at home and they would require reassurance about support needs at an early stage of an AIDS program. Therefore it is vital that the current care provision is acknowledged at the outset. It is imperative that people are accredited for their ability to perform the tasks and they must be respected for their ability to think, seek, discuss and make decisions. Self evaluation of activities within a project is vital as the people learn the consequences of their own decision making and action (Swanepoel et al., 1996).

2.4.4 MOTIVATION FOR PREVENTION

According to Campbell et al. (2000) the community can become motivated for prevention through home-based care as this community based approach is one that is owned by those groups that are suffering the most, and is therefore more likely to be sustainable in the future.

2.4.5 REFLECTION AND POSITIVE RESPONSE

Home care and community counselling are key components to community participation in response to HIV/AIDS, according to Campbell et al. (2000). Together, the community is encouraged to reflect and respond in positive ways. The authors further believe that AIDS can be controlled by a community exploring issues and choices so it can control behaviour on its own terms.

2.4.6 CONCLUSION

An integrated approach to community based AIDS care is essential whereby the community is guided through a learning process by participation, initiative and evaluation. Therefore it is vital that all action emanates at grassroots level and community efforts in care provision need to be acknowledged and supported at the outset. Furthermore a community development approach to AIDS care is believed to assist people in changing behaviour at their own pace thereby preventing further infections.

2.5 HEALTH SYSTEMS

2.5.1 INTRODUCTION

Health systems encompass all actions whose primary intent is to promote, restore or maintain health. A broad definition of the health system refers principally to the delivery of medical care. Other functions include financing, investment and stewardship. (WHO, 2000.)

Health systems comprise all organizations, institutions and resources devoted to producing health actions that function together to support and improve the health of a population. A health action is described as any effort (personal health care, public health services, through intersectoral initiatives) with the primary purpose of improving health. (WHO, 2000.)

A health system consists of a set of cultural beliefs about health, illness, health care and the societal and institutional framework in which these beliefs are turned into health and health care behaviours. Cultural beliefs form the basis for health seeking and health care delivery behaviour. The societal framework includes family and community. The institutional framework include other sectors such as the education system that impact on health and the health care system. (Katzenellenbogen, Joubert and Karim, 1997.)

Health care delivery systems include all specific institutions or systems of a society that deliver health services to a population or a specific clientele. On the micro level these would be hospitals and individual practices, whilst on the macro level they would include medical, nursing, dental services, municipal health departments, traditional health care systems, homeopathy and faith healing. These are all distinguishable systems of care in a country A national health care system encompasses the total network or system of services and provision of care in a country which includes all particular health care. (van Rensburg, Swanepoel and Pretorius, 1992.)

The providers of direct health services, whether aimed at individuals, communities or the environment, are tasked with defending society against illness and promoting health.

Therefore health providers need to be adequately trained, informed, financed, supplied, inspired and led, to be successful. These health systems include care provided by the formal health system; the non-formal health system (actions of traditional healers/indigenous healers/medicine) and self care, that is, self medication and home-care. (WHO, 2000.)

The roles of the formal health systems are briefly discussed below.

2.5.2 THE FORMAL HEALTH SYSTEM

According to Lankester (2000), health care in the formal system takes place in the hospital or clinic at the convenience of the doctor or health worker. The health worker is an outsider with specialist and scientific knowledge, who is inclined to direct and dominate the treatment of the patient. Although often effective, this approach may be frightening, inconvenient and expensive. Furthermore the poor may not use it at all.

2.5.2.1 Role of the formal health system

Primary health care was vigorously promoted as a route to achieving affordable universal coverage, that is, the health for all. Although this system had many virtues, a criticism has been that it gave too little attention to people's demands for health care, but rather concentrated on people's perceived needs. Systems have experienced difficulties when these two concepts did not match, because the supply of services offered could not meet both the demand and needs of the people. There has been a gradual shift towards the "new universalism" in the past decade. This means that instead of all possible care for everyone, or only the simplest and most basic care for the poor, delivery of essential care needs to be of high-quality to all. This is defined by effectiveness, cost and social acceptability. This concept implies that there would need to be a precise choice of priorities among interventions, respecting the ethical principal that it may be necessary and efficient to ration services, but that it would be inadmissible to exclude whole groups of the population (WHO, 2000).

There have been significant political and economic changes over the past 20 years including the shift from centrally planned to market-related economies, reduced state intervention in national economies, fewer government controls and more decentralisation. People's expectations of health systems are greater than ever before and the result is increasing demands on the health systems, including both their public and private sectors, in all countries, rich and poor. Therefore it is clear that governments are limited to what they can finance and on what services they can deliver (WHO, 2000).

2.5.3 THE NON-FORMAL HEALTH SYSTEM

2.5.3.1 The traditional health system

According to Lankester (2000), a traditional health system is where health care takes place in the community according to the wishes and convenience of people and patients. This system has value in its own right. Senior family members such as grandmothers are the traditional source of wisdom. In serious situations, other health workers who are community members, using traditional skills or knowledge, are called in. Each community has its own traditional health practitioners, for example, shamans, priests, herbalists, traditional midwives and aryuvedic practitioners.

2.5.3.2 The role of traditional medicine

Health systems of some sort have existed for as long as people have tried to protect their health and treat diseases. According to Chatora (2003), the World Health Organization defines traditional medicine as the combination of knowledge and practices that are drawn from past experiences and observation that are handed down from generation to generation, either verbally or in writing, in order to diagnose, prevent or eliminate physical, mental or social disease.

Samba (2003), believes that in many parts of Africa, traditional health practitioners far outnumber conventional health practitioners, with the estimated ratio of 1:200 and 1: 25, 000 people, respectively. According to the literature, people throughout Africa, have a long tradition of seeking traditional health care simultaneously with, or even before

considering modern medical services and traditional practices are regularly integrated with spiritual counselling and providing both preventive and curative care (WHO, 2000; Samba, 2003.)

The literature shows that, in many African countries, few traditional healers consider AIDS as an ‘African’ disease (Green, 1992a; Green et al, 1993, cited in UNAIDS, 2000). Traditional beliefs about the causes and mode of transmission appeared to be understood, as the healers recommended the following to their patients: limiting the number of sexual partners, wearing protective charms or tattoos, having ‘strong blood’, using condoms to reduce the risk of ‘pollution’, or undergoing a ‘traditional vaccination’ that consists of herbs introduced into skin in skin incisions (Green, 1992a; Green et al, 1993, Nzima et al, 1996; Schoepf, 1992, cited in UNAIDS, 2000).

In conclusion as the demands for health care increase with the growing AIDS epidemic in South Africa, the financial burden of health care will also increase. However this should not be an excuse for health care providers to ignore the health care needs of people infected with AIDS. Neglect and indifference to this vulnerable sector of the population would be tantamount to human rights abuse.

It would be prudent to note that the majority of African people have utilized traditional medicine simultaneously with modern western medicine according to their traditional practices and beliefs in order to protect their health and treat disease. Therefore it would be incumbent upon all health care providers to respect and acknowledge these practices.

2.5.4 COMMUNITY-BASED HEALTH CARE

According to Lankester (2000), community based health care (CBHC) is health care that commences in the community, with referral to the clinic or hospital if necessary. The health worker, usually a non professional community health worker (CHW), is an insider who lives in the community, understands its traditions, and provides effective health care. Prevention of ill health becomes the dominant activity.

CBHC is based on the principles of community development that includes all people regardless of status and wealth. It is believed to encourage ownership by the community where the community participates, becomes a partner and eventually owns the program. Co-operation with all health providers and other agencies and integration into the health services of the country is essential. (Lankester, 2000.)

CBHC responds to the needs of the people, that is, it starts with the people, helps them identify their needs and works with them in finding answers. It also leads to self-reliance as people become armed with knowledge and therefore rely less on outsiders. Sick people are treated in their homes or as near to their homes as possible. CBHC also helps to foster behavioural change within a community, whilst learning new ideas and different practices that could inspire real changes in lifestyle and health begins to improve. (Lankester, 2000.)

Therefore community based health care can be seen as a valuable component of the health system as it is facilitated and managed by members of the community. It can contribute significantly to the prevention of disease and the promotion of health thereby lessening the burden on the formal health system.

2.5.5 MODELS OF COMMUNITY-BASED HIV/AIDS CARE IN SOUTH AFRICA

The high HIV prevalence rate (see 2.2) and the increasing demands on the health services (Department of Health, 2001), are reasons for exploring suitable models of care and support for PWA's. Communities and families have increasingly assumed the burden of AIDS care and there are many types of programs that have emerged throughout the country. (Russell et al, 2000.)

The five general care models found in South Africa are discussed.

2.5.5.1 Funding, technical assistance and support program

These are umbrella structures channelling funds, providing technical assistance and monitoring, and evaluation. Two non governmental organizations (NGO) are examples of such models, that is, the AIDS Foundation of South Africa in KZN and the Mpumalanga

Support Association and they provide support function to community based organizations (CBO). According to Russell et al (2000), these organizations have the potential for public/NGO partnerships to promote the development of community based action and could also play a role in setting standards and co-ordination.

2.5.5.2 Advocacy and community mobilization

This model is essentially community structures that are designed to protect the rights of individuals and facilitate access to health and welfare services and schooling. The Thandanani project in Pietermaritzburg, KZN, is a project based on this model and its focus is on children orphaned or abandoned due to AIDS (Aadnesgard, unpublished report, cited in Russell et al, 2000). Community Child Care Committees (CCCC) was formed and was tasked with identifying vulnerable children whom they refer to helping agencies. These committees do not provide services but created linkages and referral relationships with social, medical, nutritional, child welfare and other service providers. (Russell et al, 2000.)

2.5.5.3 Drop in centres/ support groups

This model consists of a simple physical facility that provides a space to run a support group and income generating activities. Support groups are purported to facilitate a safe environment for people to cope with their diagnosis and assist HIV infected adults to engage in discussions about the future placement of their children and to acquire documentation which was necessary to access welfare grants. (Russell et al, 2000.)

2.5.5.4 Home visiting programs

This model consists of home visiting, assistance with chores and psychological support. Drop-in centre activities may include a home visiting service by volunteers. Their activities would include visiting people in their homes to assess the PWA's needs: provide support with cooking, cleaning, assisting with errands and accompanying patients

to health facilities. They may also arrange to access food parcels and other material support. (Russell et al, 2000.)

2.5.5.5 Comprehensive home based care (HBC)

This model is a package involving palliative care and a well developed referral network to health facilities and welfare agencies. The model includes fund raising, technical assistance and support, advocacy and community mobilisation; drop in centres and support, home visiting and varying degrees of palliative care. These programs were run by more established NGO's such as Hospice, Red Cross Society and church linked groupings. A number of such projects exist in South Africa. Building partnerships with welfare agencies, schools, businesses, hospitals, respite care facilities and clinics were reported to be time consuming, but once established, this offered infected people and their families more comprehensive services. (Russell et al, 2000.)

In conclusion, these models of community-base AIDS care in South Africa all have their merits. However, the selection of a particular method for a program would largely depend on the community's needs and resources. There is no simple solution to program planning and implementation.

2.5.6 CONCLUSION

It can be concluded that both the formal and non-formal health systems have the capacity to play equally important roles in the delivery of AIDS care and that a co-ordinated effort with community participation can improve the quality of life of people living with AIDS in their home environment.

2.6 CONTINUUM OF CARE

The model of the "continuum of care" for HIV/AIDS was developed and popularised by the World Health Organisation (Van Praag, 1995, cited in Russell et al, 2000). It is a combination of two key ideas: the model is designed to address the range of needs of PWA's, from diagnosis through to death and bereavement; and to create effective referral linkages between all role players in order to meet these needs.

According to the UNAIDS (2000), the content of care delivered across a continuum requires a range of comprehensive services that includes counselling and testing, clinical management, nursing care and community-based social support. The provision of care within the continuum involves the PWA, their family and various service providers, with linkages from the community to the hospital or the health facility to the community. The patient and their families enter in and out of the continuum at different points, depending on their needs. Russell et al. (2000) are of the view that the earlier the PWA enters the continuum, the more beneficial the effects. The provision of care within the home, by the family, the community and health services is described in the following section.

2.6.1 HOME CARE AND THE PERSON WITH AIDS

Home care is given to sick people in their homes. This might include people caring for themselves, or care given by family, friends, neighbours, health and social workers and others. Such care can be physical, psychosocial, spiritual and palliative (UNAIDS/WHO, 2000). According to Green (1999), self-care comprises the care in respect of the necessities of life such as food, clothing, accommodation and hygiene. Physical care impacts directly on mental well-being of individuals, therefore one's existence becomes more meaningful as a result of care.

Various factors including the nutritional status, psychosocial needs, home care health requirements, physical environment, and informational needs must be considered when assessing home care for a PWA (Hoeman, 1996). These factors are discussed below.

2.6.1.1 Nutritional status

The importance of understanding the relationship between nutrition, HIV infection and the immune system is discussed below.

The late conversion phase of AIDS manifests in progressive, involuntary weight loss also known as 'slims disease' (Evian, 2000). According to Hoeman (1996) this weight loss can be due to reduced intake of food, malabsorption, and altered metabolism. The

nutritional status of PWA's is further compromised by medication and drug interaction. The etiology of this syndrome can include anorexia, conditional nausea, chronic diarrhoea, and malabsorption and food availability. Malnutrition occurring with weight loss may adversely affect the immune system and further impair the individual's ability to avoid or recover from repeated infections and other stressors (O'Brien and Pheifer (1991), cited in Hoeman, 1996). Therefore, according to Hoeman (1996), appropriate home management is imperative in order to assist the PWA's with improving their nutritional status that would delay disease progression and improve the quality of life.

Evian (2000) suggests that dietary advice needs to be specific according to the severity of the symptoms. Dietary information should be kept as simple as possible taking into account the circumstances of the patient. Practical suggestions for food intake in symptomatic AIDS would be invaluable.

The family and the PWA need correct information in order to manage problems related to nutrition. Foods such as high energy meal-in-glass drinks provide all the required nutrients if the patient cannot eat a full meal or, too tired to eat or if the patient has difficulty in swallowing. Non-acid foods such as pasta, mince, cereals, yoghurt, sour milk and custard are suggested for a patient with a sore mouth. Fermented foods such as sour milk and sour porridge are suggested for a patient with oral thrush. Excessive weight loss is a serious problem in people with AIDS. Foods such as full cream milk, yogurt, Soya products, meat, fish, eggs, chicken, peanut butter, lentils, oats, rice maize and fruit will assist in weight gain. (Department of Health, 2001).

2.6.1.2 Psychosocial factors

Concerns related to isolation, stigma associated with HIV infection, home management and impaired communication, will be discussed.

- Loneliness and isolation

A study by O'Brien and Pheifer (1993) as cited in Hoeman (1996), found that people with HIV infection identified loneliness and disturbed self concept due to changes in body image and self-esteem, as the most common psychosocial issues. Isolation may be due to external factors such as the loss of a job or a relationship; physical limitations;

societal responses; or it may be self induced isolation caused by apathy or changes in physical appearance.

- Stigma associated with HIV infection

According to Hoeman (1996), the stigma associated with an HIV positive diagnosis and the importance of disclosure to family and friends is an additional facet of the psychological response to infection that must be considered. Serovich (2000) explains that disclosure of HIV-positive diagnosis can be difficult and anxiety provoking. Individuals fear the negative reactions in the form of rejection, shunning, abandonment, or fear. However, as disclosure is often vital for the acquisition of support services, it almost becomes inevitable. Therefore HIV positive people need counselling and continued psychological support that could reduce the stress associated with disclosure (DOH, 2000).

- Home management of a person with AIDS

As an individual succumbs to uncontrollable infection, becoming increasingly debilitated, feverishly ill and malnourished, their ability to function independently and carry out activities of daily living diminishes (Hoeman, 1996). This creates a sense of helplessness that can impact negatively on the individual. According to Orem (1990, cited in Kindlen, 1994), the individual has the right and responsibility to attend to his own self-care basics. The challenge in caring for the chronically ill in the home is to encourage the individual's right to self-care (Kindlen, 1994).

- Impaired communication

Impaired communication is often related to involvement of the central nervous system. According to Levinson and O'Connell (1991), as cited in Hoeman (1996), advanced AIDS involves diffuse and focal central nervous system disorders as well as peripheral neutralities. AIDS-dementia complex (ADC) or HIV encephalopathy is the presenting feature of AIDS in many cases. Persons diagnosed with ADC may present with signs of cognitive, behavioural and motor disturbances. Hoeman (1996) reports that a significant number of PWA's eventually develop some degree of cognitive motor and emotional impairment that responds favourably to counselling and therapeutic interventions.

2.6.1.3 Assessing the physical environment

According to the Department of Health (2001), the physical environment for home care needs to be assessed. Suitable housing, the availability and access to adequate water and proper sanitation impacts directly on care provision and infection control respectively. Attention to environmental hygiene and safety from injury are also important factors that need assessment. Communities with limited or inadequate basic resources have great difficulty in coping with home care. Families would require health information and ongoing support in order that their efforts can be effective (Lahoud, 1997).

2.6.1.4 Informational needs

It is imperative that the PWA and the caregiver are provided with appropriate information and knowledge on the disease process, infection control, the management of common opportunistic conditions in the home and basic home nursing skills (Hoeman, 1996). This knowledge base together with support will foster the level of confidence and competence that these individuals need to achieve a satisfactory quality of life.

As can be seen from the foregoing, the care of people with AIDS begins with assessing care provided in the home by families. Therefore it is essential to assess the level of care needed and the capacity for families to provide this care. Each of the essential factors discussed is critical for an individual's well being. It can be concluded that it would be extremely difficult to provide any level of quality care in the home, if any one of these factors are unmet.

2.6.2 THE FAMILY IN RELATION TO HOME BASED CARE OF PWA's

According to Pequegnat and Bray (1997) AIDS is chronic disease that requires long-term family commitment to the patient In addition to it being a fatal disease. AIDS is changing the demographics of families by forming new structural relationships. (Anrah, 1991 cited in Pequegnat et al., 1997.) There may be anger in low income families in which everyone is expected to contribute to the household but the sero-positive person is unable to do so because of fatigue and unpredictable health. The authors further were of the belief that the generation that should be parenting the next generation and participating

actively in the workforce is experiencing the highest infection rate. (Pequegnat et al., 1997)

Some of the problems that affected families experience, according to Pequegnat et al., (1997) are described below.

- Fears

Families have fears about recurring acute illness episodes and impending losses. Affected families have the fear of further infection through physical contact with the PWA's. They also had to cope with the fear and anxiety related to the lack of financial support and the medical outcome.

- Isolation

They face isolation from other family members and friends contributing to the deterioration of marital and nuclear family relationships. This could be attributed to the difficulties experienced in disclosure of HIV status to other family members as AIDS is a sensitive issue. They would therefore carry the stressors of care of an infected individual on their own.

- Psychological issues

They experienced uncontrollable emotions resulting from the illness and caring responsibilities. Family caregivers had the overwhelming task of relating to multiple health and welfare providers and the lack of good medical care and counselling. Furthermore, family members may have caretaking concerns that include helplessness associated with being overwhelmed by the needs of their family members in terms of time, energy and money. Siblings and spouses may have additional concerns, for example, their needs may be ignored as the family attends to the sick member. Therefore major adjustments may be required if the ill family member lives at home.

The ability of families to maintain a normal life is a problem.

- Lack of housing

Many families in low-income communities have to cope with the lack of available and affordable housing services due to the stigma associated with AIDS.

It can be concluded that affected households have to cope with a multitude of issues related to AIDS home-care. These families would therefore require sustained support and care from the health and social systems in order to cope with the additional stressors of home-care.

2.6.3 COMMUNITY CARE OF THE PWA

According to Green (1999), mantle care refers to care that includes lay care, non-professional and non-specialized providers of care that encompasses all types of care that is administered by members of small communities or groups to one another in an agreed, supportive manner. The givers and recipients of care know each other personally. Furthermore, Green (1999) is of the opinion that mantle care is not necessarily the ideal form of care as it could lead to a loss of privacy and a feeling of helplessness for the chronically ill recipient.

2.6.3.1 The role of the community

The key to a successful program for AIDS care is community participation. The two essential components include home care and community counselling (Campbell et al., 2000). The authors believe that together they encourage the community to reflect and respond in positive ways to care, prevention and control of HIV/AIDS. Community volunteers can play a key role in facilitating behavioural change and thereby assisting in preventing the spread of infection.

2.6.3.2 The role of the community volunteer

According to Campbell et al. (2000), community counselling is ideally carried out by community volunteers who have been selected by the community and trained by the health team. It is believed that such ‘insiders’ often work more effectively than outsiders who are less able to understand community attitudes and beliefs. The role of the community volunteer would include:

- opening up concerns in the context of the community's own strength and capacity to respond;
- linking the community and the health services;
- helping to implement community specific strategies;
- referring patients to the health facilities when necessary; and
- counselling in bereavement.

2.6.3.3 Voluntarism in under-resourced South African communities

Volunteers provided the bulk of services in most programs in South Africa, according to a study by Russell et al. (2000). However, it was reported that voluntarism was problematic as programs with inadequate or no funding found it difficult to maintain volunteer commitment. They reported high turnovers of volunteers, who once trained, moved on to other opportunities, dropped out or were unreliable and felt little loyalty to the organization. Conversely, programs that had successfully recruited and retained volunteers had sought people who were well respected in their communities.

In view of the above, it is clear that community care is vital in the continuum of care of people with AIDS. Communities have the capacity to mobilize its resources in the form of community volunteers who provide most of the home care services and play a key role in community advocacy as they are able to understand the dynamics of the community they live and serve in.

2.6.4 HEALTH SERVICES

According to Osborne (1996) cited in Russell et al. (2000), the content of care of people with AIDS delivered across the continuum contains a range of services including counselling and testing, clinical management, nursing care and community based social support. This section discusses the health and social service within this continuum.

2.6.4.1 Assessing the level and type of need

It is important to establish the local attitudes towards AIDS, how PWA's are viewed by their families and communities and the felt needs of PWA's and their families (UNAIDS/WHO, 2000). The existing care at health facilities, the impact on the health services and staff, the trends for hospital admissions and bed occupancy rates need to be determined. Furthermore, the availability of appropriate medication at the sites of care, the most commonly used medicines for treating HIV related infections and adequate supplies of condoms and other household and medical supplies needs to be determined. (UNAIDS/WHO, 2000)

It is also important to verify how HIV related illnesses are treated within the community, that is, who treats the PWA and in what manner (UNAIDS/WHO, 2000). Existing community services such as programs for the care of the chronically ill, needs to be determined and the possibility of including the care of PWA's could be explored. The discharge procedure and subsequent contact with the PWA needs to be verified. (DOH, 2001)

2.6.4.2 Respect for human dignity

In order to provide accessible and acceptable programs of care and prevention, caregivers and institutions should not be discriminatory or judgemental. All programs must be based on the principle of respect for human dignity. Furthermore, confidentiality must be respected at all times and basic rights observed. (UNAIDS/WHO, 2000)

2.6.4.3 Integrating HIV prevention and care

The PWA and the family are central to the principle of the continuum of care, as the immediate need is to listen to and learn from them in order to plan for the future (UNAIDS/WHO, 2000). Furthermore, it is important to combine care with education and prevention strategies. Counselling services, STI clinics, maternal and child health clinics, and other health and social services can play an important role as this would facilitate voluntary testing and counselling, education about risk behaviours and the distribution of condoms. Such activities should be combined with counselling, clinical management and physical care. (DOH, 2001)

2.6.4.4 Utilizing existing community-based care

In many countries, PWA's and their families are good advocates and a useful resource in planning and providing comprehensive, holistic care (UNAIDS/WHO, 2000.) It is essential to build on the care that people are already providing for themselves within their communities. Incorporating and strengthening existing programs such as cancer care or care for the chronically ill are significant strategies. (Russell et al. 2000; DOH, 2001)

To conclude, it is important to assess the level and type of needs as this information would determine the intervention strategy. Health service provision by caregivers and institutions to people with AIDS needs to be based on the principle of respect for human dignity and confidentiality must be respected at all times and basic rights observed. HIV prevention and care can be integrated into existing health and social service programs as this would reach a greater number of people. AIDS education when integrated into regular health promotion activities can assist in reducing the stigma associated with AIDS. Any existing community care services for the chronically ill needs to be acknowledged as this could be useful when planning community care for PWA's.

2.6.5 SOCIAL SERVICES

According to UNAIDS (2004), AIDS causes the loss of income and production of a household member in high prevalence areas. If the infected individual is the sole bread winner the impact is especially severe. Poor households are in particular danger of losing their economic and social viability and of eventually being forced to dissolve with children migrating elsewhere. (Rugalema, 2000, cited in UNAIDS 2004). Studies of AIDS-affected households in South Africa, where most of them were already poor, found that the monthly income fell by 66% to 80% due to coping with AIDS-related illnesses (Steinberg et al, 2000, cited in UNAIDS, 2004).

A study conducted by Russell et al. (2000) in South Africa found that PWA's and home care service providers experienced many difficulties in applying for and accessing disability and child welfare grants. Firstly, there appeared to be a lack of protocol or standards regarding the criteria for eligibility for AIDS disability grants. The mobile PWA applicants were sometimes reportedly doubted by the medical staff and denied the

benefit. The study found that the majority of PWA's interviewed were not receiving any benefits. Secondly, child welfare grants were also difficult to access, as care providers were unable to find the necessary documentation on the death of a parent. Furthermore many children did not have birth certificates and family members were unable to furnish the appropriate documentation. Finally, applications for documentation from the Department of Home Affairs often required people travelling repeatedly to the offices. Transport was costly and they soon became discouraged. (Russell et al. 2000) Therefore an enabling environment was required to assist infected individuals and affected households to access financial support.

The Department of Home Affairs in South Africa is currently responsible for distributing social and disability grants to people with AIDS after being assessed by the Department of Social Development. The criteria to qualify for a disability grant of R740 per month include: a Doctor's medical report, a sero-positive test of a CD4 blood count of less than 200 cells/mm³ and infected individuals with a stage 4 or stage 5 level of HIV disease will be considered. (Department of Social Development, 2005)

According to UNAIDS/WHO (2000), a workable structure needs to be set up and this would require co-ordination with the hospital, clinic, voluntary and confidential counselling and testing and other support agencies in order to create support services for PWA's. Therefore, developing a good referral system between the hospital, home, clinic traditional healers, community health workers and social service agencies was essential.

It can be concluded that a well co-ordinated social support systems in the form of social services, support groups and referral systems are vital to the continuum of care of people with AIDS and their families.

2.7 THE IMPACT OF AIDS ON POVERTY

AIDS causes a loss of income and production of a household member who may be the sole bread winner. The impact on the family may be especially severe as expenditure rises to include medical and related costs. In a South African study, Steinberg et al.

(2002) cited in UNAIDS (2004), reported that the monthly income in impoverished AIDS affected households fell by 66 % - 80% due to coping with AIDS –related illness.

AIDS depletes family income that would normally purchase food. To cover AIDS related costs households often reduce spending on food, housing, clothing and toiletries (World Bank, 1999 cited in UNAIDS 2004). In Zambia research shows that the poorest economically active households rely heavily on cash income for food. (Food Economic Group 2001, cited in UNAIDS, 2004).

Household responses to AIDS can also differ between urban and rural settings. In urban settings households resort to informal borrowing and using their savings. Rural households may sell their assets and migrate or rely on child labour (Mutangadura 2000, cited in UNAIDS, 2004).

2.8 THE THEORETICAL FRAMEWORK

The Mc Donnell et al. (1994) assessment matrix for assessing and planning home-based care for persons living with AIDS was used as the framework for this study.

According to Mc Donnell et al. (1994), there are two key components necessary for any program to be sustainable:

- self reliance (the ability of the community to provide quality care over time)
- self sufficiency (resources needed to realize these decisions should come mainly from the community itself).

However a home-care program can also be seen where the community may be forced to provide services that the health system has been unable to deliver (Mc Donnell et. al, 1994).

The theoretical framework of this study was guided by a rapid assessment tool in the form of an assessment matrix for HIV/AIDS developed by Mc Donnell et al. (1994). It is intended to resolve some of the possible conflicts and result in a program design that can be adapted to local needs.

2.8.1 THE ASSESSMENT MATRIX

The assessment matrix facilitates a systematic community evaluation of the problems with and resources for current home care. Rapid assessment techniques are used to examine 4 key categories specifically created to assess current AIDS home care provision in a given community. The 4 key categories include: HIV prevalence and awareness; perceived needs; community capability; social and health system (Mc Donnell et al. 1994). These are each examined at 3 levels: the individual, the household and the community, in order to provide an outcome that would guide an action plan at the appropriate level. Indictors developed for each category are used to provide answers to the enquiry at the three levels. The matrix is shown in Figure 2.1 below.

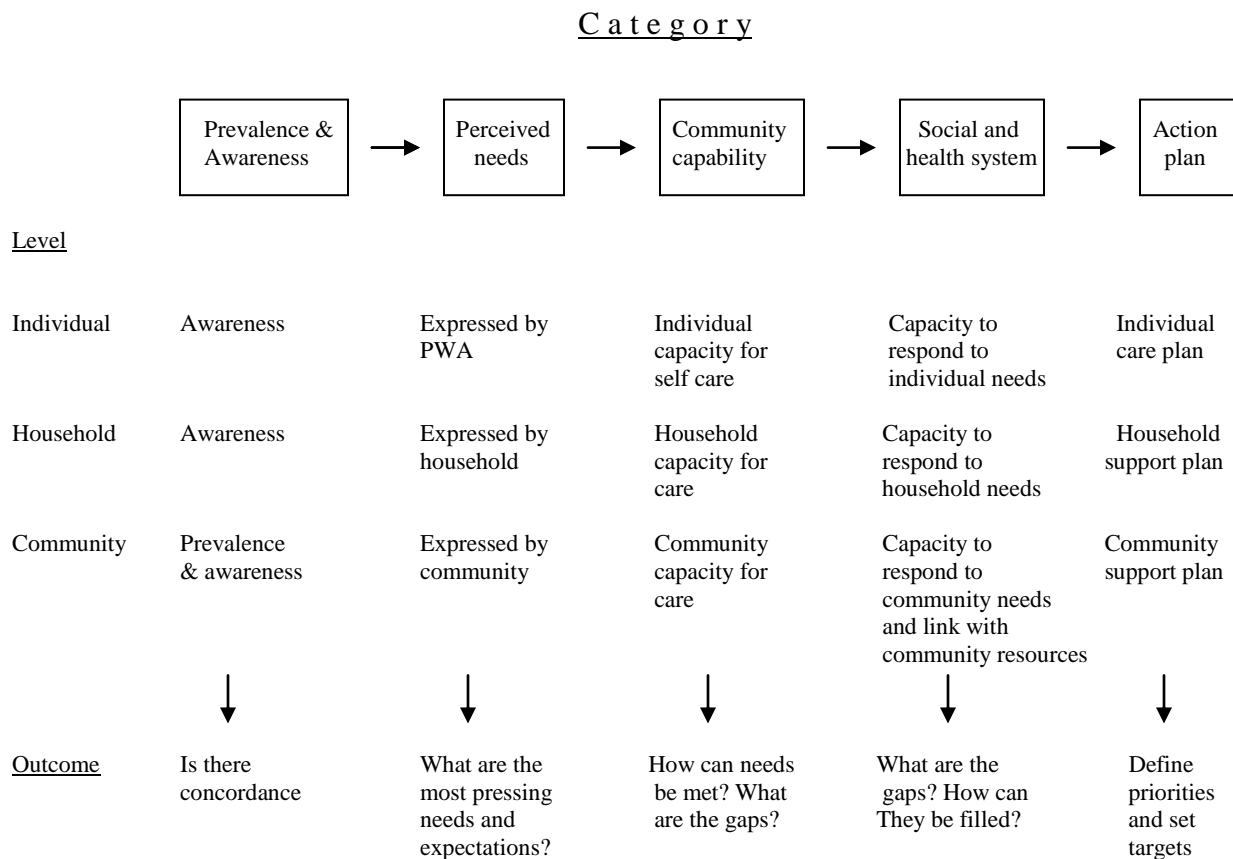


Figure 2.1: The Mc Donnell et al. (1994) Assessment Matrix

Each category will be described below.

2.8.1.1 HIV prevalence and awareness

In this category, the magnitude of the problem and the community's perception of their vulnerability to HIV/AIDS are examined, through a combination of quantitative data and through qualitative assessment. The prevalence is then compared with the community's perception of risk to HIV infection. The concordance of these is then examined to determine whether the community's concern and interest match the actual situation. According to Mc Donnell et al. (1994), this assessment at the outset is of importance, particularly in areas of increasing or already high prevalence, as the community may not have knowledge of the seriousness of the problem.

2.8.1.2 Perceived needs

The perceived needs of individuals, families and the community are examined in this category. Needs are specific to the understanding of individuals, therefore perceived needs are examined. According to Mc Donnell et al. (1994), these needs must be taken into account in any program, even if they are deemed unrealistic. This assessment is intended to provide information on each level, to determine what people think is required to meet the minimum needs of AIDS home care, and this would identify areas for negotiation between the community and the source of assistance.

2.8.1.3 Community capability

The community's organizational ability and present or future capacity to care for persons with AIDS in the home, is examined in this category. The ability of individuals living with AIDS to care for themselves is examined, and as the PWA lives in a household and is part of the family, the ability of the family to provide support and care for the PWA is examined. As families live within communities, it is important to examine the community's ability to offer support to these families. This assessment is intended to identify points of contact between the community, health system and political structures. The outcome is that certain interventions may have to be targeted directly at the individual or household, especially in poorly organized communities. Other interventions might include developing and strengthening the community's capacity to organize and respond to individual demands and needs (Mc Donnell et al. 1994).

2.8.1.4 Health and social system

This category examines the ability of the public health care system to meet the needs generated by the AIDS pandemic. This assessment includes examining the ability of the health system to provide minimum services such as medical care and counseling in its facilities for PWA's, as experienced by the people. The ability of the health system, and other relevant social organizations such as social welfare agencies, religious organizations and support groups to reach out into the community and offer support to a given community is also examined. (Mc Donnell et al. 1994.)

The assessment matrix, as shown in Figure 2.1 is two dimensional. In one dimension, the respective categories, namely prevalence and awareness, perceived needs, community capability and the social and health system are examined in relation to the three levels: the individual, household and community in order to arrive at an outcome. In the second dimension, each level, that is the individual, household and community is examined in relation to the four categories culminating in an action plan for that level. The strengths, weaknesses and barriers that have become apparent when completing the matrix, will determine the structure of the action plan.

2.7.1.5 Development of an action plan

The contents of the action plan will be determined by the strengths, weaknesses and barriers in the current provision of AIDS home care, that have become clear when completing the matrix. The information gathered and conclusions drawn should be taken back to the community and key informants for discussion and confirmation, before any intervention can be initiated. The actual project or home-based AIDS care program undertaken will be the result of community negotiation and will depend on available resources and priorities. (Mc Donnell et al. 1994)

2.7.2 DEVELOPMENT OF INDICATORS

As circumstances differ widely, a decision to develop appropriate and available indicators, according to relevancy and that will yield the most useful information, is recommended by Mc Donnell et al. (1994). A broad overview of possible indicators for a community needs assessment is discussed below.

Some of the indicators for the prevalence of HIV/AIDS could include, percentage hospital bed occupancy of patients with AIDS- related illnesses; the percentage of women attending antenatal clinics who are seropositive; and indicators for awareness of susceptibility to HIV infection could include, the number of people known by community members to be living with AIDS. Indicators for perceived needs could include, how chronically ill people were taken care of within a community; the ability of family members to maintain their income generating activities; how costs care impacted on household income; and the availability of funds for the care and education of affected children. Indicators for community capability could include evidence of community organization and governance such as a health committee, a communal garden, income generating activities and a burial society to assist with funerals. The indicators for assessing the minimum care and support from the social and health system could include, the availability of treatment and discharge protocols for patients with AIDS problems; the availability of essential drugs; adequacy of AIDS counseling at all health facilities; the existence of community outreach through education programs or health workers and whether support exists for community based programs for AIDS care. (Mc Donnell et al. 1994)

2.8.3 A CASE STUDY USING THE MODEL

Mc Donnell et al. (1994) use information from a hypothetical country, struggling with the AIDS problem, to illustrate the application of this model in a specific district of this country. Only the community level of enquiry is discussed in this case study. The information used was readily available from key local community informants and Medical Officer of Health data. A description of the case study is provided hereafter, to indicate how the matrix can be used.

In category one, the study showed a discordance between HIV prevalence and community awareness to their susceptibility to infection. This indicated that the first step in this area would be to address this discordance by developing an intervention to increase awareness to the risk of HIV infection by education on the modes of transmission.

According to Mc Donnell et al. (1994), the community in the case study expressed several real needs in the second category, which is perceived needs. Addressing these needs would

depend on the available resources, in terms of the program itself, and the information elicited about community capabilities in category three. Some interventions to address these real needs could be: linking patients with religious groups identified in category three and training some of these groups in home nursing skills; and improving patient access to treatment for common opportunistic AIDS related conditions. A further suggestion is initiating a discussion with the established health committee about the problem of dependants and the elderly, which could stimulate the community into action.

In the third category, that is community capability, the most important features in this case study were: the inability of the individual patient to care for themselves when ill, which could be resolved by counseling and education at the health facility before discharge or training the patient and family in basic nursing care skills such as maintaining hydration and the preparation of ORS. The most important resource in this study was the church groups visiting homes. These groups could be trained in simple care skills, providing the community is willing to provide and support volunteers to visit homes of PWA's. Assisting the PWA and the family with the simple tasks of daily living, such as fetching water, chopping wood and caring for children, could be the most needed and appreciated form of assistance.

In the fourth category, that is the social and health system, the information showed several areas where improvement could be made to better meet the perceived needs and capabilities of the community. Mc Donnell et al. (1994) suggested that interventions at the health facility could include developing discharge protocols and education of the PWA and their families about preventing transmission and the care of basic health problems, without incurring additional health costs.

It can be seen from the foregoing discussion that the principles of community development are firmly embedded in the assessment matrix and procedures for its use. This was important for the study as the project was a community development one and the external resources for care of PWA's were lacking. Therefore people in the community had to provide care. This made it suitable for use as the theoretical framework in the study setting.

2.9 CONCLUSION

In view of the increasing prevalence of HIV infections and the number of people living with AIDS in South Africa the social impact of the epidemic will also escalate bringing untold hardship to already struggling communities. Therefore it is imperative that a collective effort is made by government and the private sector alike, to address the problem. Although the determinants of the epidemic have been identified as being multi-faceted and these have been well documented by the Department of Health, the response to the epidemic in South Africa has been slow.

Immune deficiency often presents with a range of signs and symptoms and it may not be necessary to confirm a positive HIV test antibody result if the patient has obvious signs and symptoms of immune deficiency or AIDS. However, obtaining a definite clinical diagnosis is significant in the early stages of the disease as this would facilitate a care plan for the infected individual and a support plan for the affected family.

The literature shows that an integrated approach to community based AIDS care is essential whereby the community is guided through a learning process by participation, initiative and evaluation. Therefore it is vital that all action emanates at grassroots level and community efforts in care provision need to be acknowledged and supported at the outset. Furthermore a community development approach to AIDS care is believed to assist people in changing behaviour at their own pace thereby preventing further infections.

As the demands for health care increase with the growing AIDS epidemic in South Africa, the financial burden of health care will also increase. Delivery of essential care needs to be of high-quality to all. Care should be appropriate, cost effective and socially acceptable. This concept implies that there would need to be a precise choice of priorities among interventions, respecting the ethical principal that it may be necessary and efficient to ration services, but that it would be unacceptable to exclude whole groups of the population such as people living with AIDS.

It is important to recognize that the majority of African people have utilized traditional medicine simultaneously with modern western medicine according to their traditional

practices and beliefs in order to protect their health and treat disease. Therefore it would be incumbent upon all health care providers to respect and acknowledge these practices.

Community based health care is a valuable component of the health system when it is facilitated and managed by members of the community. Furthermore, it can contribute significantly to the prevention of disease and the promotion of health thereby lessening the burden on the formal health system.

It is clear that various models of community-base AIDS care in South Africa all have their merits. However programs are largely dependent upon on the community's needs and resources as there is no simple solution to program planning and implementation although components from each model could be adapted to meet the needs of individual communities.

The care of people with AIDS begins with assessing care provided in the home by families. Therefore it is essential to assess the level of care needed and the capacity for families to provide this care. Each of the essential factors that have been discussed is critical for an individual's well being.

Appropriate home management is imperative in order to assist the PWA's with improving their nutritional status that would delay HIV disease progression and improve the quality of life. It has been shown that disclosure of HIV-positive diagnosis can be difficult and anxiety provoking. Individuals fear the negative reactions in the form of rejection, shunning, abandonment, or fear. Therefore HIV positive people need counselling and continued psychological support that could reduce the stress associated with disclosure.

With the progression of the disease, the ability of persons with AIDS to function independently and carry out activities of daily living diminishes (Hoeman, 1996). This creates a sense of helplessness that can impact negatively on the individual. Therefore the challenge in caring for the chronically ill in the home is to encourage the individual's right to self-care. However, persons diagnosed with AIDS-dementia complex (ADC) may present with signs of cognitive, behavioural and motor disturbances and many PWA's

eventually develop some degree of cognitive motor and emotional impairment that responds favourably to counselling and therapeutic interventions. Communities with limited or inadequate basic resources such as suitable housing, adequate safe water and proper sanitation have great difficulty in coping with home care.

It is imperative that the PWA and the caregiver and families are provided with appropriate information and knowledge on the disease process, infection control, the management of common opportunistic conditions in the home and basic home nursing skills. Health information especially on managing problems related to nutrition is also very important. This knowledge base together with support will foster the level of confidence and competence that these individuals need to achieve a satisfactory quality of life.

Community care is vital in the continuum of care of people with AIDS and the key to a successful program for AIDS care is community participation. Communities have the capacity to mobilize its resources in the form of community volunteers who provide most of the home care services and play a key role in community advocacy as they are able to understand the dynamics of the community they live and serve in.

AIDS affected households have reduced coping capacity in the face of poverty and food insecurity especially when the infected individual is the only breadwinner. Caring for sick household members may further reduce the capacity to seek other food sources.

It is important to assess the level and type of needs as this information would determine the intervention strategy. Health service provision by caregivers and institutions to people with AIDS needs to be based on the principle of respect for human dignity and confidentiality must be respected at all times and basic rights observed. HIV prevention and care should be integrated into existing health and social service programs in order to reach a greater number of people. AIDS education when integrated into regular health promotion activities can assist in reducing the stigma associated with AIDS. Any existing community care services for the chronically ill need to be acknowledged as this could be useful when planning community care for PWA's. Mc Donnell et al. (1994) framework

provides a comprehensive approach to the assessment of home-based care needs for people living with AIDS.

Finally it can be concluded that a well co-ordinated social support system in the form of social services, support groups and referral systems are vital to the continuum of care of people with AIDS and their families.

CHAPTER THREE

RESEARCH METHODOLOGY

3.1 RESEARCH DESIGN

The study was a cross sectional descriptive approach using individual interviews and a focus group. The purpose of the study was to assess the Bhambayi community at the individual, family and community levels in terms of the provision of home-based care for people living with, and affected by AIDS; and to develop an action plan for an appropriate intervention.

The intention was to produce an assessment based on the community's perceptions of their needs, taking into account their strengths and weaknesses and the availability of resources. The resultant action plan would be one that would be implemented by the community.

3.2 APPLICATION OF THE THEORETICAL FRAMEWORK

3.2.1 INTRODUCTION

Home care that is provided by families and communities to their sick community members is a natural phenomenon that is practised the world over, and South Africa is no exception. However, caring for people with AIDS, within the context of epidemic proportions, demands quality care, in order to meet their specific needs. This level of care may not be within the capacity of all communities, especially those that are poorly resourced, such as Bhambayi, which is a young developing community. Therefore, it was essential that the status of the existing home-care program in Bhambayi be examined to determine its resources, limitations, processes and outcomes in the context of individual needs. (Mc Donnell et al 1994.)

It should be noted that the Mc Donnell et al. (1994) framework formed the theoretical framework for the study. Many variables determine a community's ability to cope with the

social implications of HIV/AIDS. The methodology advocated in the Mc Donnell et al. (1994) framework, uses an assessment matrix (Figure 1) for a systematic evaluation of the problems and resources with current home care. The indicators for this study were developed from the appropriate literature and these formed the conceptual framework.

The structure of the theoretical framework required that four key categories be examined to assess the community's capacity to provide care for PWA's. Each category addressed the study objectives. These categories included: HIV prevalence and awareness, perceived needs, community capability and health and social systems. Each category elicited information from the study sample and provided answers to each objective.

Although the Mc Donnell et al. (1994) assessment matrix was intended as a rapid assessment tool, it was used as a framework in this study due to the following reasons:

- People's perceptions of the phenomenon was sought to meet the objectives of the study.
- The inquiry was intended to record the views as experienced by the people.
- The inquiry required their unique perspectives on issues related to the phenomenon.
- Furthermore, quantitative data as suggested by the Mc Donnell et al. (1994) assessment matrix was not available for this community.

Prolonged contact with the community as a field worker afforded the researcher the opportunity of sharing in and observing the people first-hand.

The four key categories as recommended by the Mc Donnell et al. (1994) theoretical framework (Figure 1) will be discussed in relation to the community under study.

3.2.2 HIV PREVALENCE AND AWARENESS

In order to assess the community's perception of their susceptibility to HIV infection in relation to the magnitude of the problem, existing data from recent HIV prevalence studies were used. The community's perception of risk was elicited through interviews with persons at the individual, household and community levels, that is, the person living with AIDS, the principal family caregiver and the community leaders respectively. The community level also included a focus group discussion with a group of community volunteers currently providing home-based care in the area. Prevalence of HIV was then compared with the community's perception of risk to HIV infection. The concordance of this was then examined.

3.2.3 PERCEIVED NEEDS

The perceived needs of individuals, families and the community were examined. Interview schedule guides and a focus group discussion guide were developed using defined indicators drawn from the literature and the researcher's field experience. (Appendix 3)

3.2.3.1 The individual level

At the individual level, that is the person living with AIDS, the indicators for the interview schedule guide was guided by literature relating to rehabilitation principles and the person with AIDS (Hoeman, 1996) and the Department of Health (2001) comprehensive home/community based training manual.

The questions were developed with holistic needs in mind: the ability to care for self such as personal and environmental hygiene, the care required when ill, financial resources to meet basic needs including food, clothing, caring for family, family support, and living conditions (Hoeman, 1996). This enquiry facilitated discussion that brought the PWA's needs firmly into focus.

3.2.3.2 The household level

The indicators for the household level were guided by the comprehensive home/community based care training manual (Department of Health, 2001). This assessment was intended to determine the current ability of the family caregiver to provide care to the PWA including: financial resources and cost implications of care; the ability to meet nutritional needs; family support in the caring process; living conditions that would impact on the provision of care and the possible impact of the illness on the children of the household. This enquiry was essential to place the family caregiver's perceived needs into proper perspective.

3.2.3.3 The community level

The indicators for the community level that is , the community leaders, were guided and adapted to the research setting (Mc Donnell et. al, 1994) and comprehensive home/ community based training manual (Department of Health, 2001). This assessment was intended to determine the impact of AIDS on the community and how the provision of current home care was perceived by the community leaders. The areas of enquiry included: health concerns related to home care, the provision of care, the impact of care on children attending school, the impact of AIDS on income generating activities and sustainable employment and concerns expressed by family caregivers.

The focus group discussion indicators were guided by the comprehensive home/community based training manual (Department of Health, 2001). This assessment was intended to provide a holistic insight into the current provision of home care by community volunteers. The enquiry included: care provision for the chronically ill including PWA's, information and resources needed for AIDS home care, problems encountered in meeting the provision of home care, the type of assistance rendered to PWA's, concerns expressed by family caregivers and what would make the provision of AIDS home care easier.

3.2.4. COMMUNITY CAPABILITY

Community capability examined the Bhambayi community's organizational ability and present capacity to care for PWA's in the home. As already explained in 1.6.4.6, the researcher was

engaged in a community development project over a period of three years with the principal focus on home-based care. This enabled the researcher to engage with the relevant community structure, key informants and community members during the project process. The observations made in the course of field work and literature was used to guide the development of indicators for this level of the study. This was further guided by the literature (Department of Health, 2001 and Mc Donnell et al., 1994).

3.2.4.1. The individual level

At the individual level, that is, the person with AIDS, the enquiry included: the source of health care; managing AIDS related health problems; the contact person who can assist with health; and social concerns and assistance from community leader, community health worker, and community volunteer. This assessment was intended to provide an insight into the available resources within the community and how they were being utilised (Department of Health, 2001).

3.2.4.2. The household level

At the household level, that is, the family caregiver, the enquiry included: the source of assistance in the provision of home care, including nutritional support, accessing health care and addressing social problems and nursing care of the PWA; access to and assistance from community leaders, community health worker and community volunteer (Benjamin, 2000).

3.2.4.3 The community level

At the community level, that is, the community leaders, the enquiry included: the existence of recognised community leaders and their method of appointment; their participation in capacity building activities and responsibilities; the structure of the committee; the community's major health concerns; the existence of a health committee in Bhambayi; what is understood by HBC for PWA's and does such a program exist in Bhambayi; the activities, benefits and concerns related to the program. This assessment determined the community leaders' insight into the strengths and weaknesses of the community's capacity to care for PWA's in the home environment (Mc Donnell et al., 1994).

The focus group discussion with the community volunteers included: the motivation for becoming a volunteer and the benefits; concerns related to caring for PWA's and the community's attitude to the service being provided. This assessment provided insight into the sustainability of current home care provision and areas of weakness in the program (Benjamin, 2000).

3.2.5. HEALTH AND SOCIAL SYSTEM

The Health and social system category examined the ability of the public health system to meet the needs generated by the HIV/AIDS pandemic, including the provision of minimal health care services and community outreach support. The development of indicators for this assessment was guided by the literature (Mc Donnell et al. 1994; Department of Health, 2001).

3.2.5.1. The individual level

The individual level, that is , the person with AIDS, enquiry included: the physical ability and cost in accessing health care; the availability of counselling, health information and quality of medical care at the health facility; the process and problems experienced in accessing social welfare grants; nutritional support, support from faith- based organisations. This assessment was intended to evaluate the PWA's experiences within the health system and the available social support system in Bhambayi (Department of Health, 2001; Benjamin, 2000).

3.2.5.2. The household level

At the household level, that is the family caregiver, the enquiry included: experiences when seeking health care from the public health system for the PWA; relevant information received on the AIDS condition, concerns related to social welfare assistance, assistance received from faith based and other organisations. This assessment was intended to evaluate the support available for AIDS care provided by families in the Bhambayi community (Department of Health, 2001; Benjamin, 2000).

3.2.5.3. The community level

At the community level, that is, the community leaders, the enquiry included: problems encountered by PWA's in accessing public health care; the availability and quality of AIDS

counselling and information from health facilities; the availability of equipment for AIDS care provision, the success rate and problems experienced by PWA's and their families in accessing social welfare grants; assistance with funerals by the community; the existence of a communal garden; the provision of support from faith based organisations to PWA's and their families and the availability of any support for PWA's and their families from other organisations. This assessment was intended to evaluate the ability of the health and social systems to support the provision of home care in the Bhambayi community (Mc Donnell et al. 1994).

The focus group discussion with the volunteers enquiry included: the assistance rendered to PWA's and their families; the availability of adequate information to provide care; common problems experienced in the provision of AIDS care; support or lack thereof in care provision. This assessment was intended to evaluate the support systems available for sustainable home care provision (Department of Health, 2001).

3.2.5.4 Development of indicators

As this was a cross-sectional study, the prevalence of HIV infection and awareness of susceptibility to infection was based on the community's experience of the AIDS epidemic. The indicators for the perceived community needs for home-based AIDS care including assessing the nutritional status, psychosocial needs, home care health requirements, physical environment, and informational needs were guided by the literature (Hoeman, 1996; Green, 1999; Evian, 2000; Serovich, 2000 and Department of Health, 2001). The indicators for the assessment of community capacity and capability to provide care were lead by the principles of community development (de Beer et al. 2000; Campbell et al.2000; Monaheng, 2000). The assessment of support by health and social systems to communities within the context of AIDS was guided by the literature (WHO, 2000; Lankester, 2000; Chatora, 2003; and Samba, 2003).

3.3 STUDY SETTING

The setting in which the study was conducted was the Bhambayi community, located in the district of Inanda, in the Province of Kwa Zulu Natal (KZN). Bhambayi is a peri-urban informal settlement with a population of approximately 13,000 people. It was a young

developing community. The only formal community structure was the Bhambayi Reconstruction and Development Committee (BRDC) that was elected through a democratic process. The BRDC was responsible for co-ordinating all aspects of development in Bhambayi. Permission to conduct the study was negotiated with the BRDC.

Although development of infrastructure and provision of government housing had been under way since 2001, Bhambayi was yet to achieve township status, unlike its immediate neighbours. The history of political instability had until 2000, hindered development in the area.

A group of community health volunteers were providing rudimentary HBC for the chronically ill, including AIDS, in the Bhambayi community. These were self-motivated concerned individuals from the community, who were an essential link between the community and the formal health care system. Their functions included basic care and support of people in need, including those individuals living with AIDS. These volunteers were part of the study. A full description of the setting is provided in Chapter 1 (see 1.6).

3.4 STUDY POPULATION

As the research setting was the Bhambayi community, the population included the following groups of people in the Bhambayi community, in accordance with the Mc Donnell et al. (1994) framework: individuals living with AIDS, the principal family caregiver of the PWA's, key community leaders and a focus group of community health volunteers.

The researcher, who was engaged in a community development project in Bhambayi, that included a comprehensive HBC program, had access to the community through regular contact with its members during fieldwork. A good rapport had been established.

3.5 SAMPLING STRATEGY

The sample method, size and selection criteria in respect of each of the groups will be explained below. Four groups of study participants were selected, in accordance with the framework.

3.5.1 SAMPLING METHODS

Non-probability, convenience and purposive sampling were used. In terms of purposive sampling, the sample included a selection of typical cases and extreme cases in order to maximise information richness. The selection of people for purposive sampling were based on selecting people who would be good informants as they were known to the researcher and would be most productive. (Polit, Beck and Hungler, 2001) Consenting informants were selected from the following groups:

- individuals living with AIDS;
- principal family caregivers of these individuals;
- community leaders; and
- community health volunteers.

It was necessary to include these groups in accordance with the dictates of the framework.

3.5.2 SAMPLE SIZE

There are no firmly established criteria or rules for sample size in qualitative research. Sample size is mainly a function of the purpose of inquiry, the quality of informants used and the type of sampling strategy used. (Polit et al 2001). It is therefore not appropriate to discuss percentage of sample size.

The participants selected were those family members involved in caring for PWA's, individuals living with AIDS and concerned community leaders as they were in the best position to meet the study information needs.

A total of at least 28 participants from a population of 88 were selected to represent the different levels of the assessment matrix. This was considered manageable, given that the researcher personally conducted all the interviews and the focus group discussion.

3.5.2.1 Sample realization

A total of 5 community volunteers were selected for a focus group discussion. However, on the appointed day only 3 of the 5 participants were available. One male participant, who was also a police reservist, was summoned on urgent police business, whilst the second participant who was also a person living with AIDS, was ill and required urgent medical attention.

3.6 GROUPS OF STUDY PARTICIPANTS AND THEIR SELECTION CRITERIA

3.6.1 INDIVIDUAL LEVEL: PERSONS LIVING WITH AIDS

Participants were persons living with AIDS (PWA's) who were the home-based care program database. The first 10 consenting PWA's from the existing known population of 30 PWA's were selected by convenience sampling for individual interviews. These were the most readily available participants for this level of the study. This database was created by the researcher, who had been working on the community outreach project, over the past three years, during voluntary counselling of patients in their homes and at the drop-in centre. The database was an essential record that served to evaluate the program. The home-based care program record showed that increasing numbers of people were willing to disclose their HIV status during counselling.

3.6.1.1 Selection criteria

- The PWA was an adult person living in Bhambayi.
- The participants had voluntarily disclosed their HIV positive status and were living with full-blown AIDS.
- The PWA was in the current HBC program.

3.6.2 HOUSEHOLD LEVEL: PRINCIPAL FAMILY CAREGIVER

Participants were a principal family caregiver, (a spouse, partner, adult child, grandparent, or an elderly parent), who provided care for the PWA in the same dwelling. Ten consenting caregivers were selected by purposive sampling for individual interviews. These caregivers had the experience of actual care provided to the PWA in the study. The information yielded provided a holistic view of caring needs and resources, a critical element in the study.

3.6.2.1 Selection criteria:

- The participant resided in the same dwelling in Bhambayi as the PWA.
- The PWA being cared for was part of the sample of the PWA's in this study.
- Only one caregiver per PWA in the study was selected. (The caregiver and PWA were required to give consent or they were not included in the study.)

3.6.3 COMMUNITY LEVEL: COMMUNITY LEADERS

Participants for this level included community leaders from the BRDC executive and BRDC committee members for the three sections of the Bhambayi Settlement. A total of five community leaders from a group of twelve recognised leaders were selected by purposive sampling for individual interviews. These informants were in the best position to provide information required for this level of the study.

The five community leaders were made up as follows:

- **Two executive members of the BRDC**

The BRDC comprised of 5 executive members. Two participants were selected for the study. Bhambayi is a young developing community. The BRDC was created in 1991 to bring political stability into the area. The executive members that were selected were long serving members who have been in office for at least 3 years. They were key informants who were knowledgeable in the needs of the Bhambayi community. Another reason for selecting them was that they would have used their office to attend to health concerns and needs in their experience as community leaders.

- **Three BRDC committee members**

One committee member from 3 different sections of Bhambayi was selected. One committee member was selected from the ANC section and the second member from the IFP section of Bhambayi. As Bhambayi had grown and developed around political affiliations, it would be prudent to note that different perceptions and needs within these party political groupings existed. Furthermore, the IFP section had better housing with larger dwellings as opposed to the crowded poorly constructed dwellings in the ANC section. These differences in basic living conditions impacted on people's health and well being. The third committee member was selected from the new housing development. Experience had shown that despite the provision of improved housing, that is, from the previously informal dwellings to government housing, people's living conditions and needs did not necessarily improve. This community leader was able to provide insight into conditions and needs that could impact on people's health.

3.6.3.1 Selection criteria:

- These committee members were community leaders who had served the Bhambayi community for at least 10 years.
- They would have participated in all aspects of community development, including community conflict resolution, interaction with service providers in Bhambayi, housing development, and skills development projects.
- They had, in their capacity as community leaders, been responsible for addressing a range of community concerns including home care for the chronically ill, as demonstrated at regular meetings attended by the researcher.

3.6.4 COMMUNITY LEVEL: COMMUNITY VOLUNTEERS

There were a total of 16 active volunteers in the team providing HBC in Bhambayi. A total of five volunteers were selected by purposive sampling for a focus group discussion. These community members were recommended by the community to serve as home-based care workers.

3.6.4.1 Selection criteria:

- The participants had previously been engaged in HBC in the Bhambayi area under the auspices of the St John's Ambulance.
- They had the ability to express their concerns about health issues and needs in their provision of HBC, as demonstrated during negotiations and discussions around home-based care at community meetings.
- They were community leaders in their own right. They played a critical role in dissemination of health information to the community and their performance in the area of community advocacy, had earned them their place as community leaders.

3.6.5 IMPLEMENTATION OF THE STUDY

As AIDS is a sensitive subject and collecting data in a resource poor area can be difficult, the key factors in implementing the study are discussed below.

3.6.5.1 Establishing contact with prospective participants

The volunteer working in the area where the PWA resided facilitated this process by identifying possible participants, as they knew their charges well. This was followed by a visit from the researcher in order to introduce the study and confirm the PWA's disclosure to the family caregiver.

3.6.5.2 Assessing the PWA's mental state

Participants at the individual level, that is the person living with AIDS, needed to be assessed for soundness of mind before being selected as a study participant. Several visits were made by the researcher to assess the suitability of the PWA. Any evidence of signs of psychosis, confusion or abnormal behaviour as observed and reported by the family caregiver was noted. The researcher immediately discontinued the prospect of including the individual as a study participant.

3.6.5.3 Explaining the purpose of the study

The purpose of the study was explained with the use of the information sheets (see Appendices 9a to 12 a), that were translated into Zulu. The Zulu version of the information sheets were left with prospective participants for perusal for a few days.

3.6.5.4 Explaining issues of confidentiality

Queries regarding all aspects of confidentiality were further clarified by the researcher during subsequent visits prior to obtaining consent for the study.

3.6.5.5 Obtaining consent from PWA's

An informed consent form was translated into Zulu (see Appendix 13b) so that the participants could have a better understanding of its contents. The English version of the consent form (see Appendix 13a) was then signed for the purpose of the study.

3.6.5.6 Difficulties with implementation

The difficulties with implementation of the study are discussed below.

- Keeping appointments

Many trips had to be made to the participants' homes as they were unable to keep appointments for the interviews. PWA's had gone to the hospital or clinic for medical treatment as their condition were want to unexpectedly complicate. Furthermore, caregivers were busy with other responsibilities and several appointments had to be re-scheduled.

- Environmental conditions under which interviews were conducted

Lighting and ventilation in most homes was of poor quality. Most of the homes did not have any furniture to facilitate the administration of the interview process. The researcher improvised in most instances. Interviews were conducted in the mornings when the weather was cooler and the participants were more comfortable.

3.7 DATA COLLECTION

The data collection methods; types of instruments and their administration; and the key categories of the study are discussed below.

3.7.1 METHODS

The data was collected using the self-report method. This method yielded information that would have been difficult to gather by any other means. Furthermore, this approach allowed the researcher to ascertain what the basic issues were, how individuals conceptualised and talked about the phenomenon, and what the range of opinions were, relevant to the topic (Polit et al., 2001).

3.7.2 DESCRIPTION OF THE INSTRUMENTS

Appendix 1 shows the development of the instruments. It deals with the first 4 objectives. The fifth objective was dealt with in the data collection section and involved the determination of the action plan on the basis of the strengths, weaknesses and barriers, which had become apparent when the matrix was completed. Therefore Objectives 1, 2, 3 & 4 were used to address Objective 5 (see Appendix 2).

Appendix 1 shows how each objective was addressed independently: the conceptual framework is described, the data collection method is described, followed by the data collection tools to be used, and finally the actual interview questions that appeared on the interview schedule are indicated.

Appendix 1 thus shows how the particular items embedded in the data collection tools; address Objectives 1, 2, 3 & 4.

There are 4 separate instruments as follows:

- Interview schedules using semi-structured, open-ended questions in order to illicit discussion were developed to enable the data collection process. The interview schedule was used as a guide that ensured all relevant areas of the topic were covered. A checklist for each question was developed and this served as a guide for the researcher. The checklists are shown in Appendices 3 for the PWA, 4 for the family caregiver and 5 for the community leaders.
- The Focus Group Discussion was guided by an interview schedule that was developed containing semi-structured, open-ended questions with a checklist as shown in Appendix 6.

3.7.3 ADMINISTRATION OF THE INSTRUMENTS

The researcher personally conducted all the interviews, given the sensitive nature of the study. The researcher was able to speak Zulu fluently and did not require an interpreter. The focus group discussion was audio taped, translated and checked by a recognised translator. The translation and transcription of the data was checked by two senior academic staff members. The total time take for the individual interviews was 18 hours over a period of two months and the total time taken for the focus group discussion was two hours.

3.7.4 KEY CATEGORIES

As explained earlier in 3.2, four key categories that were guided by the Mc Donnell et al. (1994) theoretical framework were examined, using indicators developed from the literature.

3.8 PILOT STUDY

3.8.1 INTRODUCTION

A trial run of the instruments and data collection plan for the PWA's, caregivers, volunteers and community leaders was conducted with the AIDS Support Group and Community at Amaoti, Inanda, which is outside Bhambayi. This group was introduced to the researcher by the support group coordinator, whom the researcher had become acquainted with at the Inanda Health Forum monthly management meetings. The decision to conduct the pilot study in the Amaoti community was taken because the population composition, political structure and community dynamics were similar to that of the Bhambayi community.

3.8.2 STUDY PARTICIPANTS

The support group coordinator selected the participants for the pilot study. A total of eight participants were used in the study that is two people per instrument. One- on- one interviews were conducted with the PWA's, family caregivers and community leaders. A focus group discussion was conducted with two community volunteers.

3.8.3 OBTAINING CONSENT

Verbal consent for the study was obtained from the community leader and the participants after the information sheets (English version) were discussed and the study process was clarified. The participants were all literate people with a satisfactory understanding of the English language, and were therefore comfortable with the usage of English for the interview process. Written consent was not obtained as the data would not form part of the study.

3.8.4 IMPLEMENTATION OF THE INSTRUMENTS

The manner in which the questions in the interview guide had been set out resulted in the tool consisting of a number of pages. These were found to be too bulky to handle. It proved time-consuming and awkward due to the number of pages in the document. Each interview took an average of one and a half hours, instead of the allocated one hour time frame. Furthermore, the first few questions yielded a substantial amount of information that made documentation cumbersome as many of these responses belonged in different sections of the schedule.

3.8.5 RESOLVING THE TIME FACTOR

Given that these interviews were to be held in varied settings in Bhambayi, such as dwellings with conditions like poor lighting, limited space and a lack of furniture to facilitate the documentation process, the instrument needed to be redesigned to make the administrative process simpler.

The interviews were restructured using a spreadsheet format (Appendix 14), without altering neither any of the sequence or the content of the questions. This substantially reduced the number of the pages per interview schedule so that it could be handled in any environment, within the set timeframe of one hour per interview.

3.8.6 CONCLUSION

The pilot demonstrated that items in the tool were appropriate and that the participants showed no hesitation in their response, indicating their acceptability of the sensitivity of the enquiry. The changes that emanated from it improved the efficiency of the data collection.

3.9 DATA ANALYSIS PROCESS

The data was analysed whereby categories were developed based on the examination of the raw data. (These categories are not the categories used in the assessment matrix). Important themes that emerged were given a label to clearly reflect the nature of the material. All of the data was reviewed for content and coded for correspondence.

3.10 FEASIBILITY OF THE STUDY

As HIV/AIDS is a sensitive subject, all the individual interviews and the focus group discussion was conducted by the researcher using the face-to-face method, with no other person present, to maintain absolute confidentiality.

3.11 CREDIBILITY OF THE STUDY

Data was collected from multiple sources in this study. Interviews were conducted with diverse key informants about the same topic, also known as source triangulation (Polit et al. 2001). External checks of the data were done, whereby feedback was provided to the study participants regarding preliminary findings and interpretations after the data was collected and analysed.

3.12 DEPENDIBILITY OF THE STUDY

An enquiry audit was conducted whereby the study supervisor, with the relevant supporting documentation scrutinized the data. An audit trail was developed that allowed an independent auditor to come to conclusions about the data. These records included: raw data (interview transcripts), instrument development information (pilot forms), data reduction and analysis (notes from member check sessions), materials related to interviews and dispositions (personal notes on interviews), and data reconstruction products (drafts of final report). (Polit et al., 2001)

3.13 ETHICAL CONSIDERATIONS

The following ethical principles of research as suggested by (Polit et al., 2001) was addressed, namely the principle of beneficence, respect for human dignity and the principle of justice.

3.13.1 THE PRINCIPLE OF BENEFICENCE

The researcher is a professional nurse, who was a full time field worker in Bhambayi. She consulted with the community leaders, outlining the need for a community assessment in the provision of home-based care for people with AIDS and the potential of the study findings to assist with planning and implementation of a HBC program. She also reassured the participants that the information they provide will not be used against them. The input of the persons living with AIDS was completely confidential. Interviews were conducted at a time and place at the participant's convenience to prevent psychological harm. Furthermore, they were reassured of continued assistance from the program, regardless of the outcomes of the interview. They were also reassured that they were free to discontinue the interview should they feel any discomfort. All participants were informed of the time commitment required. Should the time be insufficient to complete the data collection, consent would be renegotiated to prevent exploitation.

3.13.2 THE PRINCIPLE OF HUMAN DIGNITY

There was no coercion to participate in the study. Full disclosure was achieved by the information sheets for all the prospective participants, in order to obtain informed consent. (See Appendices 9 to 12.)

3.13.3 THE PRINCIPLE OF JUSTICE

Due to the sensitive nature of the study, confidentiality was observed by:

- Only the researcher conducted the interview.
- The interview response sheets were coded, no names appeared on the sheets.
- Names of participants did not appear in any form on the audiotapes.
- The final report did not bear names that can identify participants in any way. Pseudonyms were used when reporting qualitative data.
- The research findings were shared with the participants for comment before the final report is written.

CHAPTER FOUR

DATA ANALYSIS

4.1. INTRODUCTION

As this study was on a relatively new area of research, and it was important to capture the experience of the people living it, the qualitative data was collected using the self-report method. This method yielded information that would have been difficult to gather by any other means. Furthermore, this approach allowed the researcher to ascertain what the basic issues were, how individuals conceptualised and talked about the phenomenon, and what the range of opinions were, relevant to the topic. (Polit et al. 2001)

In this chapter the data for each objective for the three levels of the community according to the assessment matrix has been provided. The data has been analyzed and organized into categories within themes. Quotes are used to provide supportive evidence for interpretation of important categories. Square brackets -[]- are used to explain Zulu words for example 'putu' and 'donga' and round brackets - ()- are used to indicate words that have been added in to make quotes more understanding. Summary figures are presented for each level and category of the matrix. Symbols are listed within figures 4.1 to 4.4 to indicate the frequency with which the comment or point occurred to show commonalities and differences.

Tables (4.1 to 4.4) are provided at the end of each objective, giving a summary and comparison of themes and categories in relation to the level of the framework. They highlight the commonalities and differences in each category.

The original interviews and the transcripts for the focus group discussion are provided in a separately bound document and as an appendix (14 a and 14 b) respectively, for purposes of the audit trail.

4.2. DATA ANALYSIS FOR OBJECTIVE 1:

To determine the concordance between the prevalence of HIV/AIDS and the community's awareness of their susceptibility to HIV infection

The purpose of this objective was to understand the magnitude of the problem and the community's perception of their vulnerability to HIV/AIDS. This required a comparison of the actual situation that is the known prevalence, to the community's perception, in order to establish whether there was concordance between the two.

The actual quantitative assessment of the prevalence was drawn from an external source and the Bhambayi project (see 1.5.3). A brief summary of these findings for the quantitative assessment is presented in 4.2.1.

The community perception was determined by asking the broad question of "how serious is the problem". The responses to the question were analyzed and three themes emerged:

- The magnitude of the problem, based on their knowledge of events in the community;
- The impact on the people, as experienced by the participants and
- The susceptibility to infection.

These findings are presented in 4.2.2 to 4.2.5.

4.2.1. QUANTITATIVE ASSESSMENT OF PREVALENCE

Projections made using the ASSA600 (Actuarial Society of South Africa) model estimated that a total of 6.5 million people were infected with HIV/AIDS and that Kwa Zulu Natal accounted for 27% of the infections (Dorrington et al, 2002). Furthermore, in 2002 Kwa Zulu Natal recorded the highest HIV prevalence rate of 36. 5% according to the national HIV Sero-Prevalence survey among public antenatal clinic attendees (Department of health, 2002). A baseline survey, using UNAIDS guidelines to assist in

making an unorthodox diagnosis of HIV/AIDS that was conducted by the researcher in Bhambayi, found that 28.5% of the sample could possibly be infected with HIV/AIDS (Benjamin, 2000). Therefore it can be concluded that the prevalence for this community is high, probably in the region of at least 25%.

4.2.2. INDIVIDUAL LEVEL:PEOPLE LIVING WITH AIDS

This section of the study sought to determine the magnitude of the problem in Bhambayi. It describes the possible reasons for the high infection rate as perceived by the participants living with the disease. The impact of the disease was described by the participants from their personal experiences and from observation of other community members living with AIDS in Bhambayi.

Theme 1: The magnitude of the problem

The participants all felt that that HIV/AIDS was a serious problem. They had come to this conclusion because of their knowledge and their observations of events and behavior in their community. They expressed their concern as follows:

- **Number of possible AIDS- related deaths**

All the study participants described the large numbers of young people, aged 20-49 years with HIV and dying of AIDS in Bhambayi.

“...there are at least 5-10 funerals a week in Bhambayi.”

- **Disclosure of HIV status only before death**

Non-disclosure of an HIV positive status was the norm, as people are afraid of isolation, losing everything including their home and family. One PWA, a mother of a set of teenaged twins, described how her friends aged over forty years, disclosed their status to her, just before death.

“....my friends were very sick and I used to visit themthey only told me that they were HIV positive, just before they died....this is what made me to go for a test.”

- **The power of observation, indicates the possibility of HIV infection**

Some participants had observed people in the community losing weight rapidly. A once healthy individual with no known illness, who suddenly became gravely ill, showing signs of obvious weight loss and was secretive about their illness, was seen as a person who could possibly have AIDS. These signs and symptoms of advanced HIV disease are true to the clinical description (see 2.3.4).

“.....a person can drop from a size 40 dress to a size 34 in less than 6 months, shows that this person could have AIDS.”

PWA's also expressed their concern about the incidence of young women afflicted by ongoing illness after their first pregnancy and the subsequent loss of the first child. In their view, this could be attributed to AIDS.

“.....many young schoolgirls get very sick after the first baby. The baby also dies. The girls do not get better. Maybe they have AIDS.”

- **TB, a more acceptable diagnosis**

PWA's have difficulty in discussing their illness. The most common explanation offered was TB, as this was known to be more acceptable in the community. However, with the increasing number of deaths from TB, they were less inclined to believe this explanation from someone whose health was deteriorating, despite being on treatment. Their assumption was that the individual could have AIDS, as the people knew that TB is curable from the health information available.

“.....people just say they have TB.... but they die so quickly.....we know TB can be cured.....it must be AIDS that the person has.”

Theme 2: Impact of AIDS

- **Impact on a young mother**

The impact of AIDS on a young educated mother, who enjoyed family support and was fortunate to be included in an anti retroviral treatment program, speaks volumes.

“....AIDS has robbed me of my youth, of my life.”

The findings indicated that all the participants expressed their concern at the number of people dying of AIDS, the belief that non disclosure was a norm and that TB was a more acceptable diagnosis in the community than AIDS. Some participants were able to identify people who could be infected by describing some of the more obvious physical signs of AIDS. One young participant expressed her despair at being infected and another individual described the disclosure by a dying friend that inspired her to be tested for HIV. An older participant, who was a resident in Bhambayi for at least 20 years, had observed young women either becoming ill and never recovering after their first pregnancy or dying within five years of getting ill.

Theme 3: Awareness of susceptibility to HIV infection

The participants described the possible reasons for the spread of HIV infection. All the participants believed that multiple partners were taken for purposes of survival, citing unemployment as a major reason. Some participants believed that women who had many children from different partners were reliant on the government child support grant but this also made them vulnerable to HIV infection. The only male participant in the study said that men took many partners as a show of strength and these men did not care if they infected their partners. Some participants believed that younger women appeared to favor older men as partners who could meet their financial and material needs but were also at risk of being infected. Most participants believed that prostitution was a major contributing factor to the spread of AIDS.

Some participants believed that poor moral values such as men deliberately infecting their partners under the influence of substance abuse, were further contributing factors to the spread of AIDS in the community. Other participants felt that environmental factors, such as overcrowding and the lack of privacy, resulting in the exposure of young children to inappropriate sexual behavior had increased the incidence of rape. One participant believed that the myth of virgin sex as a cure for AIDS placed young females at risk of HIV infection. Another participant cited the location of 'shebeens' within clusters of houses as a contributing factor to women being raped by drunken men. One participant believed that AIDS awareness campaigns were of no value as people did not attend them.

The participants described their awareness of their susceptibility to infection as follows:

- **Multiple partners taken for survival**

The high unemployment rate and the consequent socio- economic struggle for survival were factors that contributed to women of all ages taking multiple partners. These women hoped to be financially supported by their partners. This practice was cited as the main reason for the spread of AIDS, as women had no way of knowing whether the men were free of any disease.

“.....we look for jobs, but there are no jobs.”

“.....women have many partners....they think that it is better as they can get some money to live. But as a woman, you do not know who is clean. A person can get AIDS easily.”

Having many children from different partners was also felt to be a way of survival, as women were able to access the government child support grant and this became their sole source of income.

“.....people have many babies because of this grant for children.”

- **Younger women and older partners**

The older women in the study believed that younger women preferred older men as partners, as they were seen to be more financially stable, and were in a position to meet their needs. As the vast majority of school leavers were unemployed, this was a common practice among the youth.

“.....these young girls go with older men because they have money. They will do anything for money for food, drink and good times. The next thing you hear is that these young girls are sick, and maybe this older man’s previous girlfriend has died. This can only be AIDS.”

- **Moral issues**

Most of the participants believed that the disease was spreading fast in Bhambayi and that people did not care enough about the AIDS pandemic. People who knew their HIV positive status did not care and deliberately spread the disease. Young people, whose parents could be infected and had no source of income, were said to indulge in amoral behavior such as prostitution, just to survive. AIDS awareness campaigns were said to be poorly attended and the participants felt that they were of little value.

“.....this disease is spreading fastpeople can know that they are HIV positive, but sleep around anyway. They are spreading the disease on purpose. People don’t care enough about others.’

“.....these young ones, whose parents are sick and unemployed, just do anything for money, like selling their bodies for some food and clothes.”

“.....AIDS campaigns do not help. We are fed up. Most people don’t care about such things.”

- **Behaviour**

PWA's felt that men took many partners as a show of strength and to prove their manhood. They also behaved badly when overcome by drug and alcohol abuse. They did not care how they treated their partners.

“.....our men do not care how they treat their partners when they drink and smoke ‘dagga’ [cannabis]. They have many women to show how strong they are.”

- **Prostitution and AIDS**

PWA's believed that prostitution was a major contributing factor to the spread of HIV. They believed that poverty had driven many women of all ages into prostitution.

“.....prostitution is easy money. Once started, it is difficult to stop. Women can get money for food, clothes and toiletries in this way.....some known prostitutes have died from this HIV....they got very thin and were very sick for a long time.”

- **Environmental factors**

The living conditions of the majority of the Bhambayi community, was one of overcrowding. A total lack of privacy was cause for concern, as it was believed that children were subjected to witnessing adult sexual behavior at an early age. This exposure was believed to be a major factor in the increased incidence of rape in the community.

“....the houses are too small and some adults don't care how they behave in front of the children. the children see everything at a young age....many children have been raped in Bhambayi.”

‘Shebeens’ are places where mainly men and women gather and drink. These places are in abundance in Bhambayi. They are mainly situated amongst the closely clustered homes and are easily accessible to young women. The behavior of men under the influence of alcohol was cited as a possible cause for the high infection rate in Bhambayi.

“....a person can easily get raped, even if you are going outside to the toilet at night. The ‘shebeen’ is just behind the house and there are many drunken men looking for young girls.”

- **Rape : a virgin cure**

The myth that AIDS can be cured by having sexual intercourse with a virgin was a serious concern in the community.

“.....men don’t care what they dothey will even sleep with a young child, thinking that they can be cured of AIDS.”

Figure 4.1 below shows the data summarized for the perceptions of the person with AIDS with regard to the prevalence of HIV/AIDS and awareness of susceptibility to HIV infection. The symbols ‘■’ (greater than five) and ‘▲’ (less than five) indicate the number of participants that held a particular view. Commonly held opinions are depicted in bold to highlight their significance.

Conclusion

All the participants strongly believed that AIDS was a serious problem in Bhambayi. Their ability to describe the possible reasons for the spread of infection indicated their awareness of the risks to HIV infection. The PWA’s were not required to furnish the total number of people infected with HIV. However, they clearly indicated that they were aware of the seriousness of the problem and the high susceptibility to HIV infection in the community.

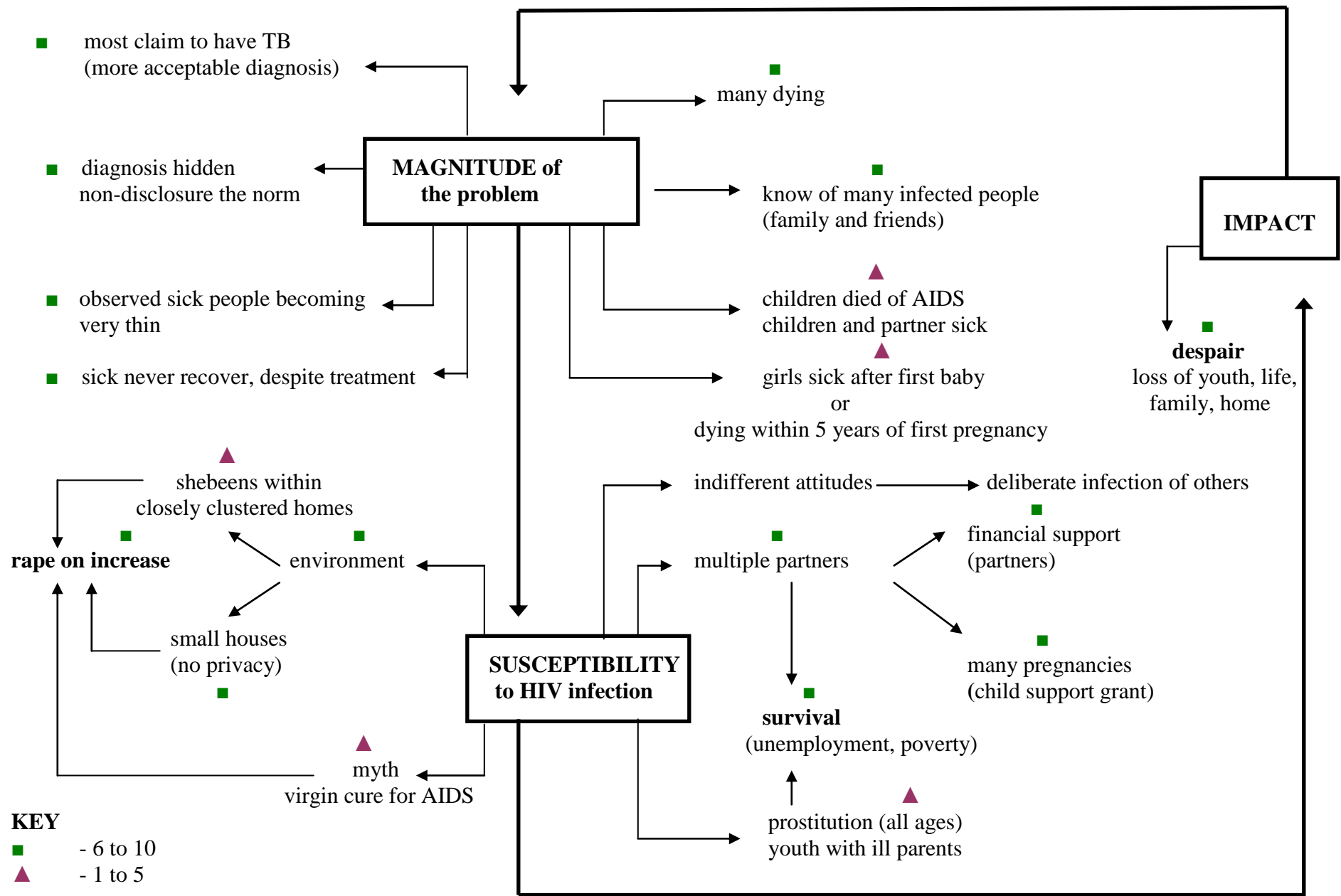


Figure 4.1: Perceptions of PWA's in respect of prevalence to HIV/AIDS and awareness of susceptibility to HIV infection

4.2.3 HOUSEHOLD LEVEL: FAMILY CAREGIVER

The magnitude of the problem in Bhambayi is outlined at this level of the study by describing the possible reasons for the high infection rate, as perceived by the participants caring for a family member infected with HIV and living with full blown AIDS. The impact of the disease was described by the participants from their personal experiences and from observation of other community members living with AIDS in Bhambayi.

Theme 1: Magnitude of the problem

The participants all felt that that HIV/AIDS was a serious problem. They had come to this conclusion because of their knowledge and their observations of events and behavior in their community. They expressed their concern as follows:

- **Number of possible AIDS –related deaths**

All the participants described the large numbers of people young people with young children dying in the community.

“....many young people are dyingleaving their young children.”

There were as many as five to ten funerals a week in Bhambayi and the participants believed that the death rate appeared to be worse than the time of political unrest in Bhambayi.

“.....there are many funerals every week in Bhambayi....sometimes five or ten....people are just dying...worse than the time of political unrest.”

They further indicated that they were tired of attending funerals.

“....we are tired of attending too many funerals.”

- **The power of observation, indicates the possibility of HIV infection**

The participants had observed people in the community who were previously healthy individuals, rapidly lose a considerable amount of weight in a short period of time and become gravely ill, never to recover. They believed that these individuals could possibly have AIDS.

“....we can see some people getting very thin and very sick and then they die ...sometimes a person can be wearing a size 34 dress, whereas she used to be fat and was wearing a size 40...this must be AIDS.”

All the participants expressed their despair at the number of people dying of AIDS in Bhambayi, and that they were tired of attending funerals. Many of the caregivers had experienced personal loss from the death of close family members to AIDS, in the past 5 years. Most of the participants were able to identify people who could be infected by describing some of the more obvious physical signs of AIDS. Many participants expressed their anguish at the fact that to their knowledge there was neither a cure nor treatment for AIDS and perceived AIDS as a death sentence, because the sick never seem to recover.

Theme 2: Impact of AIDS

The caregivers described the impact of AIDS in the community as follows:

- **Personal loss**

Many participants had experienced the personal loss of immediate family to AIDS.

“....this sickness is very painful to me....my daughter and her baby died of this AIDS....what can I do.”

- **AIDS perceived as a death sentence**

Participants expressed their frustration in the belief that there was neither an effective cure nor treatment for AIDS. They had observed ill people whose conditions had rapidly deteriorated over a short period of time and subsequently died prematurely.

“...it is no use...there is no cure ...no treatment for AIDS...people just die from this sickness.”

- **Stress on elderly parents**

Several concerns were raised by the family caregivers, as a consequence of the high infection rate including the fact that far too many young people were dying of AIDS and that their education and jobs were wasted by AIDS. Furthermore, children became orphaned at an early age and the burden of orphan care was carried by aging grandparents. The caregivers found it stressful to witness grandparents struggle to raise these children. These experiences are true to the psychological impact of AIDS care on families (see 2.6.2)

“.....also there are too many orphans these days....the grandmothers are suffering to look after these children....there is no help for them....it is painful to see this.”

- **AIDS robs people of their dreams for a better life**

“....I am so worried...people suffer for education and get jobs...but it this is all wasted by AIDS.”

Theme 3: Awareness of susceptibility to HIV infection

All the participants were able to describe the possible reasons for the spread of HIV infection. They described their awareness of the community's susceptibility to infection as follows:

- **Multiple partners taken for survival**

The high unemployment rate and the consequent socio economic struggle for survival were factors that contributed to women of all ages taking multiple partners. These women hoped to be financially supported by their partners.

“....we look for work....there are no jobs....women have many partners...for money to live....maybe these partners can give them some money.”

Having many partners also implied that women had many children in the belief that they could earn an income from the government child support grant.

“.....women have many children...they think they can get some grant for these children....but the money...it is so small.”

- **Prostitution**

The participants also believed that unemployment also drove many women to prostitution. They indicated that younger women were more inclined to take on older partners who were seen as having greater financial stability thereby having the ability meet their material needs.

“....many women in Bhambayi are prostitutes....they are unemployed....young girls like to go with older men....they maybe have more money...it is easy to get AIDS like this.”

- **Failure to disclose HIV status**

The participants were of the belief that the rapid spread of HIV infection could be attributed to the fact that infected individuals failed to disclose their status, as they were afraid of stigmatization and isolation by their families and the community. They continued to engage in risky behavior and infect their partners. Many affected families have to cope with isolation when caring for an ill family member (see 2.6.2).

“....people do not talk about this disease....they think they can be chased away by their families....and what will the people say....where will they go?”

- **Stigmatization being circumvented**

PWA's hid their HIV diagnosis by saying that they were infected with TB instead, as TB was found to be a more acceptable diagnosis in the community. This was to avoid being subjected to harsh treatment by community members. PWA's were reported to have disappeared without a trace after disclosure, as they could have been evicted by an unsympathetic landlord or asked to leave the family home by their family members, as their deteriorating illness did not allow them to work and contribute to the family income.

“....people just hide this disease.if they talk about it, they can be chased away...some sick people have left Bhambayi...nobody knows if they are alive or what happened to them.”

“....people with AIDS just say they have TB...it is OK to have TB... nobody can treat you badlybut they never get better...TB can be cured...I know this...they say so on the radio and in the clinic.”

“....a person with AIDS can be chased away from her home...she is not working and has no money for food and rent.”

- **Moral issues**

The participants believed the high infection rate could also be due to poor moral behavior, by the fact that men did not believe that AIDS is spread by sexual contact as they refused to wear condoms; women could not compel men to use condoms as this would end the relationship and any financial support from partners. Furthermore the participants knew of men who were taxi drivers and long distance truck drivers who apparently had many partners elsewhere and that these men were possibly infected with HIV, given their current state of health. The participants further alleged that people did not care about AIDS and had bad attitudes about the disease. They also felt that it was

unacceptable that children were often subjected to sexual adult behaviour in their overcrowded homes.

“....men don’t care what they do....they can never wear a condom....they believe you cannot get AIDS through sex....a woman cannot force a man to wear a condom....he will just leave her and she will have nothing...no money, no food...sometimes no place to stay.”

“.....these taxi drivers and truck drivers spread the disease...they are sick....their partners are sick....they have women everywhere.

- **Environment**

The participants were of the view that the limited living space and the lack of privacy contributed to children being exposed to adult sexual behaviour and child rape was not uncommon.

“....our houses are too small and adults behave anyhow in front of children.”

Rape and AIDS

The participants believed that the incidence of rape was common in Bhambayi. This was cited as a contributing factor to the spread of HIV infection.

“....we hear about many young girls and children being raped in Bhambayi...this can also make this HIV spread faster.”

Sexually transmitted infections (STI’s) and AIDS

The participants alleged that STI’s were common in the community, but people did not seek treatment for this problem, as they were of the belief that STI’s could not be cured. The failure to seek appropriate health care for STI’s was understood as being a cause for concern as infected individuals were more prone to HIV infection. Therefore it is important to combine care with education and prevention strategies (see 2.6.4.3).

“....people do not care about STD’sthey think that it cannot be cured...but I know that a person can get AIDS easily if they have STD’s and do not get some treatment.”

All the caregivers believed that multiple partners were taken for purposes of survival, citing poverty and unemployment as the foremost reason. This made individuals more vulnerable to infection as women were powerless to negotiate safe sex practices with their partners. Furthermore one caregiver believed that people did not care about AIDS and that men did not believe that AIDS was spread by sexual contact. All the participants alleged that the failure to disclose an HIV positive status by infected individuals was the source of the rapid spread of infection.

All the participants felt that infected individuals explained their condition with the false diagnosis of TB which was more acceptable by the community in order to avoid isolation from their families and by the community. One caregiver believed that the incidence of rape had increased in Bhambayi and this was a further contributing factor to the spread of infection. Another caregiver was of the belief that the failure to seek medical intervention for sexually transmitted infections made individuals more prone to HIV infection.

Figure 4.2 below shows the data summarized for the perceptions of the family caregivers of people living with AIDS, regarding the prevalence of HIV/AIDS within Bhambayi and the awareness of the community’s susceptibility to HIV infection. The symbols ‘■’ (greater than five) and ‘▲’ (less than five) indicate the number of participants that held a particular view. Commonly held opinions are depicted in bold to highlight their significance.

Conclusion

All the caregivers strongly believed that AIDS was a serious problem in Bhambayi. Their ability to describe the possible reasons for the spread of infection indicated their awareness of their vulnerability to HIV infection. Some of the probable causes for the spread of HIV infection cited by the participants included the high unemployment rate with the consequent socio economic struggle for survival, the risky behavior of individuals, the fear of stigmatization and isolation and the consequent failure of individuals to disclose their HIV positive status. Other issues mentioned were the belief that there was a high incidence of rape in the community and that people failed to seek health care for sexually transmitted infections which made women and girls more susceptible to HIV infection.

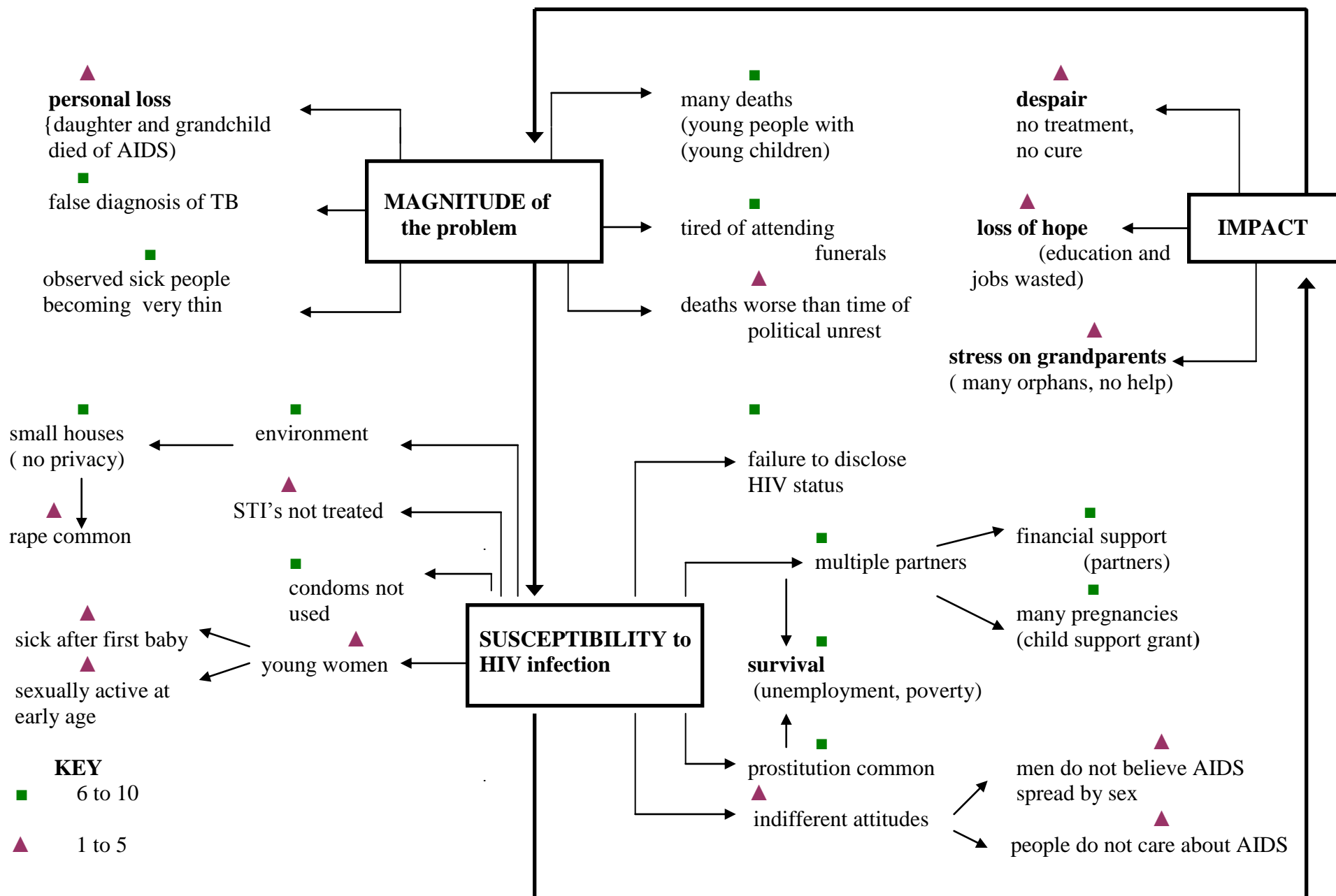


Figure 4. 2: Perceptions of family caregivers in respect of prevalence to HIV/AIDS and awareness of susceptibility to HIV infection

4.2.4. COMMUNITY LEVEL: COMMUNITY LEADERS

This level of the study describes the possible reasons for the high infection rate as perceived by the community leaders. The impact of the disease was described by the participants from their personal experiences and from observation of other community members living with AIDS in Bhambayi. Together, these assist with determining the magnitude of the problem in Bhambayi.

Theme 1: Magnitude of the problem

The community leaders described the seriousness of the AIDS problem as follows:

- **AIDS perceived as the highest cause of death**

All the community leaders believed that AIDS was a very serious problem in Bhambayi and that the epidemic was becoming worse. They perceived the disease as being the highest cause of death as determined by the number of funerals of people that could have died of AIDS related conditions.

“.....AIDS is a serious problem in Bhambayi....many people are dying from this disease....there are at least 5-10 funerals a week in Bhambayi....you can say that AIDS is the highest cause of death these days.”

- **Mainly youth affected – risky behaviour**

Their concern was that mainly the youth were affected and they believed that this was mainly due to risky behavior as condoms were not used by young men aged between 18 - 30 years old. They further attributed this behavior to normal sexual experimentation.

“.....it is mainly the youth that are affected.....they are careless with their lives....young men aged 18-30 years do not use condoms....also there is the usual sexual experimentation among the youth.”

- **AIDS education poorly attended**

According to one participant, who was actively involved in youth developmental issues, the youth had access to more AIDS information than five years ago. However, AIDS education was perceived as boring to the youth of Bhambayi and it was reported that awareness campaigns were poorly attended.

“.....there is no excuse for this careless lifestyle....the youth have more AIDS information today than five years ago....AIDS awareness campaigns are not well attended by the youth.....they feel it is boring.”

All the community leaders believed that AIDS was a serious problem in Bhambayi and that in their view the epidemic was becoming worse, with many funerals a week. One participant, who was actively involved in youth developmental issues, believed that the youth were the most affected by the AIDS epidemic, as they indulged in risky behavior and that AIDS awareness campaigns were poorly attended.

Theme 2: Impact

The community leaders described the impact of AIDS in the community as follows:

- **Breakdown in family life**

The lack of space also contributed to children being sent away to the extended families in the rural areas to be raised, whilst parents lived in Bhambayi and worked in the surrounding areas.

“.....we have to send our children away to the farm to our families to be raised....without sufficient space there is nothing we can do.....sometimes we never see our teenaged children again....the next thing you hear is that a daughter has left school and is pregnant or a child is very ill. This is very painful for our people....we have no choice...we have to work....most jobs are around the cities.”

- **Retention of jobs despite illness**

The majority of the Bhambayi population were said to be unskilled casual laborers who worked on a temporary basis for a meager income with no benefits. They were therefore compelled to retain their jobs until late into the illness in order to survive.

“.....very ill people with AIDS continue working until the end....they have no choice....they have no other wayif there is no income, their families will starve and be evicted from their home.”

- **The struggle for survival**

The high unemployment rate was attributed to the rapid rural movement of people from the rural to the urban areas in search of employment. According to the participants many people were unskilled and did not possess correct identity documentation which prevented them from obtaining suitable employment.

“.....many people have moved to Bhambayi from the rural areas, expecting to find employment.....they do not have skills and proper identity documents....they work mostly as laborers and domestic workers....some women get as little as R10 a day....it is too difficult.”

An individual could be dismissed for reasons of absenteeism due to ill health.

“.....most people in the community are unemployed....if they are sick and stay away from work, they are dismissed....employers do not care about what happens to the person....people in Bhambayi work mainly as casual workers with no benefits.”

- **Reduction in income generating activities**

The participants believed that mainly infected men were affected. They had difficulty in engaging in physical labour, especially those in the building trade, as they experienced a reduction in body strength with the progression of the disease. Therefore affected families

in this under resourced community experienced overwhelming financial insecurity (see 2.6.2).

“.....it is mainly the men who cannot continue working.....once this disease gets worse; they have no strength....especially those in the building trade.”

Theme 3: Awareness of susceptibility to HIV infection.

All the participants believed that the culture of non disclosure was the main contributory factor to the rampant spread of HIV infection in the community. The community leaders described their awareness of susceptibility to HIV infection in the community as follows:

All the participants believed that the level of poverty in Bhambayi and its consequent socio-economic ills resulted in the community's engagement in risky behavior in their struggle for survival. All the participants alleged that prostitution was common in Bhambayi and that there were as many as 20-30 families that could be involved. Two participants cited that women became sexually active at a younger age which made them easily vulnerable to HIV infection. Three participants alleged that many women took multiple partners for financial support and this practice made them more at risk of being infected. One community leader alleged that traditional practices such as dietary restrictions, were not observed by urban women and this led to young women becoming sexually active at a young age, resulting in promiscuous behavior, acquiring sexually transmitted diseases and unplanned pregnancies. Three participants were of the belief that amoral conduct by men who deliberately infected their partners, further contributed to the rapid spread of HIV in the community. All the participants attributed the poor living conditions and the lack of privacy to children being exposed to adult sexual behavior. Three participants alleged that the abuse of illegal drugs and alcohol caused people behave irresponsibly that resulted in women and children being raped and this had contributed to the increasing number of women and children being infected.

- **The culture of non-disclosure**

According to the community leaders, the people were not inclined to disclose their HIV positive status to their partners and families, as AIDS was perceived as a highly sensitive issue and people had difficulty in talking about the condition.

“.....this is a sensitive subject....people find it difficult to disclose their statusyou never know what can happen to the person after disclosure....they can lose everything...”

- **Prostitution to overcome a life of poverty**

The participants believed that prostitution was a way to make easy money and people did not pay much attention to the risks of contracting HIV infection. Many women engaged in prostitution as a means to overcome the cycle of poverty.

“.....prostitution is common in Bhambayi....there are at least 20-30 known families who do this thing for a living....they don't care about getting HIV...just as long as they can make money to live.....it is easy money for them....many of the women work in Durban.”

- **Women become sexually active at a young age**

It was alleged that women became sexually active at a young age and appeared to prefer older men who were financially stable, as their partners. These young women depended on their sexuality to sustain a lifestyle of sufficient money for the necessities in life such as clothing and food.

“.....women are sexually active at a very young agemany young women have older men as their partners....they can support them with money, for food and clothing better than the younger men.”

- **Multiple partners**

It was common practice to find that women took on multiple partners for financial support and this increased the risk of possible HIV infection.

“.....most women usually have many partners....the women get easily infected with HIV in this way.”

- **Belief systems**

One elderly female community leader believed that traditional practices and customs were neglected within the Bhambayi community. She explained that according to African custom, female sexuality is understood to be influenced and controlled by dietary restrictions. Foods such as eggs, cheese and sheep offal was believed to stimulate sexual arousal. It was alleged that failure to observe these practices, encouraged promiscuous behavior in young girls and this made them vulnerable to HIV infection.

“....these days young girls become sexually active at a very young age....they just eat any type of foods these days....foods such as eggs, cheese and sheep offal should not be eaten by young girls....this makes them to be easily sexually aroused....they end up just wanting to be with a man all the time....they fall pregnant at an early age and get STD's easily.”

- **Moral issues**

The community leaders alleged that people did not care about deliberately infecting their partners. There were instances of men who were known to have had multiple partners, many of whom were young women that had died from debilitating conditions that could have been AIDS related. These men continued to take new partners, despite having a history of spreading the disease. It was believed that men of influence with financial resources had a tendency of behaving in this manner.

“.....people really don't care about infecting their partners....it is well known that men with money behave in this way....they could have lost many partners to serious illness such as TB and AIDS, but they continue to have new women....infecting them also.”

- **Child abuse**

The participants were gravely concerned by the apparent disregard by some adults who behaved irresponsibly, as they exposed their young children to adult sexual activity.

These individuals were usually under the influence of alcohol and drugs.

“.....some adults who drink and use ‘dagga’ just do anything in front of their children....we have heard many complaints from community members.....children are said to witness sexual acts by the adultsthis is bad for our children.”

- **Rape on the increase**

The participants also believed that the incidence of child abuse and rape had increased in Bhambayi, as these incidents came to their attention as community leaders.

“.....there are more cases of rape and child abuses than previously....many cases have come to the attention of the leadership....we have to watch our children very closely.”

- **Living conditions**

The participants believed that people had no privacy in their homes due to overcrowding in the confined living space in the small formal and informal houses. Furthermore the standard of living was believed to be poor as there was little opportunity for normal family life. People were compelled to utilize a single space for food preparation, sleeping and other activities of daily living

“.....these houses are too small.....we have to use the same room for cooking, eating and sleeping.....parents cannot even talk to each other in private.....this is a problem for all the people living here.”

- **Illegal drugs contributes to irresponsible behaviour**

As the Bhambayi population was of a transient nature, the constant movement of people was difficult to monitor. This situation had been capitalized upon by foreigners who had set up a thriving trade in illegal drugs. According to one participant, the illegal drug trade in Bhambayi had been a common activity for the past twenty years.

“....it is well known that there is plenty of illegal drug dealing in Bhambayi. It has been going on for the past twenty years. It first started with ‘dagga’ from the Transkei. Now there are other drugs that these foreigners are selling.”

This activity was believed to be a major source of income for many members of the community.

“....many people are earning money from dealing in drugs. They seem be better off than most people in Bhambayi....nobody can stop them.”

The abuse of illegal drugs caused people to behave irresponsibly that resulted in women and children being raped.

“..... these men who smoke ‘dagga’ and drink alcohol at same time are the ones that rape our women and children.”

The trade was organized and run by foreigners and this activity was believed to be disruptive to the development of the community as it was alleged that there was an increase in substance abuse among the community members.

“.....these drug dealers cause many problems in Bhambayi....there are many people using these drugs....and some have even died from disputes over money from drugs. We simply stay away from such issues because it will cause more problems for the community. Service providers are afraid to work in the community because you do not always know who is a drug dealer.”

Figure 4.3 below shows the data summarized for the perceptions of community leaders in Bhambayi, in relation to the prevalence of HIV/AIDS and the community’s awareness of susceptibility to HIV infection. The symbols ‘■’ (greater than five) and ‘▲’ (less than five) indicate the number of participants that held a particular view. Commonly held opinions are depicted in bold to highlight their significance.

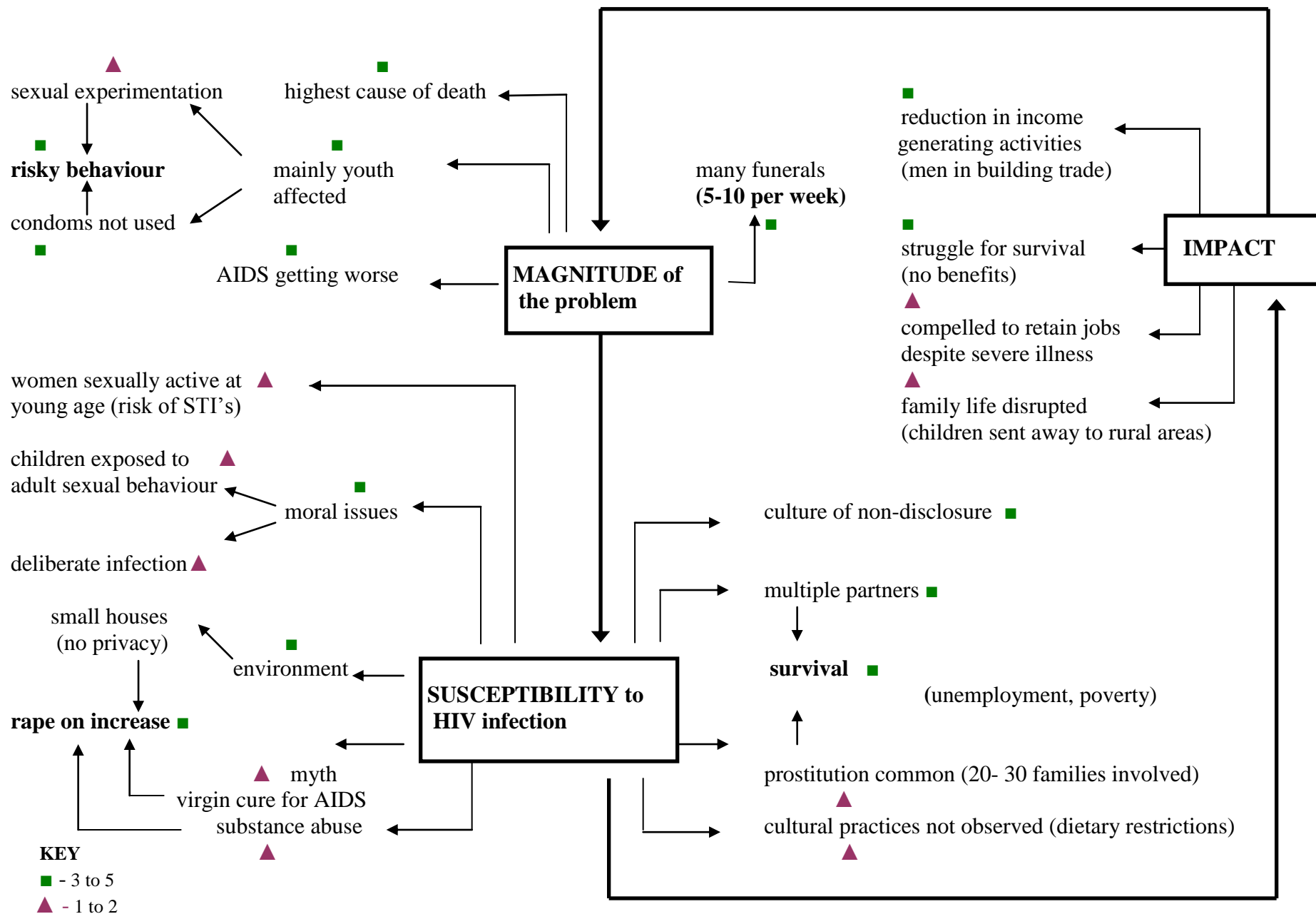


Figure 4. 3: Perceptions of community leaders in respect of prevalence to HIV/AIDS and awareness of susceptibility to HIV infection

Conclusion

The study found that the participants were able to describe the possible socio economic and psychosocial causes of the increasing infection rate. Some of the probable causes for the spread of HIV infection as cited by the participants included the culture of non-disclosure; the high unemployment rate with the consequent struggle for survival; the myth that virgin sex is a cure for AIDS; the failure to observe customary practices by urban populations and restricted living space that contributed to improper adult behavior. The participants further alleged that substance abuse caused people to behave irresponsibly that resulted in women and children being raped and this had contributed to the increasing number of women and children being infected.

4.2.5. COMMUNITY LEVEL: COMMUNITY VOLUNTEERS

The magnitude of the problem in Bhambayi is described from another community perspective. This level of the study describes the possible reasons for the high infection rate as perceived by the community volunteers. The impact of the disease was described by the participants from their personal experiences and from observation of other community members living with AIDS in Bhambayi.

Theme 1: Magnitude of the problem

All the volunteers believed that AIDS was a serious problem in Bhambayi. They expressed their concern as follows:

- **Identification of people possibly infected with HIV**

The volunteers increasingly identified new people with possible dual infection of TB and HIV whilst supervising patients on TB treatment.

“....many sick people say that they have TB but never improve....even on treatment....we encourage them to take an HIV test.”

- **Increasing numbers of neglected frail PWA's identified**

The volunteers had identified an increasing number of frail PWA's that were referred to them for attention by the community members. These ill people were found in a neglected condition.

“....there are many ill people needing our care....a person can find someone on their own...having passed urine the night beforeunable to do anything (for themselves)...and their food not even eaten.....all this needs the volunteers care...”

Theme 2: Impact of AIDS

The volunteers, who were in constant contact with community, were able to describe the impact of AIDS as follows:

- **Families overwhelmed by AIDS**

They reported that sick people, especially those with the dual infection of AIDS and TB tended not to be cared for by their families, but appeared to be abandoned. They were left on their own with nobody to assist them. The families were disempowered by the fear of the disease. This observation is true to the psychological impact of AIDS on affected families (see 2.6.2).

“.....sick people with TB or AIDS are not loved by family members any longer....this patient is on his own in the house....there is no one who can comfort her or do anything for her”.

“...mostly the people living with the patient usually run away from him, leaving him all alone in the house.”

“...people are too frightened and they don’t know what to do for the sick person.”

- **Affected children surviving poverty**

Some older affected children in Bhambayi had nobody to care for them and their younger siblings. They stopped attending school and roamed the streets, turning to prostitution in order to provide for their families.

“.....some children are up and down in the streets. Maybe they are prostitutes because they don’t know what to eat....”

- **Inability of extended family to assume care of affected children**

The safety net of the extended family in a time of crisis has broken down due to rapid urbanization of people. Families were also very poor and most people simply lost contact with family over time. Older children would then assume responsibility of caring for their younger siblings, by any means.

“..... and how they are going to care for their little brothers and sisters as they don’t have someone to get them to school and the children don’t have something to eat. ”

- **Stress on grandparents**

As the volunteers identified the increasing number of orphaned children in the community, they were concerned about the lack of financial aid and support from the government.

“.....grandmothers do not have any help to care for these orphans....it is painful to see this...many children do not have birth certificates or anything.....we try to help them...but it is very difficult.”

Theme 3: Awareness of susceptibility to HIV infection

All the participants were able to describe the possible reasons for the spread of HIV infection. They described their awareness of the community’s susceptibility to infection as follows:

- **Multiple partners to overcome poverty**

The high infection rate in this community was mainly attributed to the difficulties in finding employment, especially that the majority of people in Bhambayi were unskilled workers. Women would there take on multiple partners, in order to survive. A woman could have as many as five partners, for financial support, in order to care for their family. She could therefore easily become infected.

“.....I can say that what makes our community to get this disease so much is mostly unemployment. The person ends up having five partners trying to get money to live with the family such that she can get the HIV disease because of many partners trying to live, and there are no jobs.”

“..... and there are no jobs so they think that it is better to fall in love with a man. When they broke up she falls in love with another man and that makes this disease travel faster and the way people live.”

- **Rapid urbanization**

The movement of people from the rural areas to the city, in search of employment, had resulted in people from different places with diverse cultures settling in Bhambayi. Many had taken partners and were living together.

“..... my opinion is that what makes people get this disease here, is that people are living together from different places and these people are from different homes looking for jobs....”

- **Cultural differences**

It was believed that having people from different ethnic groups living in one community such as Bhambayi, could cause problems. Cultural practices and belief systems differed greatly among the various ethnic groups.

“..... People are from different cultures. Having different cultures within a community leads to lots of different things. This is why the disease is so high.”

- **Failure to seek health care: diagnosis delayed**

The volunteers found that some people did not attend the health facilities, despite having a history of long illness. They preferred attending the traditional healer. The volunteer would then encourage the individuals to visit the health facility in order to establish a correct diagnosis.

“....a patient may tell you that they do not know what sickness they have.....they may have been sick for a long time....some (people) do not visit the clinic at all...I advise that the clinic can help and find out exactly what sickness she may have....because she may not get much help from the traditional healer.”

- **Culture of non-disclosure**

Stigmatization associated with AIDS was a common fear expressed by PWA's in Bhambayi. People were afraid of their family's reaction to disclosure. They were also afraid of isolation by the community should their AIDS condition become known. The fear of isolation is a real threat to people living with AIDS (see 2.6.1.2).

“.....they are afraid of what their families would say if they found out.....if someone in the community found out....if someone in the community knows about the illness, they would not visit that person anymore”.

PWA's felt that their disclosure and the serious social implications of the disease were not taken seriously, even by partners.

“....AIDS patients do not like to talk about the disease... because some people take it as a joke.....when partners have a fight, he will shout at her about the AIDS problem.”

Figure 4.4 shows the data summarized for the perceptions of community volunteers engaged in home-based care in Bhambayi, in respect to the prevalence of HIV/AIDS and the community's awareness of susceptibility to HIV infection. The symbols '■' (greater than two) and '▲' (less than two) indicate the number of participants that held a particular view. Commonly held opinions are depicted in bold to highlight their significance.

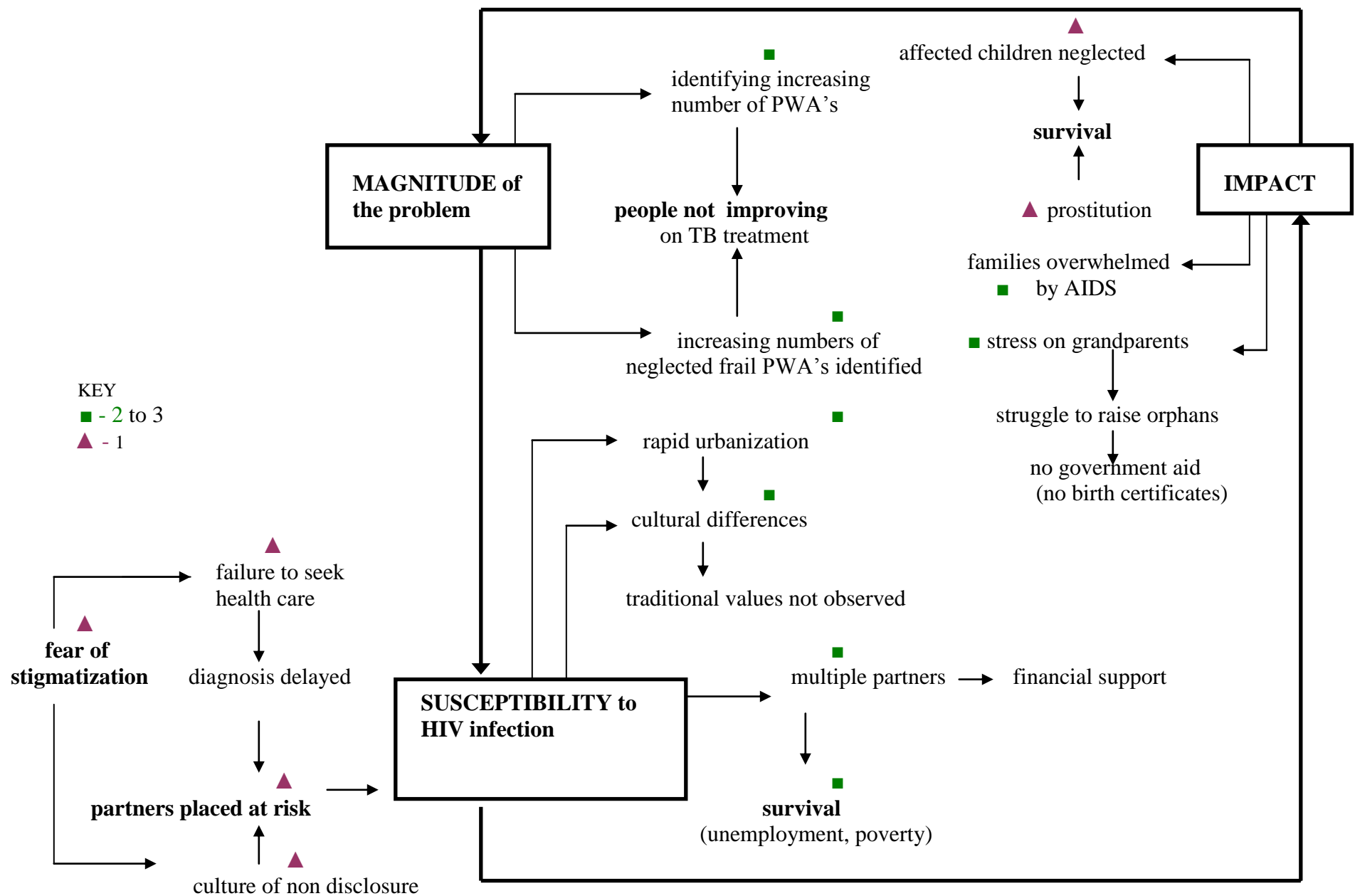


Figure 4.4: Perceptions of community volunteers in respect of prevalence to HIV/AIDS and awareness of susceptibility to HIV

Conclusion

The volunteers were acutely aware of the seriousness of the problem of AIDS in Bhambayi, as they had first-hand knowledge of the situation as caregivers in the community. The main cause cited for the rapid spread of AIDS was that women had multiple partners as means of survival. The urban movement of people was given as a further reason for people having multiple partners thereby increasing their risk of HIV infection.

4.2.6 OUTCOME FOR OBJECTIVE 1

4.2.6.1 Community perception

As explained earlier, three themes emerged in response to the enquiry and all the participants showed awareness the magnitude of the problem and the extent of the community's vulnerability to HIV infection. This section summarizes the findings and presents the important commonalities and differences between the levels.

Theme 1: Magnitude of the problem

All the participants, at the four levels in the study agreed that HIV/AIDS was a serious problem in Bhambayi. The participants knew many people in their families and amongst their friends in the community, who were infected with HIV or had recently died of AIDS.

At every level, participants expressed their concern at the number of people dying of AIDS, especially young people with young children and others in the 20-49 age groups. There were as many as 5-10 funerals per week in Bhambayi. The community leaders believed that the highest cause of death in Bhambayi was due to AIDS. Participants in the household level felt that the death rate from AIDS among younger people was higher than the death rate from political violence in the last decade.

Theme 2: Impact of AIDS

Although the study participants were not required to describe the impact of AIDS, they did so in response to the “seriousness of the problem”. The PWA’s expressed their despair at the loss of family support and care, of being robbed of their youth and home. Caregivers expressed their desolation by the fact that as there was no treatment or cure for AIDS. Therefore they perceived the disease as death sentence. They were also disturbed at the stress that grandparents were subjected to, in caring for the increasing number of AIDS orphans in the community. The community volunteers further described the reasons for the imposed stress. They believed that the lack of appropriate documentation prevented access to government assistance for these orphans. They had also observed affected children being neglected in the community. Some children were reportedly resorting to prostitution in order to survive poverty. The community leaders were concerned by the disruption of family life, where younger children in affected families needed to be sent away to the extended family in the rural areas to be raised. Parents could easily lose contact with these children. The community leaders further reported that most people continued working well into the late stages of the illness in order to survive. They had no benefits with casual employment. There was also a reduction in income generating activities, as observed in male laborers in the building trade. They were unable to cope with the demands of the physical effort, with the progression of the disease.

Theme 3: Susceptibility to HIV infection

All the participants’ at all four levels were able to describe the possible reasons for the high HIV infection rate in Bhambayi. They attributed this to people having multiple partners, the fact that men refused to wear condoms and irresponsible individuals deliberately infecting their partners through unsafe sexual practices. Women were said to be powerless to negotiate safe sex practice in their relationships, as they feared the loss of material and financial support. One family caregiver alleged that men did not believe AIDS was spread by sexual contact. Participants believed that the myth of virgin sex being a cure for AIDS was a significant contributing factor to the spread of AIDS, and reporting of these incidents to the community leaders had increased.

The community leaders believed that the youth chose to ignore the possible risks of infection and indulged in sexual experimentation and unprotected sex. All the participants believed that prostitution by young and older women alike was a risk to HIV infection. Women were driven by poverty and unemployment into prostitution as a means of survival. One community leader was of the opinion that the failure of urbanized people to observe cultural practices, such as dietary restrictions on young women, contributed to them becoming sexual active at a very young age. This encouraged promiscuous behaviour and increased their risk of infection.

Participants reported that members of the Bhambayi community believed that STI's could not be cured. Furthermore they were embarrassed to seek treatment for STI's and they understood this to be a high risk to infection. All the participants were of the view that the community was reluctant to be tested for HIV as they believed AIDS to be a death sentence that had serious socio-economic and psycho-social implications and the culture of non disclosure of a positive HIV status to partners and family members, was a serious risk of spreading infection.

The findings can be summarized as follows:

- They identified that many people were sick and dying, including the young, based on their knowledge of events in the community, such as the number of funerals and evidence of once healthy people afflicted by illness caused their condition to rapidly deteriorate and ending in premature death.
- They identified the impact on people, for example, the increasing number of orphans, the disruption of family life where more families sent the children away to the extended family in the rural areas to be raised, grandparents caring for grandchildren orphaned by AIDS, children resorting to illegal activities such as drug dealing and prostitution in order to support themselves and their families.
- They identified the reasons that people were getting disease, related to risky behaviour and this illustrated an awareness of the vulnerability of the community to HIV infection.

Although three themes emerged, they are interrelated as shown in Figure 4.5 below, which illustrates the relationship between the magnitudes of the AIDS problem, the impact of the seriousness on the community and the susceptibility of the community to HIV infection.

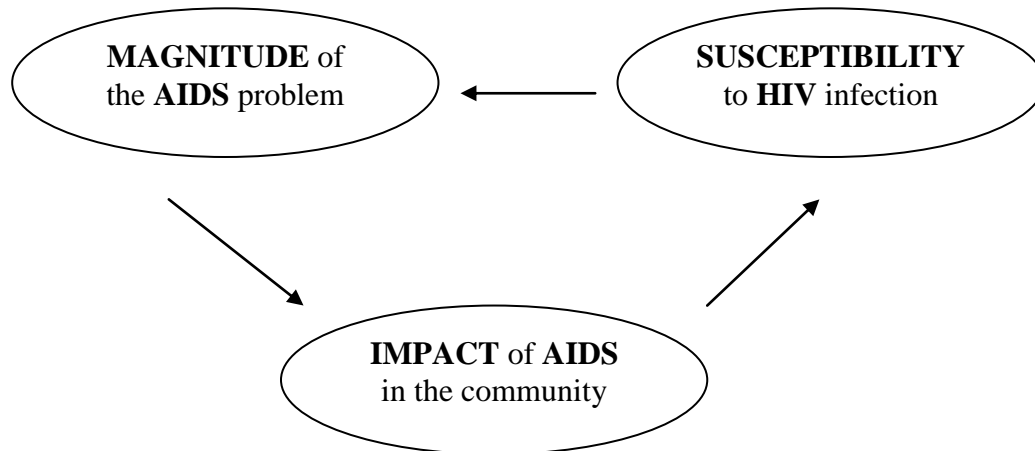


Figure 4.5

4.2.6.2. Concordance between actual prevalence and community perception

Therefore, ‘seriousness’ was related to the magnitude or the extent of the problem, how it was impacting on the community and also that there were many factors present in the community, contributing to the risk of infection. Consequently, the problem will not decrease in the near future. In fact it is more likely to increase. There is no immediate solution in sight.

4.2.6.3 Quantitative assessment

The quantitative assessment in section 4.2.1 indicated a high prevalence of HIV/AIDS in the community. The manner in which the community has identified that AIDS is a serious problem indicates a very good understanding of the disease, its causes and its impact. This mirrors what appears in scientific literature. Therefore they have an accurate understanding of the picture although they cannot furnish a prevalence figure.

The findings above show that there is concordance between the quantitative and qualitative data. It can therefore be concluded that the community concern and interest match the actual situation. According to Mc Donnell et al (1994), this enquiry and the concordance is extremely important for a successful program, especially in areas of high prevalence.

Table 4.1 shows a summary and comparison themes and categories in relation to the level of the community. It highlights the commonalities and differences in each category.

The themes and categories are listed in the left hand column. To the right of this the actual expressions of participants are aligned to the categories for each level of the community that was studied. In places there is an absence of a comment which shows differences between levels.

Table 4.1 : Summary and comparison of themes and categories for Objective I in relation to levels of the community

Themes and Categories	Level Community			
	PWA	Caregiver	Community leaders	Community volunteers
1. Magnitude of the problem	AIDS perceived as a serious problem	AIDS perceived as a serious problem	AIDS perceived as a serious problem	AIDS perceived as a serious problem
2. Impact	loss of life, youth, family, home	no treatment, no cure, loss of hope		
despair				
family		stress on grandparents	family life disrupted	stress on grandparents feeling overwhelmed
work			compelled to retain jobs despite illness, no disability benefits	
struggle for survival			young females leave school work to support family	affected children engage in prostitution
3. Susceptibility	multiple partners, prostitution	multiple partners, prostitution	multiple partners, prostitution	multiple partners
multiple partners				
myth	virgin cure for AIDS		virgin cure for AIDS	
environment	small houses no privacy deliberate infection	small houses-no privacy	small houses -no privacy deliberate infection	rapid urbanization cultural differences
indifferent attitudes	AIDS education ignored	men do not believe AIDS spread by sex, people do not care about AIDS	do not observe traditional practices	
women at risk	sick after first baby	sick after first baby sexually active early	sexually active early children at risk-behaviour	failure to seek health care
		condoms not used	condoms not used	

4.3. DATA ANALYSIS FOR OBJECTIVE 2:

To examine the perceived needs of individuals, households and the community in order to identify the basic needs that are necessary to care for people with AIDS.

Individual health has physical, social and psychological dimensions. Health problems occur in all these dimensions resulting in needs, that is, what is needed to deal with the health problem. The environment that the person lives in can increase or meet these needs. It has physical, social and psychological dimensions. Needs can be met by different types of support.

The purpose of this objective was to determine the perceived needs of the individuals living with AIDS, the needs of families caring for a family member with AIDS and the needs of the community in which these individuals lived. These included the basic care and support required for physical, psychological and social health and as well as the material needs that are deemed necessary for a PWA in the home environment. It was important that these needs be taken into account in the planning of a program however unrealistic they might be. The information on areas for negotiation between the community and source of assistance could emerge from it.

4.3.1. INDIVIDUAL LEVEL: PERSON LIVING WITH AIDS

This objective was intended to determine the perceived needs of individuals living with AIDS in the Bhambayi community that included the basic physical, psychological and social care and support as well as the material needs that are deemed necessary for a PWA in the home environment. The purpose was to establish the needs as experienced by the PWA.

Five themes emerged on the subject of AIDS care needs as perceived by people living with the disease. These included physical needs; actual home nursing care; social and psycho-social needs; and support from other family members which are discussed below.

Theme 1: Physical needs

According to Orem (1980, cited in Kindlen, 1994) the individual has the right and the responsibility to attend to his own self-care basics. The ability to maintain one's basic human needs is influenced by life cycle changes and life crises, such as disability and terminal illness. The challenge in caring for the chronically ill in the home is to encourage the individual's right to self-care (Kindlen, 1994).

As all the participants were people living with full blown AIDS, it was imperative to determine their ability to perform the activities of daily living in order to determine the level of care that would be required. Therefore responses regarding these needs were specifically sought.

- **Environmental hygiene**

Some PWA's were able to tidy the house only when well. They were unable to clean and tidy the yard as they experienced varying degrees of dyspnoea and fatigue. This was done by family members.

".....I can sometimes dress the bed when I am well, but I can't clean anything outside as I am too weak and get short of breath."

- **Laundry**

.All the participants were only able to do their personal laundry (underwear) and needed assistance with everything else. However, PWA's with young babies continued to do their baby's light washing only for as long as their condition would permit. Despite their debilitating condition, PWA's felt that it was important to maintain their independence and dignity for as long as possible.

PWA's felt that they needed to attend to their personal hygiene so that they preserved their self respect and dignity, despite their illness.

“.....it is not right that someone should wash your underwear....I try to do it myself.”

The ability to care for one's children was a rare source of normalcy and an expression of independence, in the PWA's otherwise troubled lives.

“.....I like washing my baby's clothes.....it makes me feel better....not so sad.”

- **Collecting water**

Sufficient easily assessable safe water for domestic use is an essential commodity especially in the homes of PWA's that were all at risk of cross infection.

None of the PWA's were able to collect the required amount of water for their daily use, as they had insufficient body strength, which relates to the physical dimension. Water was collected from municipal communal standpipes, some distance away from the dwelling. Water was stored in 25 liter plastic containers. The researcher observed that some were clean whilst many were in an unhygienic condition. It was reported during the project process that each household required approximately six 25 liter containers of water per day. Other members of the family performed this chore.

“.....when I was well I used to fetch my own water. Now I have no power to carry the container....the tap is too far.”

In the light of these findings it is evident that the ability of PWA's to function independently diminishes with progression of the disease (see 2.6.1.2).

Theme 2: Actual home nursing care

In order to be selected for the study, the participants had to be cared for by a family member living in the same house. Therefore the enquiry found that the family caregivers included: teenage children; adult children; a cousin, as it was convenient to access the health facility from the cousin's home; siblings and a mother who lived with the PWA. A male partner in a long standing relationship was an exceptional case.

“.....I am now living with my cousin, the clinic is near and she takes good care of me.”

“....when I am sick, my daughters help me. They are good children”

“.....I live with my mother and she takes care of me and the baby. She has so many problems, but she tries to find some money to take care of me and the baby.”

“.....my sister cares for me when I am ill.”

“.....my boyfriend takes care of me when I am sick. He can even bath me if I let him. He has kept his word that he will never run away, like other men do.”

Not all family caregivers were tolerant of the PWA's problems. Affected families have difficulty in coping with AIDS home care (see 2.6.2).

“.....my sister looks after me when I am sick, but she talks too much. She gets cross if I have diarrhea and mess myself.”

- **Feeding and meal preparation**

PWA's in the study refused any assistance with actual feeding, even when very ill. They wanted to maintain their independence for as long as possible.

“.....I can eat by myself, very slowly....I have some sores in my mouth....that are painful when I eat....sometimes I cannot eat what the children eat....I just have some porridge or some soup, if I get some from the volunteer.....my mother sometimes buys some vegetables and bread when she gets her pension.”

Food was prepared by the family caregiver in order to prevent any accidents due to physical incapacity that could occur whilst cooking.

“.....I do not cook anymore.....I feel too weak and dizzy.”

Theme 3: Social needs

The social needs for a person living with AIDS would include financial, nutritional, psychosocial and housing. (Department of Health, 2001.) Therefore the responses regarding these needs were sought.

Financial support

In order for PWA's to take care of themselves, they would require some form of income. All the participants had ceased working since their condition had deteriorated and had no source of personal income. Most of the PWA's had attempted to apply for the government disability grant and were awaiting a response

- **Child support grant as a source of income**

PWA's with young children depended on the child support grant that they received on a monthly basis. This was a meager sum that could barely cover the cost of food. According to the Department of Home Affairs, children under the age of eleven years in an urban household with a monthly income of less than R800 per month qualified for a government child support grant of R170 per month.

“.....I buy some food with the child's ‘pension’ money.....it is very small....I can only buy very little food....for about one week....the rest of the time we just see what we can do....maybe if I can find some ‘herbs in the bush’.... I will make some ‘putu’ with it.”

[These ‘herbs’ were a wild, edible, green leafy vegetable, which grew in abundance near most of the homes]

- **Money for children's needs**

One PWA who had two teenaged children, resorted to borrowing money from her neighbors out of sheer desperation, in order to send her children to school. She did this in the hope that when her disability grant was approved, she could repay the loan. This mother, like many others in the program, experienced a level of stress that manifested in other health problems such as, severe headaches and hypertension.

“I sometimes borrow money from the neighbor for my children....they have to go to school....maybe I can pay it back when my grant comes....I worry so much, I have these headaches and now they say that I must take treatment for pressure.”

- **Money for food**

The struggle to find the financial resources in order to meet the needs of the PWA was experienced in every household in the study. Some family caregivers appeared to show love, care and concern, but the limited funds prevented them from converting this concern into action. Recommended foods that would constitute a balanced diet were unaffordable. Most PWA's consumed only vegetable protein in their diet. They would consume whatever was prepared for the whole family. The only source of protein food for most of the PWA's was the fortified Soya soup powder and granules provided by the HBC project. Health information is important to maintain a healthy lifestyle but financial insecurity as experienced by the participants was a serious problem.

“.....my mother worries so much that there is no money for the foods they say I should eat....I just eat whatever the others eat.....sometimes there isn't enough and my mother goes without....when my grandmother visits, she buys some fruit and sometimes some meat.”

- **Money for transport**

Although it would appear that the PWA's needs were taken care of by family members, some people resented the demands made on their meager resources. One PWA was unable to keep an essential medical appointment at a tertiary hospital as her sister refused to fund her transport costs. A round trip by public transport would have cost six rand, which was expensive and beyond her means. The sister had a meager income from the monthly child support grant that was barely sufficient for food for a family of four. The patient's condition deteriorated due to this delay.

“.....my sister cannot help me. ...she refused to help me with bus fare to the hospital....I am even scared to go back to the clinic.....now I am still sick.”

- **Money for clothing**

PWA's had not bought clothing either for themselves or their children, since their illness as they had no source of income. They clothed themselves with donations from the project and whatever was given to them by family members.

“.....I do not have money for food, let alone for clothing....I just wear anything I have or if someone gives me something.”

Nutrition

Good nutrition plays an important role in helping people with HIV stay healthy, in counteracting the loss of weight due to HIV infection and in boosting energy levels. (UNAIDS, 2004)

All the PWA's in the study experienced a chronic food shortage. Most families could only afford the very basic staple foods. The majority were solely dependant on their families and the community volunteer for food.

“.....the problem is we do not have food.....my family sometimes help, if they have some money.....I eat 'putu' and soup and some spinach and potatoes if I have any.”

['Putu' is a staple dish cooked with ground maize, known as mealie meal, and water into a crumbly consistency]

“.....I eat only one meal a day...I try to save the food for my twins.

- **Housing**

Living conditions within this particular community were sought as the PWA under study was being taken care of in the home. Adequate housing and amenities are essential for care of the chronically ill. (Department of Health, 2001)

Informal housing

Poor construction and the lack of living space

The majority of the participants lived in informal dwellings that were poorly constructed. They were very small in size, comprising of one to two rooms only. The dwellings were overcrowded, housing as many as four to eight occupants in some instances. In most instances, the PWA occupied a space that also served as the cooking and living area.

Some had poorly constructed roofs so that it leaked in rainy weather, and the interior was very dusty in the windy season. The PWA's had very little protection from the natural weather elements and experienced constant physical discomfort.

“....we are many people living in this home...it is so small.....we cook, eat and sleep in the same room.”

Poor ventilation

These homes were poorly ventilated, with small windows that did not open. One home had had no windows. The air was heavy with fumes from the paraffin cooker. The interior felt damp and smelt musty. It was very hot in the summer and very cold in the summer.

“.....these windows do not open...it was built like this...there is no fresh air.”

“.....it is too hot in summer and I feel very sick. When it rains, the roof leaks and everything just gets wet.”

“....we have to cook with the paraffin stove...the smell makes me cough too much.”

Overcrowding, poor construction and the lack of adequate ventilation were a source of tremendous discomfort to PWA's. The researcher had observed PWA's deteriorate rapidly, especially those with chest infections.

Living conditions in government housing (RDP)

Poor construction and the lack of living space:

These homes comprised of two small rooms and an ablution facility. The cooking area was the space usually delegated to the PWA. These homes were overcrowded often

housing four to six people. There was evidence of rising damp on the walls and this made the home very cold and musty.

“.....I sleep in the kitchen...we are many people living here...the house is too small.”

Poor ventilation:

The windows in these homes were not opened as the rooms were very small and furniture was placed against the windows. The interior was consequently poorly lit and musty.

“.....the windows do not open...there is too little space for furniture.”

- **Amenities : Sanitation and water**

Sanitation

Sanitation was mainly informal and of the pit privy system. The government housing development had made provision for the sewage system. The researcher was informed of the community awaiting connection to the municipal system, during the project process. The community was provided with chemical toilets whilst awaiting connection. Construction of the informal pit privy toilets was of scrap metal, sacking, wood, cardboard and whatever materials the people could find. Most had no seats, the floors were uneven and some had no doors.

“.....I am scared to go to the toilet at night....it is dark and I can easily fall.”

Toilet usage:

Toilets were shared by as many as two to ten families and maintaining any standard of hygiene was problematic. Families were said to be un cooperative in terms of assuming responsibility in keeping the toilets clean. Poorly maintained toilets were found to be infested with flies.

“.....there are many families sharing one toilet....it is a problem....people do not like to clean this toilet.

Night use by PWA:

Preventing cross infection is an essential need for physical health. The most common opportunistic condition that PWA's experienced was chronic diarrhea that appeared to be more troublesome at night. Most of the participants used buckets in the dwelling and they were embarrassed by this practice. They expressed the fear of falling and injury and of spreading germs to their children. Therefore the physical environment had a direct impact on the PWA's psychological well-being.

“.....I use a bucket at night...this diarrhea worries me at night....it is not good for the children, but the toilet is too far...I am scared of falling in the dark and there are many ‘dongas’ in the yard.”

[‘dongas’ are potholes that make the ground surface uneven.]

Distance from dwelling:

Toilets were situated some distance from the dwelling. PWA's expressed the fear of falling at night and the fear of soiling themselves.

“....I feel bad if I can mess myself, trying to go to the toilet. What is painful is that my sister shouts at me when this happens.”

There are many old toilet sites in Bhambayi that were closed when they were too full. Consequently these sites were prone to wash away in rainy weather and there was evidence of faecal matter at ground level. Some of the old sites gave off an unpleasant odour. These observations were made by the researcher. These unhygienic conditions were a risk to cross-infection; children were especially at risk as they played in the sand.

Bhambayi is a very poorly resourced community. During the project process the researcher observed that the poor quality of care rendered in the home by families was underpinned by the poor living conditions. This was despite the provision of available equipment and health education to these families.

Water

It was reported that the water to the residents of Bhambayi was supplied at no charge by the eThekweni Municipality. Water was collected by the householders from communal standpipes and stored in 25 liter plastic containers. It could take approximately one hour for a healthy individual to collect a 24 hour supply of water, depending on the distance of the standpipe from the home. The water was either carried or transported by wheelbarrow. Some residents owned wheelbarrows and hired them to other residents at R1 a trip.

“...the tap is too far and I do not have a wheelbarrow....the others in the family fetch some water....sometimes we have to pay R1 a trip for a wheelbarrow.”

Although there was no charge for the water itself, collecting water from the standpipe was costly. As several trips would be necessary to collect sufficient water for a day, a family would have to spend far too much of their limited income on accessing ‘free’ water. This money could have been used on essential food for the family.

Theme 4: Psycho-social needs:

Many physical changes including weight loss and extreme weakness occur in the course of HIV/AIDS and are likely to affect the individual’s self-esteem. Furthermore, changes in social and domestic roles and any negative domestic attitudes displayed by family and friends can alter a patient’s self esteem (Kindlen, 1994). Therefore it was important to assess the psycho-social needs of people living with full blown AIDS, in conditions of poverty and coping with the fear of stigmatization. The researcher had observed once productive, happy adults become depressed with the anxieties that are associated with the disease. Individuals in the program, who received psychological support from their families and the HBC team, coped better than those who had no support.

The participants responded as follows:

“....my family do not visit me anymore since I disclosed my illness to them....they do not want to know my problems.”

“....the volunteer has been good to me....she helps me with many things...she is like my sister.”

- **Personal hygiene**

Although most participants were debilitated with fatigue due to the disease, they said that they declined any significant assistance with personal hygiene such as bathing themselves, as they wanted to maintain their independence and dignity for as long as possible. All the participants needed assistance with fetching and disposing of the bath water, as they had significant loss of body strength.

“.....I feel bad to have my sister bath me.....she does everything else for me, even my washing. I want to be able to bath myself, at least.”

Theme 5: Support from other family members

It was important to determine the role of the extended family in terms of support and care for the PWA which would then assist the helping agency to understand the wide range of problems including that of isolation, which the PWA had to deal with. The enquiry included financial, material and psychological support.

The participants responded as follows:

- **Financial support**

Most of the PWA's did not receive any financial assistance from their families as they were very poor themselves, and were unable to provide the PWA with significant financial support. The family members who were able to provide some financial support included an elderly parent on a social pension, of R700 per month, a sister who received a child support grant of R170 per month, a father who visited his daughter occasionally and

a caring partner when he was able to earn some money. The participants responded in the following manner:

“.....my mother does not know what sickness I am suffering from.....she buys some food and gives me some money sometimes, when she gets her pension.”

“.....my sister gets a grant for the baby....she sometimes gives me some money when she likes.”

“....my father sometimes visits and he gives me some money for bus fare if I need to go to the hospital.”

“....my partner sees to me. He gives me money when he works.”

- **Material support**

Having enough to eat is an important concern for many people with AIDS as disease impoverishes families and leaves them struggling to feed themselves. (UNAIDS, 2004) None of the participants could afford to buy food to meet their needs. All the participants were assisted by family members and resources from the HBC program.

Food was bought in small quantities according to affordability by various family members including a grandmother, mother, sister and cousin for the PWA.

“.....my grandmother sometimes buys me some food, like fruit and vegetables.”

“....my mother tries her best to buy food for the family...there is so little money. ...my mother feeds the family and sometimes goes without.....she worries all the time about food.”

“....when my sister works, she buys some food. If there is no work, there is no money for food.”

“....my cousin buys foodshe makes sure that I get the right food for my illness, most of the time.”

Clothing was unaffordable in the majority of cases. It was a situation of survival and food for the PWA appeared to take priority. Most PWA's simply used whatever they had and they were dependant on donations from the project. However, one mother was able to occasionally bought clothing for her ill daughter.

“.....I am lucky...my mother sometimes buys me clothes.”

“....my family can only help me with food sometimes....it is difficult...there is no money for clothing and other things.”

- **Emotional support**

With the exception of one, all the participants had disclosed their HIV status only to their family caregiver. Disclosure of a sero-positive status is traumatic to infected individuals (see 2.6.1.2). Psychological support was therefore not forthcoming from other family members. Furthermore one PWA was traumatized by the lack of support from her sibling who was also her caregiver.

“.....my mother is the only one whom I can talk to when I am troubled.”

“.....my family do not visit me anymore since I disclosed my illness to them...they do not want to know about my problems.”

Only the one participant had disclosed her condition to other family members and received unconditional support and care. This illustrates the importance of disclosure to family members (see 2.6.1.2).

“.....my family in the farm visits me, and when I am well, I visit them....they are good to me ...all of them....they pray for me when we are together.”

Figure 4.6 below illustrates the perceived needs of people living with AID

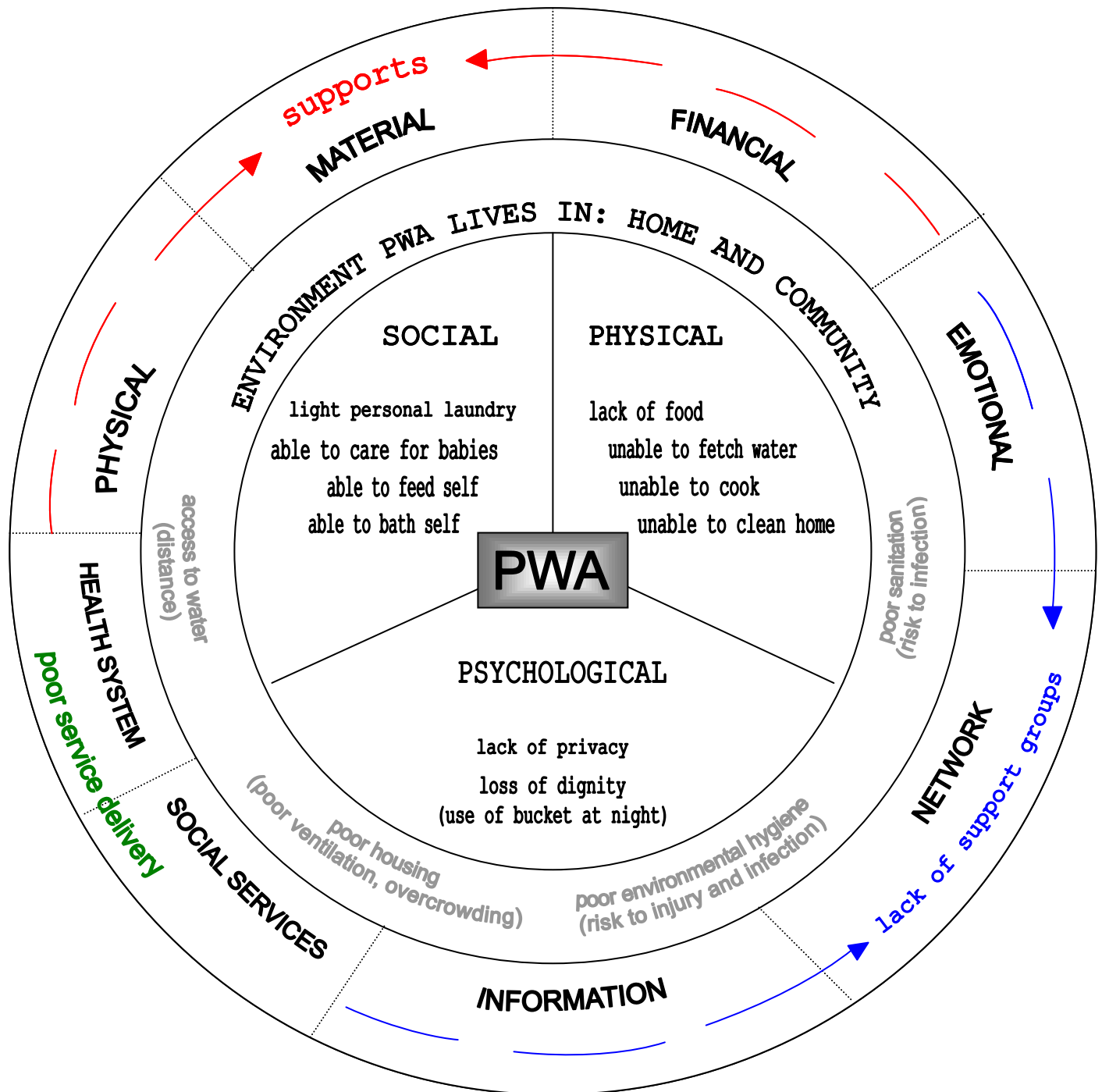


Figure 4.6: Perceived needs of a person living with AIDS

Conclusion

The lack of financial resources was evident among all the participants. They were therefore solely dependant on their families for material support such as food and clothing. The quality of care was compromised by inadequate sanitation, poor access to sufficient water and poor housing conditions. Psychological support from other family members was lacking. However, despite their circumstances, all the PWA's showed the determination to maintain their independence for as long as possible by attending to their personal hygiene needs and caring for their young children.

4.3.2. HOUSEHOLD LEVEL: FAMILY CAREGIVER

This objective was intended to examine each family in their respective circumstances in order to identify their material, financial and psychosocial resources and support, fundamental to AIDS home care. The purpose was to establish the needs as experienced by the family caregiver in the home environment.

Three themes emerged at this level of the study, namely, social needs, psychosocial needs and other concerns addressed by caregivers. These themes are discussed below.

Theme 1: Social needs

Financial

Caring for the chronically ill in the home requires financial resources. It was therefore necessary to determine whether the family's financial resources could meet the financial implications of home care. It would be incorrect to assume that home care is cheap. Given the level of poverty in Bhambayi, all the households in the study were affected by the increased costs.

- **Source of income**

The source of income for some families in the study included, child support grant, casual employment, an elderly parent's social grant, infrequent engagement in a cottage industry and a supportive spouse.

“...I get a grant for the child....it is too small...I can buy very little food with this money.”

“.....I work when I can get some washing in Phoenix [a neighbouring suburb]....the money is very little...sometimes only R10 a day.”

“....my husband is working....he supports me.”

- **Impact of care on ability to work**

The majority of family caregivers in the study were also the principal bread winners. It was therefore important to determine the effect of AIDS home care on the individual's ability to engage in income generating activities.

One caregiver was afraid that the PWA's condition would suddenly deteriorate in her absence. She therefore compromised by working fewer days in the week.

“....I was working every day, before this problem....now I work only a few days a week because anything can happen (the patient's condition can deteriorate) when I am at work.”

All the working participants were engaged in casual unskilled labor, such as domestic work. They were cautious by not disclosing their domestic problems to their employers as this would mean termination of their services. It was alleged that such employers were unsympathetic and were afraid of the implications of infection being carried by these workers. They therefore worked for a fewer number of days in the week than previously in order to accommodate caring for the family member with AIDS.

“....sometimes the person can chase you away if you tell them that someone is sick in your home... they think that you can bring some disease to their homes....it is difficult....so you just keep quiet and work.”

The caregiver, who had been generating income from a cottage industry, was unable to engage in this activity due to the demands of caring for the PWA. Another caregiver, who was also HIV positive, ceased working when she herself became ill. Therefore the ability of families to maintain a normal life is compromised by care giving responsibilities (see 2.6.2).

“.....I used to make some cakes and sell these to help my husband....now I do not have any timeit is difficult to do this when you have a sick person in the home.”

- **Meeting transport costs**

Transport to the health facility was sometimes necessary when the PWA was unable to walk. The caregiver depended on the social grant or borrowed money from neighbors and money lenders to meet the cost of hiring transport.

“.....I borrow some money from my neighbor or money lender to hire a car, if my cousin is very sick and cannot walk to the clinic.”

- **Meeting food costs**

According to the caregivers, they were unable to meet the cost of the recommended foods for the PWA; nutritional needs could not be met as they could only afford staple foods.

“....the clinic say that a person with AIDS must eat certain good food.....there is no money for such things....we can only buy some mealie meal, samp and beans (staple foods) and some vegetablesthe sick person has to eat what we eat.”

- **The cost of preventing cross infection**

Although the caregivers understood the importance of preventing cross infection, they could not afford to buy any disinfectant.

“.....they say we must wash and clean the house with something to kill the germs....there is no money for such things.”

- **The cost of caring for the PWA’s children**

The cost of caring for the PWA’s children was a further expense that was the caregiver’s responsibility. They could only afford to feed the children and there were no funds to meet other essential needs including clothing and school fees.

“...I can only feed the childrenthere is no money for school and clothing.”

Consequently, the children were sent away to the extended family in the rural areas, until the family’s circumstances improved.

“...I have sent the children to my mother on the farm. There is no money to take care of them here.”

Nutrition

- **Availability of food, a key issue**

There appeared to be a chronic shortage of food in all the households of the study participants. Most households could only afford staple foods. Other families were dependant on family members for other essential protein foods which they occasionally received. Some families had small vegetable gardens; however, the fresh produce was insufficient to sustain the household for any period of time. All the families received soya soup and granules from the HBC program.

“....we are always short of food...we have a small garden....it helps a little....sometimes my family helps with some food....we get some soup from the project....and sometimes some small food parcels....it is very difficult.”

- **Food preparation**

Some caregivers appeared to be well informed on the preparation of food, which would be suitable for the PWA, and had appeared to have changed their cooking habits to accommodate the PWA's needs.

“....I can cook the food the right way for the sick person....”

However most of the participants were uninformed about food preparation for a sick individual.

“.....sometimes the patient cannot eat ...she has sores in her mouth....I don't know what I can do to help her.”

- **Special foods**

Only one family who had a regular income was able to obtain special foods for the PWA by observing a careful budget.

“.....I must budget carefully if I can [be able to] buy some special food for my cousin.”

Living conditions: space, water, sanitation

- **Housing**

Informal dwellings

As explained in 4.3.1 (theme 3), the dwellings were small, overcrowded with limited living space and poorly ventilated. The PWA occupied a space that also served as the cooking area.

“....we are many people living in this home...it is so small.....we cook, eat and sleep in the same room.”

Conditions in a government home (RDP)

These homes were also, small, overcrowded and poorly ventilated. (refer to 4.3.1, theme 3). The researcher had observed that there was evidence of rising damp on the walls and this made the home very cold and musty in winter and the rainy period.

- **Sanitation**

Sanitation was mainly informal and of the pit privy system. The government housing development had made provision for the sewage system. The researcher had been informed that the community was awaiting connection to the municipal system. The community was provided with chemical toilets whilst awaiting connection.

Construction was of scrap metal, sacking, wood cardboard and whatever materials the people could find. Most had no seats, the floors were uneven and some had no doors.

“.....I am scared when the patient goes to the toilet at night....it is dark and she can easily fall.”

Usage

Toilets were shared by as many as two to ten families and maintaining any standard of hygiene was problematic. Families were said to be un cooperative in terms of assuming responsibility in keeping the toilets clean. Poorly maintained toilets were found to be infested with flies.

“.....there are many families sharing one toilet....it is a problem....people do not like to clean this toilet.”

Night use

The most common opportunistic condition that PWA's experienced was chronic diarrhea that appeared to be more troublesome at night. Most of the participants used buckets in the dwelling and they were embarrassed by this practice. They expressed the fear of falling and injury and of spreading germs to their children.

“.....she uses a bucket at night...this diarrhea worries her at night....it is not good for the children, but the toilet is too far...she is scared of falling in the dark and there are many ‘dongas’ in the yard.”.... [‘dongas’ are potholes that make the ground surface uneven]

There was no light to guide the PWA at night and these potholes could not be safely negotiated in the dark. Therefore they were a potential danger to injury from a fall to the frail PWA.

Distance from dwelling

Toilets were situated some distance from the dwelling. PWA’s expressed the fear of falling at night and the fear of soiling themselves.

“...the patient feels bad if she messes myself, trying to go to the toilet.”

- **Water**

Water was supplied at no charge by the eThekweni Municipality. Water was collected by the householders from communal standpipes and stored in 25 liter plastic containers. It could take approximately one hour for a healthy individual to collect a 24 hour supply of water, depending on the distance of the standpipe from the home. The water was either carried or transported by wheelbarrow. Some residents owned wheelbarrows and hired them to other residents at R1 a trip.

“...the tap is too far and I do not have a wheelbarrow.....sometimes we have to pay R1 a trip for a wheelbarrow.”

Theme 2: Psychosocial needs

Community support

- **Psychological support**

There was no psychological support from family members or the community in most cases. As AIDS was an extremely sensitive subject in the Bhambayi community,

caregivers were loathe to breach the trust of the ill family members by discussing problems and concerns related to the care of the PWA.

“....I cannot talk to anyone about my problems. AIDS is a secret and I cannot hurt my sister by discussing it with anyone.”

Family support

- **Psychological support**

The majority of participants had to cope on their own, as the rest of the family were not informed of the PWA's condition. . Non disclosure pre-empted family caregivers from acquiring essential support from other family members and this increased the level of anxiety in caregivers (see 2.6.2).

“.....the family cannot [do not] help me because they do not know about the AIDS problem.”

Only one PWA had disclosed her HIV status to more than one family member, therefore family support for the majority of caregivers was not forthcoming

“.....my family knows about the HIV problem. They help me a lot.”

- **Financial support**

Financial support was good in families with a regular source of income.

“....my husband is working...he sees to everything, even for my cousin.”

However none existed where most of the family was unemployed.

“....my family cannot help me with money....most are unemployed.”

- **Physical support**

There was no physical support from the family for day to day care of the PWA in the majority of cases, as the PWA had disclosed their status only to the caregiver.

“....I get no help from anyone with my sister.”

However, in the case where the PWA had disclosed her HIV positive status to the whole family, it was reported that the caregiver received family support with day to day care.

“...my mother and aunt help with everything when they visit.”

Theme 3: Other concerns expressed by caregivers

- **Fears as expressed by the caregivers**

Many fears were expressed by the caregivers. These included: the fear of family and other community members finding out that there was a PWA living in that household; the fear of a disorientated PWA running away and having to explain this to the rest of the family; the fear of contracting AIDS from caring for the PWA; the fear of their own children becoming ill and the fear of eviction, once the PWA is identified and the associated problems become known to the landlord. These fears are commonly experienced by affected families (see 2.7.2).

“....I am afraid of the family will say if they hear about this.”

“...I do not know what the community will say if they knew about this problem.”

“...I have to lock everything at night and hide the key... the patient may run away because she is sometimes confused.”

“....sometimes the neighbors can suspect that I also have AIDS as I am caring for my cousin who is sick.”

“....maybe I can get AIDS as I look after the patient, doing everything for her...this worries me.”

“....if the owner of this house knows about the AIDS problem, he can chase me away.”

- **Isolation**

The caregivers were afraid of the possible isolation by their families and the community once the situation was known. This was a common occurrence in Bhambayi, and caregivers made every effort to keep the real problems with the PWA away from society. They reported that they found this practice stressful and felt that they needed to be constantly on guard.

“....we cannot talk about this disease. Many sick people in Bhambayi ran away because they told somebody....they never came back....nobody knows what happened to them...maybe they died.”

- **Discrimination**

One caregiver reported that the neighbors would suspect that she was also an AIDS sufferer because she was caring for a person with AIDS. The caregiver was therefore cautious about discussing problems related to the PWA's condition.

“.....my neighbors ask me what is wrong with my cousin...I cannot talk to them....I must respect the family name and keep my problems to myself. AIDS is not for others to know.”

- **PWA behavior changes**

PWA's presented with changes in behavior that caregivers had great difficulty in explaining to others. These behaviour changes are consistent with the psychological complications of advanced HIV disease (see 2.3.4).

“....sometimes my sister does and says some funny things from this illness....it is very difficult...people ask about this...I cannot answer anybody...I try to look after her.”

- **Caring for PWA's children after death**

Caregivers expressed concern about the potential problems that could emerge in caring for the PWA's children after death. Their main concern was that they lacked the financial

resources to feed, educate and raise these children. They had witnessed families being split up on the death of a mother and the children had suffered greatly.

“...I worry about who will look after these children when sister dies...I do not have any money.”

“...it is very painful when children from one family have to be sent to different places to live. We have such children [who] suffer so much.”

Figure 4.7 below illustrates the perceived needs of family caregivers of persons living with AIDS.

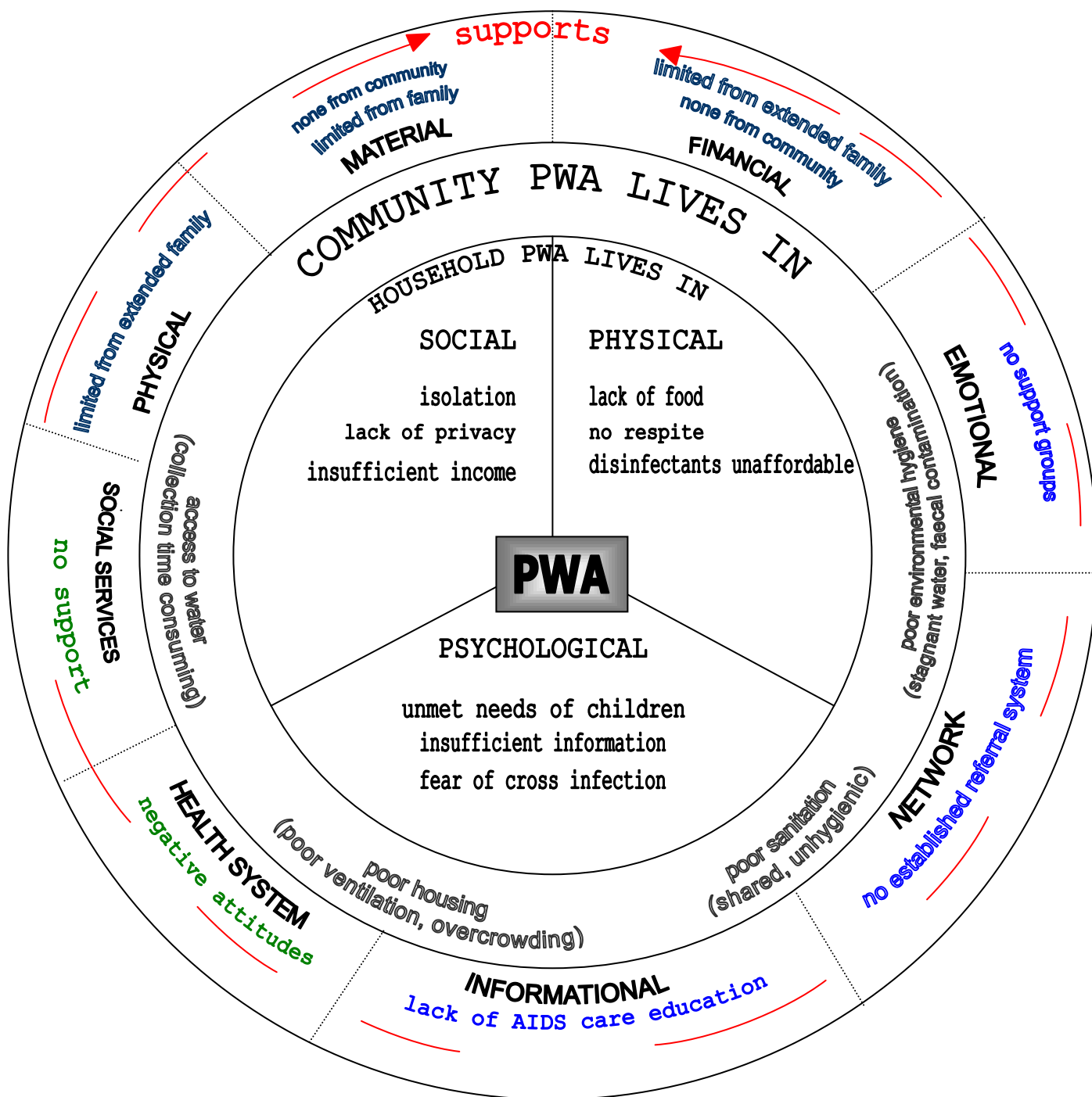


Figure 4.7 Household level: perceived needs of family caregiver

Conclusion

It would be incorrect to assume that the basic needs a household would require to care for a PWA would be the same for all communities. It was therefore imperative to determine the existing resources available to the family in order to care for an ill family member living with AIDS in the home.

The level of care provided was minimal, given the poor living conditions and the lack of financial resources in most households in the study. The majority of households lived in extreme poverty, some generating a meager income of R10 per day from domestic work. Most families experienced food insecurity. The majority of caregivers expressed their despair at being unable to afford the recommended foods for the PWA. In essence the majority of the households were barely able to afford staple foods, in small quantities. The only relief was minimal assistance from the HBC program and occasional assistance from other family members. Consequently the PWA's nutritional needs were not met. The researcher had observed their conditions deteriorate rapidly, given their existing poor health status. Caregivers were constantly preoccupied with their powerlessness to acquire sufficient food for the ill PWA. The majority of families lived in rented cluster homes with no space for any vegetable garden. Families that did have minimal space attempted to grow some of their own food which did not meet their requirements.

All the caregivers were unable to afford the additional cost of transport to the health facility. Money was borrowed from money lenders and neighbors to meet this cost.

The lack of easy access to water was a problem. The researcher had observed the laundry being done in a hap-hazard manner (mixing soiled linen with family laundry) and this made the entire family susceptible to infection.

Caregivers experienced problems in managing crises at night given the lack of privacy and other members of the household were also disturbed in these overcrowded homes.

The use of a bucket at night and in poor weather, in lieu of the toilet by the PWA who was prone to bouts of persistent diarrhea, was a serious problem that caregivers had to contend with. Caregivers were concerned about their children contracting infections.

As AIDS was an extremely sensitive subject in the Bhambayi community, caregivers were loathe to breach the trust of the ill family members by discussing problems and concerns related to the care of the PWA. There was no respite from caring for the ill as caregivers had no psychological support from extended family.

The children of PWA's were also the responsibility of the caregiver. Given the level of poverty in these households, the caregivers could barely afford to feed these children. There were no funds for clothing and school fees, which was an additional stress factor in their lives. Caregivers expressed their concern about the potential problems that could emerge in caring for the PWA's children after death as they lacked the financial resources to feed, educate and raise these children.

Furthermore other serious concerns were expressed by the caregivers. These included: the fear of stigmatization in the event of family and other community members finding out that there was a PWA living in that household; the fear of managing behavior changes in the patient; the fear of contracting AIDS from caring for the PWA; the fear of their own children becoming ill and the fear of eviction, once the PWA is identified and the associated problems become known to the landlord.

It can therefore be concluded that the majority of family caregivers of PWA's were in need of physical, psychological, social and material support in this community. However, despite the struggle for survival and the numerous psychosocial problems, the family caregivers showed a willingness to care for a family member living with AIDS.

4.3.3. COMMUNITY LEVEL: COMMUNITY LEADERS

The purpose of this objective was to determine the perceived needs from the perspective of the community leaders, as they would be better informed of the existing resources, attitudes and current activities related to HBC for PWA's within the community.

Theme 1: Material needs

- **Nutritional needs**

The single most pressing preoccupation for most people in the community was not having enough to eat. Households affected by AIDS were impoverished and families struggled to feed themselves adequately. Relieving chronic hunger was a serious concern expressed by all the participants.

“.....there is always a shortage of food in our community....there is more hunger than usual in the homes of people with AIDS....even if you are ill with AIDS, you can just eat anything for the day [any food that may come to hand], because you are always hungry.”

The participants were aware of the value of growing their own food, but the lack of adequate space prevented them from doing so.

“.....we do not have (the) space to grow our own food, like we do at home (in the rural areas).....the houses are too close to each other.”

- **Resources for the provision of AIDS home care**

The community leaders believed that resources provided by the programme, such as food and protective equipment such as gloves and aprons, were insufficient.

“.....the community is unhappy because the HBC program has too little things like gloves and aprons.....food is also a problem....the affected families receive very little soup from the program.....how can you eat when your children are also hungry?”

Although creative strategies to overcome the shortage of equipment, such as using double plastic bags for gloves, were implemented, this plan was unsatisfactory as the demand outstripped the supply. The most basic material, such as newspaper is not available in this impoverished community. The community felt that the department of health should be providing some resources.

One participant explained that support groups for PWA's were initiated at various stages in Bhambayi, but failed to become established due to apathy from the community and the fear of stigmatization.

“.....support groups were started in Bhambayi, but failed to take off. People with AIDS are afraid to attend because they will be identified as a person with AIDS and they can suffer greatly.....they can be chased away and lose everything.....most people feel that these support groups cannot help them in any way.”

Theme 2: Care of people with AIDS

- **Place of care**

Most PWA's in Bhambayi were cared for in their own homes, especially those individuals who had full blown AIDS. The hospitals did not admit terminally ill PWA's. These patients were treated mostly as out-patients and sent home, to be taken care of their families.

“.....most of these very ill people with AIDS are never admitted in hospital....they are just treated and sent home the same day.....the family then has to care for this person....sometimes the person dies within a few days time.....it is very painful for our community.”

Some terminally ill patients were sent to their extended families in the rural areas to die in order to avoid the high costs of transporting a deceased individual. Furthermore it was an opportunity for the sick person to prepare themselves for death, the traditional way. The people believe that burial in their ancestral is more acceptable because respecting the dead is of paramount importance to the family.

“.....if a person is lucky, he can be taken home by his family to die.....it costs a lot of money to transport a person to his home, when he is already dead.....its better when the person is sick but well enough to travel....to try and get them home.....the dying person also needs to do something to prepare for death....this can only be done correctly in the place of his birth.”

- **Community attitudes to PWA's**

According to the leaders, people with full blown AIDS, was the most neglected group of people in Bhambayi. They had multiple needs, as they were living in isolation, often without food, water and care. These individuals were said to be so ill that they were either unable to take their treatment or did not know how to take their medication.

“.....people with AIDS are much neglected in Bhambayi....many are living alone....they have no food, water or care. ...they are too ill to even know how to take their treatment...some just cannot help themselves.”

It was also alleged that few families cared about the sick, as they were mainly concerned about their own survival.

“.....people really don't care about the sick....they are busy trying to survive themselves....a person with AIDS is always sick....many people just give up as they do not know how to take care of this person.”

One leader further believed that the spirit of caring and sharing commonly known as 'ubuntu' did not exist when it applied to AIDS.

“.....there is no ‘ubuntu’ in this community....especially when it comes to AIDS.”

The conventional care and support for the ill from the extended family was also dying in Bhambayi.

“.....when someone is sick, the extended family would be there for you....but it is dying in Bhambayi.”

The participants believed that neighbors showed no interest in assisting families caring for an ill family member. Two of the five participants had personal experiences to draw from.

“.....neighbours do not care about another person’s problems in this place.....they can just ignore you or talk badly about a persons pain....I know this from my own experience, when my daughter was very ill.”

Theme 3: Needs of children affected by AIDS

As a result of the increasing number of AIDS related deaths in the community, the community leaders had identified an increasing number of AIDS orphans. They reported a growing concern for the welfare of these vulnerable children.

- **Young orphans sent away**

It was common practice in Bhambayi for young children orphaned by AIDS, to be sent away to the rural areas to be raised by their grandmothers. This was based on the belief that these children would receive proper care from their grandmothers. The main concern expressed by the participants was the availability of food for the orphans and protecting the children from potential abuse.

“.....the young children are sent home to their grandmothers when their mothers become very ill.... and also when they become orphans ...at least there is some food and care on the farm.....the children will also be safe from abuse.”

- **Children turn to illegal activities to survive**

It was believed that there were increasingly more children who were forced to engage in illegal activities when their parents became ill with AIDS and were therefore unable to support them. These activities included involvement in the illegal drug trade and prostitution. Some children became drug users themselves in exchange for food and accommodation from the drug dealers. The community leaders were extremely concerned about the plight of these children in Bhambayi.

“.....we are very worried about our children who will do anything to survive the loss of a parent and to escape poverty....many youngsters are using ‘dagga’ and sniffing glue....they work for the drug dealers....girls become prostitutes....all this is for food and some place to stay....these children are struggling to survive...there is no help for them.”

- **Child- headed households**

Although the researcher and the HBC volunteers knew of several households where children were caregivers of parents with AIDS, one community leader was of the view that there were no affected children caring for PWA's in Bhambayi.

“.....I do not know of children taking care of any family member with AIDS in Bhambayi.”

The other participants were of the belief that the number of child headed households were increasing in Bhambayi.

“....the numbers of older children caring for a sick parent and their siblings are increasing in Bhambayi...these children come to the leaders for help....we have referred some to the social workers.”

- **Affected schoolgirls engage in domestic work to assist family**

Children, especially the girls in affected households worked as domestic workers at weekends and after school to assist their families financially.

“.....some of the girls do domestic work after school and at weekends to make some money for their families, as the parents are too ill and they have no other help....some leave school after a while....it is too difficult....for school fees and books....there isn't enough money for most of the family's needs...after all, a child is paid very little.

Therefore it was clear that children's needs were important to this community as families were not intact.

Theme 4: Effect of AIDS on income generating activities

- **Effect on PWA**

No sick benefits

The participants were of the belief that despite infected people being very ill, they retained their jobs well into their illness, in order to survive. The majority of PWA's had no alternate source of income.

“.....people with AIDS just work until the end....there is no other income.”

Without an income the family would starve and face eviction.

“.....their families will starve and they can be lose their home if they do not work.”

Fear of discrimination

Furthermore, it was believed that a PWA could easily be dismissed from work by unsympathetic employers due to fear of infection. A person with AIDS would therefore not disclose their status or ask for any assistance and continue working until the end stages of the disease.

“.....a person with AIDS can never ask for help from their employer....employers care about a person’s suffering....they will never disclose their illness to the employer...they will surely be dismissed....they think that they can also be somehow become infected with AIDS.”

Men engaged in manual labour

According to the participants, the men were mainly affected as their body strength was reduced with the progression of the disease, particularly those who were engaged in manual labor in the building trade.

“.....it is mainly those men who are laborers in the building trade.....they become very weak with this disease and cannot manage to continue working.”

- **Family bread-winner’s response**

Given that the people of Bhambayi were living in abject poverty, people that were employed in affected households could not afford to stop working in order to care for their ill family members. They retained their jobs in order to survive. Caring for the ill was a secondary issue, and they did the best they could in the circumstances.

“.....what can a person do? You are lucky to be working at all....you have to keep your job to survive....there is nobody that can help you, [financially] if you stop working....people just do what they can with the sick person.”

Therefore a distinct need for income generating activities in the area was required to accommodate the changing needs.

Theme 5: Community concerns for the future ability to provide home care for PWA's

It was vital to establish the leaders concerns pertinent to the caring for PWA's in the home environment. The indicators included health information; managing AIDS-related conditions; the availability and accessibility to clean, safe water and resources that the participant understood to be essential for the provision of home care.

- **Health information**

The participants believed that relevant health information on AIDS home care was not reaching the majority of families in Bhambayi. They felt that appropriate health education of the community would greatly reduce the stress of families engaged in caring for their ill family members. However the leaders appreciated the health information that was made available to PWA's in the HBC program.

“.....health information needs to be more widespread than at present....the HBC program is reaching only a few families...this is causing a problem with those families that are having to care for their family members on their ownthey do not have any knowledge of what to do.”

- **Managing AIDS - related conditions**

According to the participants, the community first consulted with the traditional healers for most health related problems including HIV/AIDS. Traditional medicines for pain and improving body strength and home remedies to control symptoms of diarrhea and dehydration were also used. This finding is consistent with the role of traditional medicine in AIDS home-care (see 2.5.3.2).

“.....most of our people visit the traditional healer first when they get sick....they also use some home remedies according to our tradition....but these don't seem to help with AIDS.”

It was common practice, as was also identified by the researcher during the project process, for people in Bhambayi to use traditional medicines for most illnesses. Many PWA's in the programme utilized conventional medicine simultaneously with traditional medicines.

“.....people also use traditional medicine at the same time with treatment from the clinic.”

Patients reported that the usage of conventional medicine on its own did not appear to satisfactorily address their opportunistic conditions. More often than not, PWA's sought conventional health care as a last resort, when the disease was in its advanced stages. Furthermore, the attitudes towards PWA's and the alleged chronic shortage of medicines at some health facilities, was reported as a deterrent to people seeking conventional health care earlier.

“.....it is said that treatment from the clinic on its own does not help much. ...people go to the clinic very late....when they are very ill... and they still do not get the treatment they need....nurses in some places don't care about such people (PWA's).

This resistance to seek health care was attributed to fear of stigmatization at health facilities and the knowledge that there was no specific treatment available for AIDS. Patients received only symptomatic treatment for certain conditions. This finding implies that AIDS medical care at some health facilities is possibly lacking.

“.....people are afraid to visit the clinic...people with AIDS are not treated well....they also know that there is no treatment for AIDS....what is the use of getting a few tablets that cannot help you.....you cannot even get pain tablets regularly.”

- **The availability and accessibility of safe water**

The Bhambayi community was supplied with safe, clean water that was free of charge from the local municipality. Householders were required to collect their water from

communal standpipes that were reported to be insufficient in number. One standpipe served approximately 200 households.

“.....there are too few taps for many people....it takes a lot of time to collect enough water for the day.”

The standpipes were a distance from the homes and this was of grave concern especially as more water was required to care for PWA's.

“.....even though this water is free, a home with a sick person has problems as more water is needed for washing and cleaning.”

A community leader, who had recently lost her adult daughter to AIDS, said that she could only manage to bath the patient every alternate day, as providing care was arduous and time consuming. Her burden as a caregiver was especially heavy as water had to be fetched from a distance and sanitation and washing chores could not be carried out in the home. She had clearly felt bad about being unable to bath her more frequently.

“.....this tap is very far from my house.....I only had time to fetch about six containers and on some days when my child was very ill, I had so many things to do that I did not have the strength to fetch extra water.....I used to bath my child every other day...this was painful to me as a mother....there was no other way.”

This clearly indicates that the community understood what 'proper care' meant, but the inability to provide it, was due to the lack of resources.

- **The lack of material resources**

The participants were critical of the general lack of adequate material support and resources from the HBC program for families affected by AIDS.

“.....the leadership feels that there needs to be more support, like food and equipment from the HBC program for all those families affected.....too few people are being

helped...this program has been going on for three years now....more needs to be done...our people are suffering.”

Theme 6: Other concerns related to community AIDS care

- **Community attitude to AIDS**

The participants believed that the community was in denial of the seriousness of the AIDS epidemic despite being aware of the existence of AIDS and witnessing its impact on the community. The people of Bhambayi were afraid to get involved in AIDS care, and therefore appeared to ignore the condition.

“.....the community knows of AIDS, as they see many people in the community suffering with the disease...but people are afraid of getting involved in caring for PWA’s....they choose to ignore the problem.

- **Lack of assistance from community health worker (CHW)**

The local community health worker (CHW) was an individual from the Bhambayi community who was trained by the DOH to assist in specific community health issues including the care of community members with chronic conditions such as HIV/AIDS. The Bhambayi community leaders expressed dissatisfaction in their designated CHW’s response to the needs of PWA’s. They alleged that the CHW was unreliable and that she served the community selectively as most of the sections in Bhambayi were not visited.

“.....the community gets very little help from the CHW....she is known to visit and care for only certain people in certain sections....she does not visit all the sections.”

They further alleged that the CHW’s appointment was politically motivated and that it appeared that care was provided to families on ethnic grounds.

“.....this appointment was politically motivated many years ago.....she attends to friends and immediate neighbors only.”

The participants were further disturbed by their lack of confidence in the CHW, regarding the confidentiality of AIDS issues.

“.....this CHW is known for talking to everybody about a person with AIDS. The community does not trust her.”

- **Insufficient resources causes frustration**

The community leaders were aware of the material resources that were available from the home based care program. However, one participant alleged that these resources were insufficient, as caregivers had complained that they were frustrated by the apparent chronic shortage of supplies. The community expectations were very high, beyond the capacity of the program. Despite ongoing consultation and discussions, some leaders would not accept that the helping agency had limited resources.

“.....there needs to be more resources for the people....the leaders get many reports from the community that there is always a shortage from the HBC program....this is causing much frustration for our people.”

- **Resources not accessed due to fear of stigmatization**

There was a diversity of feeling regarding resources for HBC as two participants alleged that the community was afraid to ask for resources due to the stigma associated with AIDS in the community.

“.....people would rather suffer than ask for resourcesthe stigma of AIDS is too strong in Bhambayi.

- **More caregivers needed**

The community leaders felt that there were insufficient volunteers to cover the area even though there were people in the community that were willing to be trained. Volunteer retention was a problem in this community as some trained volunteers moved on with the acquired skills into income generating activities.

“.....there are too few committed caregivers to cover the area...many sick people still go unattended....we need more volunteers.....people are willing to be trained.”

- **Difficulties in transporting very ill patients to clinic**

The participants felt strongly about the difficulties in transporting the very ill people to the local health facility, as the absence of patient stretchers and wheelchairs compelled the caregivers to use wheelbarrows.

“.....we feel bad when our people are taken to the clinic by wheelbarrow....we need at least a stretcher and a wheelchair.”

- **Support for HBC**

A community that is under-resourced cannot be expected to care for PWA's in the home environment on their own, as AIDS presents with multiple problems that is stressful. Volunteers and families of PWA's require ongoing support from the helping agency and the health system. The Bhambayi community received regular support from the HBC program but none was forthcoming from the Department of Health.

Limited support from HBC program

Despite the support of PWA's and their families received from the HBC program, the participants felt that more support was needed.

“.....the Technikon should have more staff working in the program.....the only person in the field is Sister Benjamin. There are many issues that we as a community would like to address to the management, for example....we never see them.”

No material support from DOH

There was no material or psychosocial support from the health facilities for AIDS home care during the project process. PWA's received medical intervention only and were sent home to be cared for by their families. Attempts to develop a partnership between the

community and the local health facility had failed during the project process. Bhambayi did not fall into the local PHC catchment area, hence there was no budget allocated for home-based care in Bhambayi.

“.....a patient is seen at the clinic and receives some medication only....nobody cares about other problems they may have....such as food, the needs of their children or the need to apply for a grant.”

- **Slow response from Department of Social Development**

A referral system is essential for the continuum of care for people living with AIDS. The project was in its early stages and a relationship was being developed with other service providers. There was therefore no formal referral system established in Bhambayi. Referral was mainly by word of mouth, whereby people were provided with the relevant information on the available resources and encouraged to seek assistance from the appropriate helping agency. The slow response from the Department of Social Development was a source of frustration to the community. A similar study of AIDS care and support conducted in South Africa showed similar findings (see 2.6.5).

“.....our people are frustrated with the Social welfare.....they are so slow....especially with grant applications..... we know of very ill people whose grant was approved only after they had died of AIDS....now their children suffer with nothing.”

Figure 4.8 below illustrates the community leaders' perceptions of need in respect to AIDS home care.

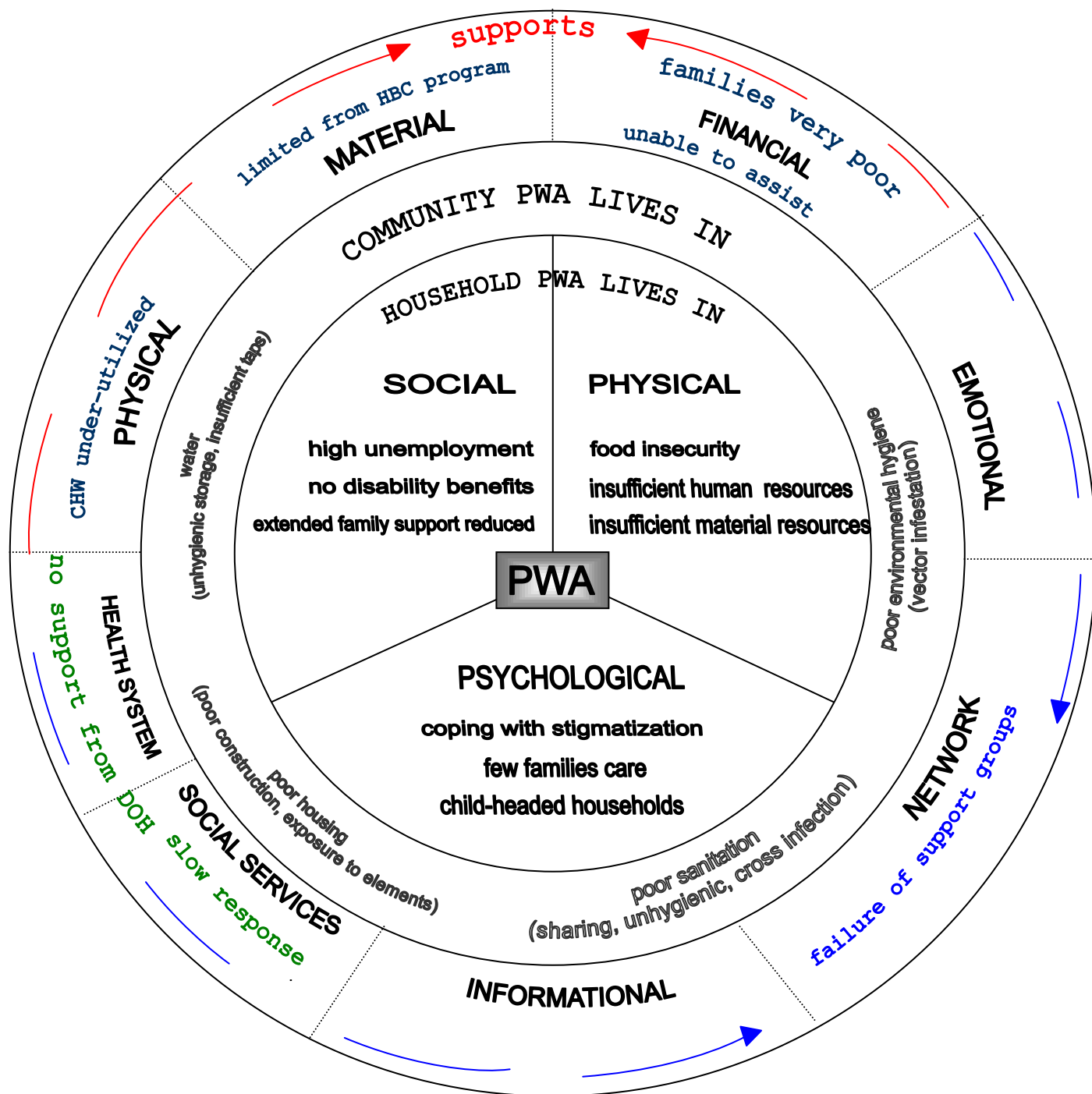


Figure 4.8: Perceived needs of community leaders

Conclusion

Each community has its own dynamics that would determine the level of commitment in addressing community concerns whether they are of political or social in origin.

The perception was that the Bhambayi community was in denial of the problems associated with caring for the ill and chose not to get involved. Neighbors were intent on their own need to survive and did not assist or support affected families in any way. However one should take cognizance of the level of poverty, discrimination associated with HIV/AIDS and the struggle for survival in this community.

There needed to be a wider distribution of health information to the greater community as the current program reached only a minimal number of families. Most terminally ill PWA's were cared for in their homes by the HBC team. It is incorrect to assume that home care is necessarily the best care for PWA's in an under-resourced community such as Bhambayi, since it emerged that the culture of caring was being eroded by the absence of extended family and the nature of this community.

Contrary to common belief, one community leader stated that he was unaware of any child headed households in Bhambayi. However, four participants stated that affected children, especially the girls in affected households, worked as domestic workers at weekends and after school in order to assist their families financially.

Food insecurity, the need for suitable equipment to transport the immobile patients to the health facility, a sustainable source of material and human resources and support from the Department of Health, were identified as serious concerns amongst all the study participants. Additionally, a more serious concern was that the valuable resource of a trained CHW was being underutilized in Bhambayi.

Despite the benefits of the existing HBC program, the service had failed to meet the high expectations of the community leaders as indicated by the participant's criticism of the apparent inadequate material resources and support.

4.3.4. COMMUNITY LEVEL: COMMUNITY VOLUNTEERS

This objective was intended to determine the perceived needs from the perspective of the community volunteers as they would be better informed of the needs required for home care for PWA's in the Bhambayi community, than the community at large. These included the physical, material and psychosocial needs that would be considered as being necessary in order to render home care for people living with AIDS.

Five themes emerged concerning this enquiry. These included physical, material, psychological, individual health care needs and support for home care volunteers which are discussed below.

Theme 1: Physical needs

The most stressful aspect of HBC, reported by the volunteers during the project process, was caring for destitute people with AIDS. The discussion is described below.

- **Housing**

Alternate accommodation for destitute PWA's

PWA's were often abandoned and neglected by their families. Given that Bhambayi is a poorly resourced area, there was no alternative accommodation for these people. They could also easily be evicted from their homes by an unsympathetic landlord, as they had no source of income since their illness. PWA's found themselves homeless and would therefore resort to living on the streets. The volunteers had difficulty in caring for them under these circumstances.

“..... some of them are staying on the streets as they do not have a place to live, because where she used to live, the owner has chased her away when she became sick and now she does not have money to pay the rent and now she sleeps anywhere.”

Homeless ill people in one section of Bhambayi were sometimes placed on the property belonging to a shebeen owner on a temporary basis, until the family could be traced. The patient required additional care and resources such as blankets and clothing and regular supervision by the volunteer.

Theme 2: Material needs

- **Nutrition**

A chronic food shortage, especially in the homes of very ill PWA, was a serious problem in Bhambayi. This could be attributed to the high unemployment rate in the area. PWA's were especially affected by the inability to generate any income due to their deteriorating health.

The volunteers prepared soup obtained from the HBC project.

“..... you find that she has not eaten in 3-4 days, not until we get soup from Sister Benjamin.”

In some instances, the volunteers shared their own food at a great cost to themselves, in order to feed the PWA. The volunteers experienced tremendous discomfort at having food for themselves, whilst some sick person in their care, was hungry.

“We end up bringing stuff (food) from home that was for our families. Because it is not nice to eat whereas you know that there is someone who is sick and does not have food. We take from our families and try and cook for them and that that makes it better.”

Many PWA's discontinued their treatment due the lack of food intake, especially when medication was to be taken after meals.

“.....the big problem is that the patient does not have food but needs to take treatment after meals. Others do not take their treatment because they cannot take their treatment without food. That is the main problem and not having the facilities (resources) to care for them. They need to get us food to help that person at a particular time we are with her.”

Insufficient food aid

Food aid for PWA's was in the form of fortified Soya soup powder and Soya mince that was distributed from the HBC program on a weekly basis. PWA's also received occasional small food parcels donated to the program. This was reported to be insufficient to meet the PWA's needs. The National Integrated Plan (NIP) was intended to assist affected families with regular food parcels, but it was reported that very few families benefited from this program. The HBC team experienced great difficulty in meeting this essential basic need.

- **Shortage of equipment**

Essential equipment such as wheelchairs and patient stretchers were urgently needed in order that very ill immobile patients could be transported to the local PHC with dignity and in safety. Other HBC equipment such as gloves and aprons were also in limited supply. The volunteers believed that these resources were essential to render quality care to their patients.

A very ill, debilitated PWA, who could be bed-ridden, also needed to access the health facility with the assistance of the HBC team.

“..... if a sick person cannot wake up, as a volunteer you do not always have money to hire a car to take her to the clinic if need be.”

The volunteers used a wheelbarrow to transport this type of patient, and were constantly aware of the discomfort that was experienced by the patient.

“.....she may not be able to walk, you do not have a stretcher, you cannot manage to carry her, you at least think of a wheelbarrow and it will hurt her also. You know we cannot work like this and we have lots of problems.”

“OK what hurts me most is that we do not have a working set (of equipment) for the community. I can be happy if someone can think about it that it is too far for us to get to the community and take the patient to the clinic. If they can maybe provide us with wheelchairs, because it is difficult to take a very sick person and put her in a wheelbarrow. That’s not good for us, (the wheelbarrow), but we end up doing it. It’s like you are killing that person if you put her in the wheelbarrow, but we do it because we have no choice.”

“They need to get us a working set like gloves and aprons, the whole set, to help that person at a particular time we are with her.”

Improvising to meet the need

Transporting a very ill patient from the settlement to the health facility was a major concern. Some homes were a distance away and hiring a car was expensive. Neither the patient’s family nor the HBC team had the financial resources to meet this expense. The volunteers therefore improvised by transporting the very ill, immobile patient, by wheelbarrow.

“.....if the sick person cannot wake up, as a volunteer you do not always have money to hire a car to take her to the clinic if the need be. She may not be able to walk. You end up asking some people to help you take her. Even if they agree, you do not have a stretcher, you cannot manage to carry her, at least think of a wheelbarrow, and it will hurt her also you know we cannot work like this and we have lots of problems.”

Infrastructure, such as roads were in the early stages of development in Bhambayi therefore the majority of homes informal were inaccessible by road. The volunteers understood the importance of assisting their charges to the health facility and made every

effort by assuming the responsibility of doing so. It was reported to the researcher, that the two wheelchairs donated to the project were damaged by excessive usage on corrugated roads during the project process.

- **Lack of funding for stipends**

The HBC team comprised of community members who were in a similar position as the rest of the Bhambayi community. The researcher was of the opinion that the majority of the team did not have any personal financial reserves. Only two members of the team had spouses who supported them financially. The other members engaged in periodic work in the domestic sector to generate income to sustain themselves and their families. Financial resources were therefore a sensitive issue within the team.

Using personal funds to meet patients' transport costs

A PWA requiring further medical management was referred from the local PHC to the District Hospital. The patient could only access the hospital by public transport, as the hospital was approximately 10 kilometers away from Bhambayi. The volunteers in attendance would utilize their personal funds to pay for transport, as they understood the importance of such a referral.

“.....sometimes the clinic refers the patient to the hospital and you have to go with her. The hospital may not admit the patient and you have to take the patient back home. You are using your own money for both of you. It is so difficult; it is not easy, very difficult.”

Using personal funds to purchase fuel

A PWA living alone may not have any fuel for the cooker in the home. The volunteer would then have to buy paraffin, utilizing their personal funds.

“.....if she does not have paraffin, we have to buy her paraffin.”

In the absence of proper funding, in the form of stipends, the volunteers were under constant pressure of drawing on own meager resources in order to meet the basic needs of

their charges, which was a source of frustration. However, despite these problems, they were committed to do the right thing to care for their community.

Theme 3: Psychosocial needs

A number of problems in the provision of AIDS community based care, were identified by the home care volunteers. These problems are discussed below.

- **Community attitudes to PWA's**

The volunteers believed that infected people needed to be cared for in Bhambayi, but found that most ill people living in Bhambayi were sent away to the village of their birth.

“.....those looking after him must love him, because others even say to take him to the village of his birth... Whereas he has to stay here and they need to take care of him.”

Sick people, especially with dual infection of TB and AIDS tended not to be loved, but appeared to be abandoned by their families. They were left on their own with nobody to assist them with essential activities daily living such as bathing and feeding.

“.....sick people in the community with TB or HIV are not loved by family members any longer. So we the volunteers have to take care of the patient as he is on his own in the house.”

- **Caring for the neglected PWA**

Sick people living in isolation are cared for by the HBC team of community volunteers. They would assist the patient with activities of daily living such as personal hygiene, food preparation and feeding. The volunteers used their own money to buy fuel for the cooker when required.

“.....you see these people who are sick are just here in the community. Maybe the person stays with a partner. The partner just leaves her like that very sick in bed. You would take your team to assist you bathing this person and feeding her with food, if you

have soup, you cook it for her. If she does not have paraffin, we have to buy her paraffin.”

“.....they’ve got TB or HIV, the family do not love that person any longer. So we , the volunteers have to take care of that patient, bath her because you find that patient is on his own in that house. There is no one that can comfort her or do anything for her.”

- **Concerns expressed by PWA’s and their families**

Although this enquiry was intended to determine the concerns of both the PWA and the family, the volunteers focused only on the PWA’s concerns. This could possibly be due to their primary focus being more keenly attuned to the concerns and needs of the PWA.

Impending death from AIDS

PWA’s were acutely aware of the nature and the course of the disease and were anxious about their funeral arrangements as they had no personal financial resources.

“..... they feel that death is near and worry about who will bury them and how they will be buried because the ill patient does not have money to care for themselves nor their children.”

Concern for their children

Most PWA’s expressed their concern for their children after their death. They worried about guardianship and the wellbeing of their children. PWA’s also expressed the fear of possible abuse of their children after their death.

“.....others are scared whom are they going to leave their children with.”

“.....most people with AIDS usually mention what my colleagues have mentioned, the concern for the children and that they are not yet ready to die. They did not know that they would find themselves in this position, they have not been working, do not have any money, and in their entire lives were unable to maintain their children, so when they die,

they worry about who will look after these children, how would the children live, will the children also die and the fear of the children being abused by anyone.”

Fear of disclosure of HIV status

Stigmatization associated with AIDS was a common fear expressed by PWA'S in Bhambayi. People were afraid of the family's reaction to disclosure. They were also afraid of isolation by the community should their AIDS condition become known. PWA's felt that their disclosure and the serious social implications of the disease were not taken seriously, even by partners. They were afraid of possible ridicule and being embarrassed by the community.

“..... they were also afraid of what their families would say if they found out. If someone in the community knows about the illness, they would not visit that person anymore. What worries the AIDS patients is that they do not like talk about this disease because some people just take it as a joke. When partners have a fight, he will shout at her about the AIDS problem.”

Inability to cope with societal interaction

Some PWA's in Bhambayi did not attend the local PHC in order to avoid the embarrassment of being identified by the nursing staff. They therefore preferred to attend other clinics, to maintain anonymity whilst receiving treatment and care for their AIDS problem.

“Some people are so scared to go to the local clinic because the nurses know them. Then we would suggest they can go to any other clinic. They like going to other clinics and tell their families and you that they have tested positive.”

- **PWA's lost touch with family**

It was common to find a very ill PWA living in isolation in Bhambayi. Some people arrived and settled in Bhambayi as teenagers and had consequently lost all contact with their roots and their families over time. At a time of grave illness, the PWA's family

needed to be informed and the patient taken to the place of his birth in order to prepare the person's passage for a peaceful death.

“.....another thing that hurts is that other people here in the community came here when they were young and they do not know their homes (place of birth), and she is sick and she does know where her parents are. They may have arrived here (Bhambayi) at the age of 13 and now she is 34 years old, that's our main problem.”

Theme 4: Individual health care needs

- **Motivating people to seek health care**

The volunteers had difficulty in meaningful engagement with very ill people, due to the reluctance of people seeking health care, especially those requiring an HIV diagnosis. A diagnosis needed to be established in order that appropriate care could be provided by the home care team. The volunteers had the ability to identify people who may be HIV positive particularly those with a history of prolonged ill health, and showed physical signs of deteriorating health. Despite the apparent difficulty of patients being reluctant to discuss their health problems, the volunteers did not abandon the patient in need of assistance. Instead, the patient was referred to the HBC sister, who would do a home visit in order to assess the situation.

“....others do not tell you the truth and we do not just leave her alone, but have to think of her life and how we can help her. We look at the treatment from the clinic and then tell our Sister-in-charge that there is a sick person in a certain house and give sister the report. The sister makes a home visit and the patient may tell the sister her problem.”

The patient would be advised to visit the local clinic for a diagnosis. People were inclined to consult the traditional healer, often as a first choice of intervention for health related problems. This finding is consistent with the role of traditional medicine in AIDS home care (see 2.5.3.2).

On enquiry, if a patient had not improved on TB treatment and loss of weight was persistent, the patient would be counseled by the volunteer and encouraged to take a blood test at the local clinic.

“.....a patient may tell you that they do not know what sickness they have and that they have been sick for a long time. Then I would ask if they have been to the clinic. Some say yes, others say no. Some do not visit the clinic at all. I would beg her to go to the clinic even if she were visiting and had trust in other places, because sometimes she cannot get much help at the traditional healer. I advise that the clinic can help an find out exactly what sickness she may have. If the patient does not get any better on treatment and is still losing more weight and power, I would encourage her to have her blood tested for the virus.”

- **People reluctant to attend the local PHC**

Community members in the HBC program had expressed their fear of identification by the health personnel at the local PHC. They were encouraged by the volunteers to visit any other clinic to seek health care. It is imperative that the respect for human dignity is observed by all health personnel (see 2.6.4.2).

People preferred to visit other clinics and found the courage to disclose their HIV positive status to their families and the attending volunteer. The volunteers believed that seeking health care and the subsequent disclosure of a positive HIV status could be attributed to the proper counseling of an individual. Therefore counseling and support of PWA's is important to facilitate disclosure (see 2.5.6.3).

“.....some people are so scared to go to the local clinic, because the nurses know them. Then we suggest that they can go to any other clinic. They like going to other clinics and tell their families and you that they have tested positive. OK, the way you have counseled the patient may have assisted her in getting help.”

Theme 5: Lack of support for volunteers

- **Informational support**

Home care for AIDS at community level, considers the physical, social and psychological aspects of caring. These areas were dealt with at length by the AIDS counseling course facilitated by DIT and the HBC training that some of the volunteers attended facilitated by the researcher and the Department of Health, during the project process. This training would have prepared the volunteer to respect a PWA, even if mental problems occurred. Existing community based- programs need to be utilized for sustainability (see 2.7.6.4).

The volunteers believed that despite the training received, more in-depth HBC training was necessary in order to cope with the multitude of problems encountered in the field.

“..... the first thing we have to know as volunteers is that when we get this training we need to have knowledge, so that we know what we are going to say to the sick person. If she is telling me about her problem, how am I going to handle it? In fact we need to be taught how to nurse a person.”

PWA's have to cope with a variety of different problems, including medical conditions and psycho-social problems.

Some of the more commonly identifiable conditions include: recurrent or persistent *Candida albicans* in the mouth and vagina (in women) ; herpes zoster and herpes simplex, skin rashes such as itchy maculo-papular rashes, seborrhoeic dermatitis and fungal infections; weight loss for no obvious reason; fever or night sweats; diarrhea that is ongoing for many days or weeks; dyspnoea, tachapnoea and cough, pulmonary and extra pulmonary tuberculosis, genital ulcers that do not heal with treatment; anaemia for no obvious reason and neurological problems, such as memory loss, personality changes, severe weakness, fits and peripheral neuropathy.

Psycho-social problems are often related to coping with the disease and crises, such as anxiety, fear or depression which may be related to the thoughts of dying. It would appear that coping with personality changes and memory loss of a PWA, presented the volunteers with difficulties.

“..... this illness comes up with different illnesses, sometimes a person is mentally disturbed and they are so traumatized including the community members around them. The patient will run away from you and you will have to run after her.”

- **More human resources required**

The limited number of active volunteers found difficulty in caring for the ever increasing number of ill people in the community needing care. It was difficult to retain an intact team throughout the project process. Volunteers were only able to commit a few hours a week to HBC as they needed to engage in paid employment in order to sustain themselves and their families.

In order to ensure greater coverage of the widespread settlement, the HBC team was divided into pairs and each pair of volunteers was allocated to the eight sections of Bhambayi.

“... I can say something what hurts about AIDS patients is that as we are divided into sections you find that there are few volunteers to care for many AIDS patients.”

In some instances the teams had to work in a different section allocated to them, as the regular team was unavailable, due to other commitments. Each section had its unique dynamics, in terms of people preferences according to ethnic differences.

“.....when I get to a home and find a patient who needs care, all on her own, she may not want me to help her, but may want some other volunteer.”

Although the community appreciated the concept of team work in the provision of home care, they were unable to consistently practice this, in the Bhambayi community. The volunteers experienced some difficulty in working with unfamiliar groups, given the nature of AIDS care. They expressed a sense of hopelessness and required reassurance and support by the researcher.

“.....and this is so painful because we work as a team, we have to help each other but the patient can chase you away from her house. It becomes difficult to help such patients.”

It was evident that not all the volunteers were accepted by the entire community, despite their apparent commitment.

- **Difficulty in accessing social grants**

Given the need for government assistance with social and disability grants amongst PWA's, volunteers experienced ongoing difficulty in assisting people to access these grants. The lacks of correct documentation such as the death certificate of a spouse, a personal identity document and birth certificates for the PWA's children were cited as the main reason for this problem. Other documentation such as proof of a positive HIV test was also required by the social welfare services in order that a PWA could be assisted. Many PWA's and their children were not registered at birth, a common occurrence in people who had delivered their children in the rural areas. This finding is consistent with a similar study conducted in South Africa (see 2.6.5).

“.....the other problem here in Bhambayi, maybe a person is sick, at the same time she does not have an ID (document) or anything. She has children and has no food. These children do not even have birth certificates. Maybe even the husband has passed away, she does not have a death certificate, she's got nothing.....maybe we try to help her. And maybe she will not even get that help, because she does not have anything.”

Figure 4.9 below illustrates the community volunteers perceptions of needs required for the provision of AIDS home-care.

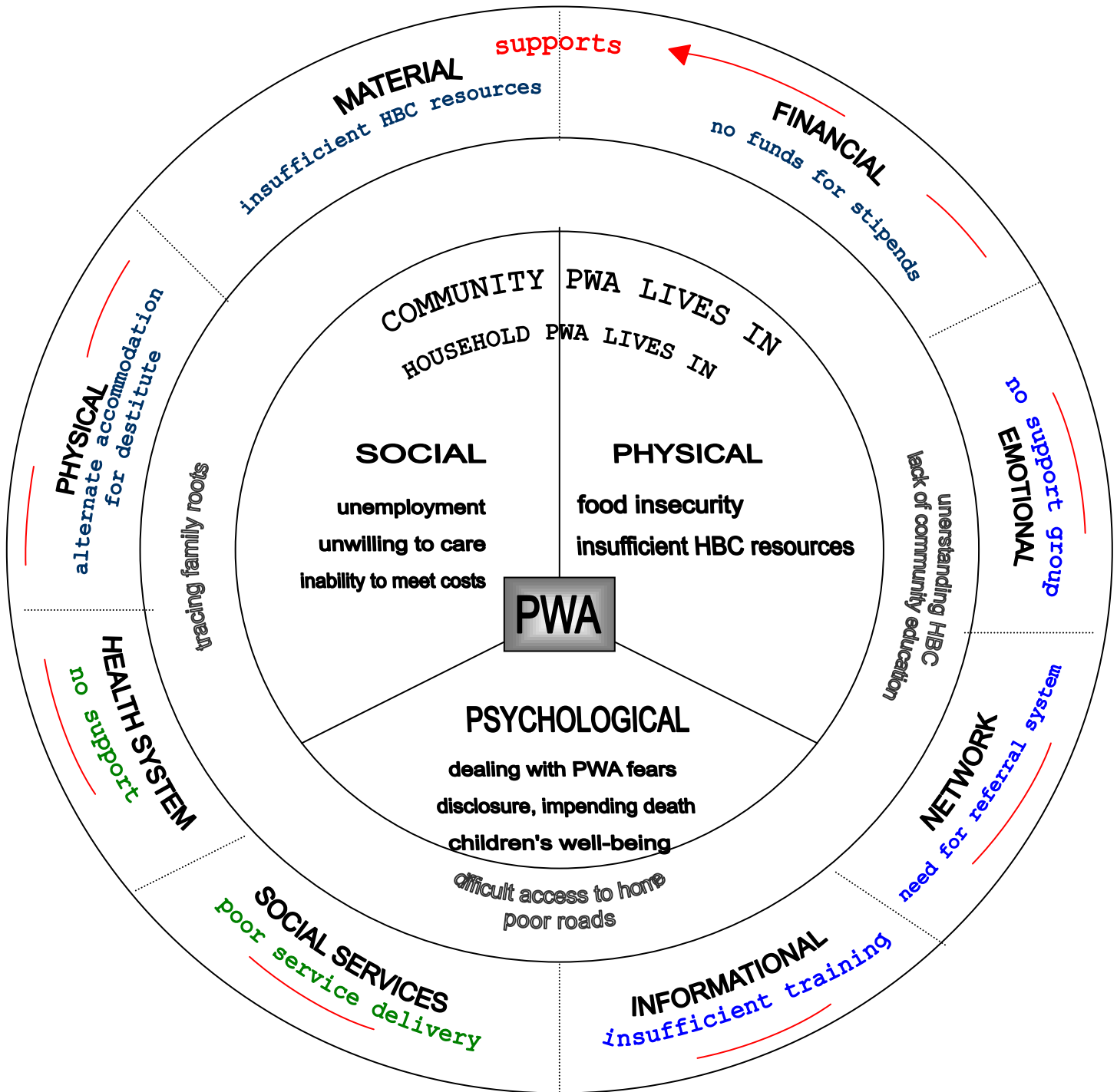


Figure 4.9 Community level: community volunteers perceived needs

Conclusion

It is often assumed that families would automatically care for their ill and frail family members. Various factors such as fear of contracting the disease, stigmatization, the erosion of extended family and family ties and level of poverty were identified by all the volunteers during the project process, as possible causes of this apparent neglect. Furthermore people were so intent on survival, that caring for the ill was left to the volunteers.

All the volunteers believed that food aid, further training to meet the innumerable challenges encountered in the field, adequate equipment to perform their work, additional human resources to reduce the ever increasing workload and stipends to reimburse costs of caring incurred, would make their work easier. Despite their personal limited resources, the volunteers were able to think beyond their own needs, in order to feed a PWA when required.

All the volunteers believed that PWA's should be taken care of in their homes in Bhambayi by their families. They had found that some families tended to isolate and neglect the very ill and frail PWA's. The volunteers had difficulty in caring for PWA's who were homeless. The volunteers made every effort to trace family members of terminally ill PWA's in their care, particularly those who were living in isolation. They believed that it would reduce the financial burden of the families as it was expensive for families to transport a deceased person to the rural areas for burial. Furthermore, the attending volunteer was also required to furnish this information to the police services, on the death of an individual.

The volunteers had experienced many problems in the process of rendering HBC. The reluctance of people to seek health care for a definite diagnosis and to disclose a positive HIV status was common problems that were dealt with by intensive counseling and support. People who were afraid to access the local PHC for AIDS care were encouraged to seek assistance from other health facilities.

The most common concerns expressed by PWA's to the volunteers included: the fear of impending death, concern for their children's welfare on their death, the fear of disclosure of their HIV positive status and their inability to cope with societal interaction.

Furthermore they believed that support from the social welfare agency in accessing financial aid for PWA's would assist in alleviating the level of distress that they shared with their patients.

It can therefore be concluded that the volunteers were a committed group of people with the fortitude to care for PWA's in Bhambayi, under very difficult conditions. They were able to use their acquired skills in HBC and AIDS counseling to provide care and support for their charges.

4.3.5 OUTCOME FOR OBJECTIVE 2

4.3.5.1 Perceived needs and expectations

Three themes emerged in response to the enquiry, and all the participants expressed their most urgent physical, social and psychological needs and expectations for community based AIDS care. This section summarizes the findings and presents their commonalities and differences between the levels.

Table 4.2 below shows the comparison of themes and categories in relation to the level of the community. It highlights the commonalities and differences in each category. Themes and categories are listed on the left hand column. To the right of this, the actual expressions are aligned with the category of each level of the community studied. In places there is an absence of a comment which shows differences between the levels.

Table 4.2 : Summary and comparison of themes and categories for Objective 2 in relation to levels of the community

Themes and Categories	Level of the community			
	PWA	Caregiver	Community leader	Community volunteer
Physical	lack of food unable to fetch water, cook, clean home	lack of food , no respite	food insecurity, insufficient human and material resources	food insecurity, insufficient HBC resources
Social				
support	limited from extended family	limited from extended family	extended family support declining	
financial	no source of income	limited income-unable to meet basic needs	high unemployment no disability benefits	no stipends, limited personal funds
housing	poor ventilation, no privacy	poor ventilation, no privacy insufficient living space	exposure to elements, poor construction	no alternate accommodation for destitute patients
sanitation	night use of bucket-loss of dignity, fear of injury due to poor construction in bad terrain	fear of cross infection sharing unclean toilets	new toilets not built due to housing development restrictions	
water	source (taps) distance from home	collection time- consuming insufficient for laundry	insufficient taps, poor maintenance	
Psychological	no support groups loss of dignity, lack of privacy	fear of infection unmet needs of children insufficient information	coping with stigmatization few families care about AIDS child headed households failure of support groups	no support group, dealing with PWA fears of disclosure, impending death, children's well-being

Theme 1: Physical needs

All the participants, at the four levels in the study agreed that there was a critical shortage of food in Bhambayi. The majority of family caregivers had no respite from caring for their ill family member with AIDS. Participants at the community level felt that there were insufficient material and human resources to meet the needs of the growing number of PWA's in the community.

Theme 2: Social needs

The majority of participants received very little material or financial support from their extended families. All the PWA's had no source of income. Their caregivers had a limited income; hence their difficulty in meeting their basic needs such as food and clothing. The community leaders felt that the high unemployment rate and the absence of unemployment and disability benefits for PWA's contributed to the lack of financial resources in affected households. The volunteers did not receive any stipends and had limited personal funds which they sometimes used to meet the PWA's needs. All the participants agreed that the poor living conditions such as overcrowding, the lack of privacy, poor ventilation and poor construction were not conducive to quality home care. Furthermore the community did not have alternate accommodation for destitute PWA's. The poor sanitation in Bhambayi was believed to be a source of cross infection as the community was un-cooperative in maintaining proper hygiene. Toilets were shared between two to ten families. The PWA's expressed embarrassment at having to use a bucket at night. They also were afraid of injury from falling at night as toilets were unlit and built on uneven ground. According to the community leaders, there was a prohibition on the construction of new toilets due to the government housing development project. Accessing sufficient water for domestic use was time-consuming for caregivers as there were few standpipes that were a distance away from the dwellings.

Theme 3: Psychological needs

There were no support groups for PWA's or their caregivers. Coping with the disease was in itself stressful for all people with full blown AIDS. This was exacerbated by the lack of privacy and the consequent loss of dignity in their homes. Caregivers expressed their sense of helplessness at the lack of adequate health information. They were in constant fear of becoming infected with AIDS. They were also distressed by their financial incapacity to meet the needs of the affected children. The participants at the community level were concerned that the attempts to establish support groups had failed due to stigmatization experienced by those who attended them. They also felt that the increasing number of child-headed households needed urgent attention. Furthermore they believed that few families in Bhambayi cared about AIDS and refrained from assisting those in need of care. The volunteers appeared to carry the AIDS community care burden in Bhambayi. There was no support group for these volunteers. They were at risk of burnout at having to deal with the multiple problems of care in this poor community.

4.3.5.2 Summary of community needs and expectations

- they identified the urgent need for food security, that material and human resources for AIDS home-care was inadequate and that family caregivers had no respite from caring;
- they identified the total lack of financial resources, poor living conditions that were not conducive to quality care of chronically ill people, poor sanitation with health risks and inadequate water standpipes that added to the burden of care for PWA's in the home; and
- support groups for PWA's and volunteers were also identified as a need. Education of family caregivers was needed at community level. The needs of affected children required attention. They also identified the need for greater involvement in AIDS care by all families.

4.4. DATA ANALYSIS FOR OBJECTIVE 3:

To examine the community's organizational ability and present and future capacity to care for people with AIDS

The purpose of this objective was to establish the source of existing structures and individuals that were available within the Bhambayi community that could be of assistance to PWA's at community level. The community's organizational ability or lack thereof, would determine the present and the future capacity to care for PWA's. This assessment would then define points of contact between the community, health system and political structures. Certain interventions may have to be targeted at the individual or household level, whilst other interventions might involve the community's capacity to organize and respond competently to individual demands and needs.

4.4.1. INDIVIDUAL LEVEL: PERSON LIVING WITH AIDS

This objective was intended to determine whether the PWA's in Bhambayi were utilizing the services of the existing individuals and structures that could assist them in coping with AIDS.

Five themes emerged with this enquiry including accessing health care, management of symptom control in the home, family involvement in care provision, community resources and information on accessing social grants. These themes are discussed below.

Theme1: Accessing health care

Physical difficulties

Although the local health facility was less than a kilometer away from Bhambayi, it was reported that some participants experienced great physical difficulty in accessing the local PHC due to their deteriorating physical state.

“.....I walk to the clinic, very slowlyI feel weak and have to stop now and then to rest.”

These frail participants were assisted to the health facility by the volunteer.

“....the volunteer helps me to the clinic”.

Financial cost of accessibility

One participant reported that her family hired a car at enormous cost to get her to the health facility for medical treatment. The family borrowed the money from a money lender, as they did not have the budget to meet this cost. The PWA, being aware of the financial constraints on the family, expressed her distress at incurring this cost.

“....when I was very sick, my cousin borrowed some money and hired a car....it cost R100....she has helped me, but it is too expensive....I must try to walk.”

The researcher had observed that some people simply did not seek health care as their physical strength failed them. Attempts to negotiate transport for these patients with the local taxi association by the researcher during the project process had failed.

Theme 2: Managing symptom control in the home

This enquiry was essential to determine the source and type of care that PWA's received in the home (see 2.6.4.1).

- **Source of advice**

Family caregiver

Although the PWA would discuss any health problems with the family member providing care, the caregivers were not able to assist in a significant manner, as most caregivers were not part of the care plan within the health system and were consequently ill informed about the disease.

“.....I speak to my family about my sickness but when I have problems they cannot help me...they do not know what is happening with this sickness....they do not know what the doctor said to me at the clinic....it is too difficult.”

The volunteer

The volunteer, who is better informed than the family caregiver about the disease, was sometimes able to provide some helpful information that could assist the PWA.

“.....if the volunteer visits, I tell her my problems and maybe she can help me...if the volunteer cannot help me, then the HBC sister comes to visit me.

The health professional at the AIDS clinics

PWA's who were attending the AIDS clinics at the tertiary hospital and the PHC in the neighbouring suburb, consulted with the health professional in attendance.

“....I just tell the sister or the doctor my problems when I visit the clinic.”

• Treatments used

Traditional medicines

PWA's used a variety of herbal medicine obtained from traditional healers. They believed in these remedies and some were reported to be more effective than some conventional western treatments.

“....we believe in the medicine from the traditional healer.....sometimes it is better than the medicine from doctor...we have been using this for a long time.”

Home remedies

They would also resort to all known home remedies for symptom control.

“.....if I have diarrhea I mix some flour and water and drink it....if I can have some rice water I drink it....it helps to stop the diarrhea.”

“.....I burn this special wood if I have a headache.”

- **Attention to activities of daily living**

All the participants displayed a determination to maintain their independence for as long as possible by declining assistance with personal hygiene, personal laundry, feeding and caring for their young infants. Their responses are discussed below.

Personal hygiene

“.....I can try to bath myself slowly....my cousin helps me with preparing the bath water.”

Personal laundry

“.....it is not good for someone to wash your underwear....I just try to do it myself...as it is my cousin helps me with everything else.”

Nutrition

“....I try to eat slowly by myself....sometimes the sore in my mouth are too painful...my cousin makes some soft food for me....”

Caring for young infants

“....I like to care for my baby....I do his washing and feed him....it makes me happy....not so sad....”

Theme 3: Family involvement

Members of the household did all the heavy chores in the home of the PWA. These included food preparation, fetching water, heavy laundry, attending to environmental hygiene and caring for the children. (See 4.3.1, theme 2).

Theme 4: Community resources

- **Community leaders**

All the participants knew their community leaders.

Generally no assistance from community leader

It was believed that these leaders were to be consulted purely on political and community matters. PWA's did not consult these leaders on any health related matters as they considered it a private issue. Furthermore they did not trust the ability of their leaders to keep such information confidential. Community leaders therefore had not assisted these PWA's with any AIDS related problems.

“.....I cannot talk to the community leader about my sickness....he may tell others...I may even be chased away...these leaders are here for political problems in the community.my sickness is not for him to know.”

However, one PWA in the study was assisted by the community leader who was also a landowner and a relative. The PWA was exempted from paying any rental for her dwelling.

“....when I got very sick my uncle said that I do not have to pay rent anymore. He has helped us as we would have no place to stay. He is also the community leader for this section.”

- **Community health worker**

All the participants knew of the community health worker (CHW) who was also a resident in Bhambayi.

No assistance from the community health worker

According to the PWA's, the CHW had not assisted them in any way.

“.....yes I know the CHW....she cannot help me.”

CHW assistance was selective

They alleged that the CHW visited and cared for people in only selected areas in Bhambayi and that this practice was politically orientated.

“.....she only visits and helps certain people in certain sections.....she has never visited me, or anyone in this section.”

Lack of trust with confidentiality issues

They also felt that the CHW could not be trusted with sensitive health information, especially if it was related to AIDS. The CHW appeared to have the tendency of discussing the AIDS diagnosis with other community members, which was a serious cause for concern amongst AIDS patients.

“.....she talks too much about people suffering with AIDS....I will never talk to her or ask for her help...she will talk about my illness and problems to everyone in Bhambayi.”

• Community volunteers

All the participants knew the community volunteers engaged in HBC and were widely accepted as a reliable source of assistance.

Volunteers do regular home visits

The community volunteers played a critical role in HBC for people with AIDS in the Bhambayi community as researcher had observed that the community volunteers were regular visitors to people with AIDS in Bhambayi

“.....the volunteer is like my sister. She visits me at least once a week.”

Volunteers are the first contact for PWA's

In most instances the volunteer was the first contact within the community for very ill people.

“...I was very sickthe volunteer was the first person to advise me to also go to the clinic for some treatment. She has helped me; I can ask her about many things that worry me.”

A range of assistance provided to PWA's

The volunteers assisted the PWA's by providing relevant health information, referring people to appropriate agencies for assistance, distributing resources, counseling and assisting patients to the health facilities.

“.....the volunteer gives me some knowledge about how to look after myself and what I can do when I am sick”

“.....she told me how I can apply for a grant for my illness.”

“.....she reminds me to go to the clinic for treatment.”

“.....she checks that I take my treatment every day.”

“.....she brings me some soup and some clothes sometimes.....she gives me some gloves and teaches me how to use them.”

The volunteers had developed a relationship of trust with the PWA's and their families.

“...I can be happy with the volunteer. My secret is safe with her....I can talk to her about anything.”

Referral to the ward councilor

The ward councilor was a political leader accountable to the eThekweni Metro Council and not a Bhambayi community leader. However he was available to the community members who required assistance with legal and social matters. He was also a

Commissioner of Oaths and assisted people with compiling legal documents such as an affidavit. The volunteers referred PWA's requiring such assistance to the councilor.

".....she helped me to fix my ID. The councilor made me an affidavit."

Theme 4: Information on accessing social grants

It was reported that the PWA's consulted mainly with the traditional healer for all their needs including social problems. However, the researcher had observed that other sources of assistance only became known to the community, during the project process. As the community developed greater confidence in the program, they began to discuss these problems with the members of the HBC team. The volunteer would identify the problem and refer the PWA to the helping agency as required.

"....the volunteer knows these things....where to go and what to do...sometimes we get the right help....other times it is not so good."

".....I can go to the sister if I need to know something...she can help me sometimes."

Figure 4.10 below illustrates the community capability of support for PWA's.

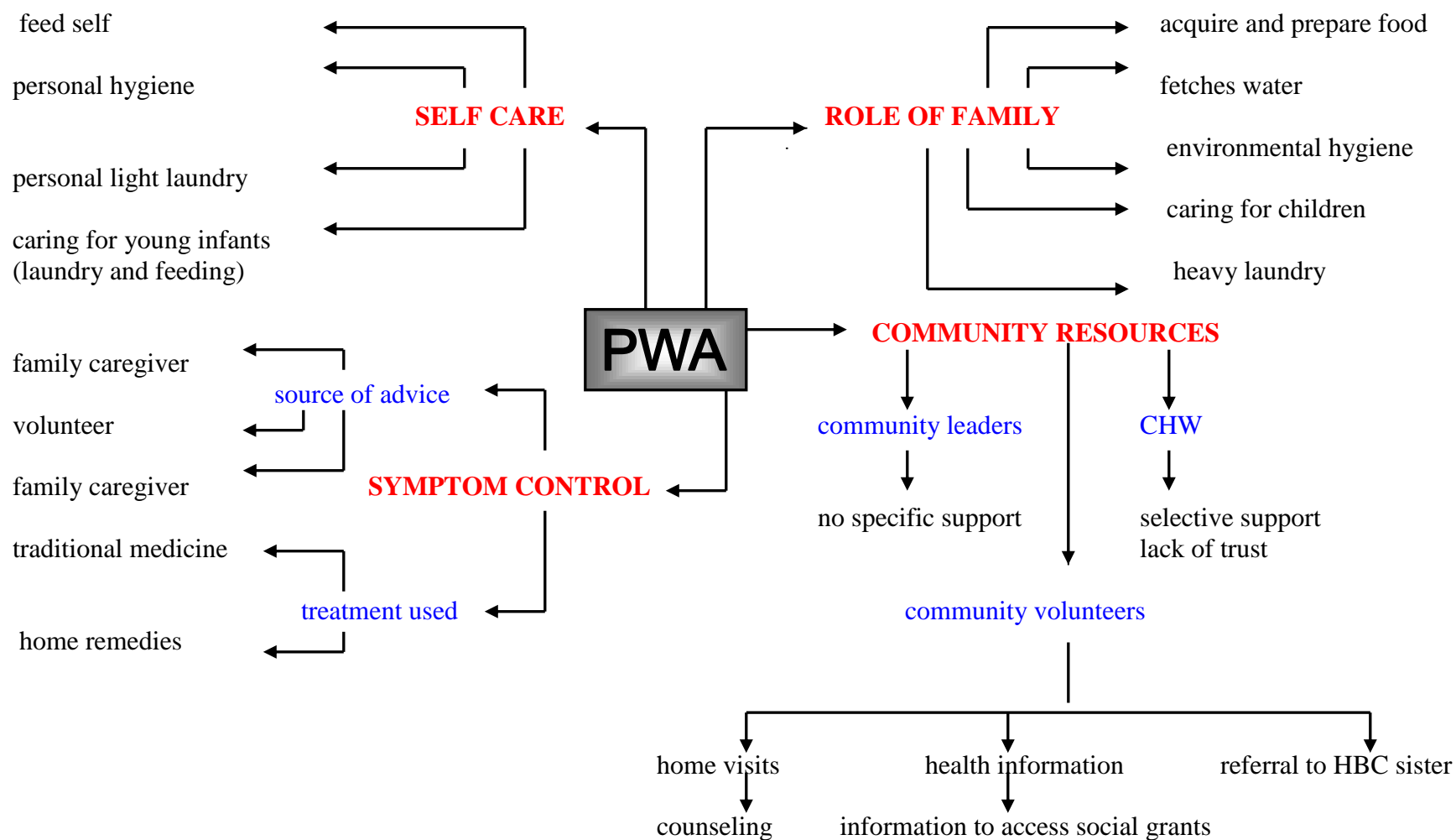


Figure 4.10: Community capability of support to PWA

Conclusion

PWA's believed in traditional remedies that they obtained from the traditional healer and home remedies that were part of their tradition. They would continue with these remedies to treat the symptoms for as long as possible and would only visit the health facility as a last resort when the symptoms were much worse. It was therefore not uncommon to find PWA's make the initial visit to a health facility in the advanced stages of the disease.

The quality of care and support varied at the health facilities. Individuals who received adequate medical care, counseling and empathy appeared to cope much better with the disease. Those individuals who did not receive this care at the health facilities were often distressed.

The principle source of assistance for the majority of PWA's was the HBC team. They helped in a variety of ways. The volunteers had developed a trusting relationship with the community during the course of the project process. Individuals who had reservations about this apparent trust, preferred to consult the HBC sister directly.

Community leaders were not consulted on AIDS related problems by the participants as they believed that health related issues were personal. Given the sensitive nature of AIDS, PWA's were wary of discussing these issues with their leaders as they feared the possible consequences of disclosure.

Although the community health worker (CHW) was well known to all the participants, none of the PWA's consulted with her on any AIDS-related issue. They feared a breach of confidentiality as the CHW was apparently reputed to discussing the community member's health and social problems with unauthorized individuals.

It can be concluded that the main cause for concern among PWA's was the lack of confidence in their leaders and the CHW which resulted in the underutilization of their expertise. The varied quality of health care for AIDS at health facilities was a further source of distress among the participants.

4.4.2. HOUSEHOLD LEVEL: FAMILY CAREGIVER

This objective was intended to determine the source and type of support that existed for families engaged in home care for PWA's in the Bhambayi community.

Five themes emerged with this enquiry including the source of assistance for home care, the role of the community leaders, the role of the community health worker (CHW), the role of the community volunteer and assistance from church organizations. These themes are discussed below.

Theme 1: Source of assistance for home-care

This assessment was required to establish the source and type of assistance that caregivers could access within the community.

The most common areas where assistance would be required as cited by the caregivers during the project process included: food shortage, social and health and social problems related to AIDS and nursing care.

- **Food shortage**

The caregivers depended on assistance with food from their families, the volunteer and food donations from the project.

“....the volunteer helps me with soup”

“....she sometimes helps me with food from her own home....I am struggling as I am not working.”

“....my family sometimes helps me with food, when they have some money.”

Attempting to overcome food shortage

Affected families had great difficulty in acquiring sufficient food for the family. However, some households grew their own food in whatever space they could utilize. This indicates that these individuals had the capacity to help themselves, no matter how small that may be.

“.... I try to grow some vegetables....the place is too small...but it is something.”

- **Health problems**

The caregivers addressed the AIDS related health problems to the volunteer and the HBC sister. The HBC team was easily accessible as the volunteers lived in the area. They would then access the health facility or the traditional healer for treatment as the project was not equipped to prescribe and dispense treatment. Many caregivers would report back to the HBC sister on the outcomes of a health facility visit, mainly to affirm the guidance received.

“....I speak to the volunteer about such problems....maybe she can speak to the sister who will see how she can help.”

“...If I need some help, I speak to the sister.”

- **Home nursing care**

The day to day care of the PWA was done by the caregiver and they were occasionally assisted by family members who may have been visiting. The volunteers assisted with basic nursing care on a regular basis as required.

“....the volunteer helps with the patient...like helping to bath her when we have to go to the clinic.”

“....my family helps me when they visit.”

Theme 2: Role of the community leader

All the participants knew their community leader. This enquiry was necessary in order to establish the degree of specific assistance that families could obtain from the Bhambayi community leaders. The participants' responses are discussed below.

- **Generally no assistance from community leader**

Caregivers did not consult these leaders on any health related matters as they considered it a private issue as it was believed that these leaders were to be consulted purely on political and community matters. Furthermore the stigmatization associated with AIDS inhibited families from discussing AIDS-related issues with the leaders. Therefore community leaders did not assist the affected families in any way.

“.....I cannot talk to the community leader about my family's sickness...I may even be chased away...these leaders are here for political problems in the community.my family's sickness is not for him to know.”

Theme 3: Role of the community health worker (CHW)

The CHW is perceived as an extension of the health system. They are trained as community advocates and promoters of health care. However, although all the participants knew of the community health worker (CHW) who was also a resident in Bhambayi, they reported that the CHW had not assisted them in any way.

“.....yes I know the community health worker....she cannot help me. She has never visited me.”

- **CHW assistance was selective**

They alleged that the CHW visited and cared for people in only selected areas in Bhambayi and that this practice was politically orientated.

“.....she only visits and helps certain people like her friends, in certain sections and those living around her house....she has never visited my home, or anyone in this section.”

- **Lack of trust with confidentiality issues**

They also alleged that the CHW could not be trusted with sensitive health information, especially if it was related to AIDS. The CHW appeared to have the tendency of discussing the AIDS diagnosis with other community members, which was a serious cause for concern amongst the caregivers.

“.....she talks too much about people suffering with AIDS....I will never talk to her or ask for her help...she will talk about my family’s illness and problems to everyone in Bhambayi.”

Therefore it was apparent that the valuable resource of a trained CHW was under-utilized in Bhambayi.

Theme 4: The role of the community volunteer

This evaluation was intended to establish the response of the caregivers to the community volunteers. All the caregivers knew the community volunteers and the service that was offered by the HBC program.

- **Response to volunteers engaged in HBC**

Although the volunteers played a significant role in assisting families with home care for PWA’s, they were not acknowledged by some families in Bhambayi.

Lack of trust by some

One caregiver reported that she did not want the volunteer to visit her at all. She appeared to have developed distrust in the team citing that AIDS issues were discussed randomly with other community members.

“...I do not want any volunteer visiting me. I do not trust the one working in this section...she talks too much.”

Appreciated by majority

The caregivers were appreciative of this service and had largely accepted the important role of the volunteer in the provision of HBC. The majority of the caregivers reported that they welcomed the visits from the team who visited and assisted them regularly.

“....I look forward to seeing the volunteer. She can maybe help me with something.”

• **Type of assistance offered**

The volunteers assessed the family's needs, provided physical assistance with care, provided material resources, counseling and support. They assisted the caregivers by providing relevant health information, providing information to access social grants, distributing resources, counseling and assisting patients to the health facilities.

Regular home visits

“.....she visits me once a week to see what I need for the patient.”

Health information

“.....the volunteer gives me some knowledge about how to look after the patient and what I can do when she is sick...like how to mix some glucose if she is having diarrhea.”

Assisting PWA to the health facility

“.....the volunteer takes the patient to the clinic when I am working.”

Assisting with treatment compliance

“.....my sister takes many tablets.....the volunteer checks that she takes her treatment every day.”

Assisting with chores

“.....the volunteer helps me with fetching water sometimes....”

Attention to personal hygiene

“....she helps to bath the patient when she is very sick....”

Distributing resources

“.....she brings the patient some clothes sometimes.....she gives me some gloves and teaches me how to use them.”

Provision of information for disability grant application

“.....she told me how the patient can apply for a grant for her illness.”

Counseling

“....there are so many problems in this home....I can talk to the volunteer (because) I trust her....she has helped me so much....”

This finding illustrates the vital role that community volunteers played in the provision of AIDS home care (see 2.6.3.2).

Theme 5: Assistance from the church organizations

Although there were many church organizations in Bhambayi, none were active in AIDS care. Therefore the affected families did not receive any assistance with home-care.

“....the churches in Bhambayi do not help us (affected families) in any way. We don’t talk about AIDS to the church people.”

Figure 4.11 below illustrates the community capability of support to households.

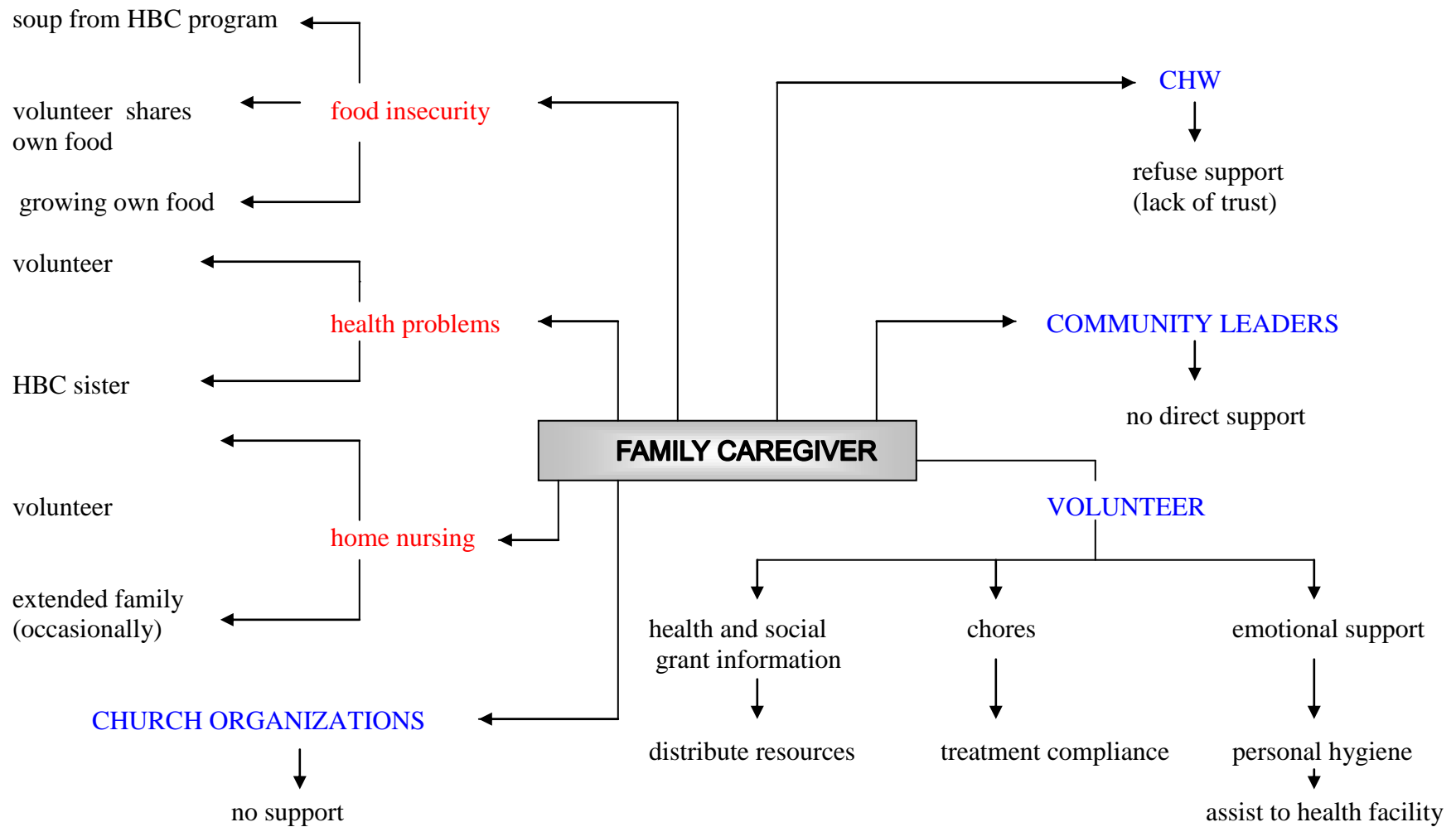


Figure 4.11: Community capability of support to households

Conclusion

Caring for PWA's in the community requires the support of the community. In every community there are people and structures that do facilitate support for most activities. The HBC team was the only existing source of assistance within the community that was available to families engaged in caring for people living with AIDS.

Caregivers were constantly pre-occupied with meeting their families' nutritional needs. Some caregivers had started growing their own vegetables in the limited available space near their homes. This indicates the individuals' capacity to help themselves, no matter how small that might be.

The main cause for concern was the caregivers' apparent lack of confidence in the CHW and their leaders' lack of specific support to families affected by AIDS.

It can therefore be concluded that, despite Bhambayi appeared to have a particular social structure, community referral and support systems for PWA's needed to be developed.

4.4.3. COMMUNITY LEVEL: COMMUNITY LEADERS

This level of the study was intended to determine the source and type of support that existed in the Bhambayi community from the community leaders' perspective. The resources or the lack thereof could assist in planning appropriate interventions.

Three themes emerged from this enquiry including community leadership, major health concerns as expressed by the community leaders and home based care for PWA's in Bhambayi. These themes are discussed below.

Theme 1: Community leadership

The researcher had understood Bhambayi to be a young developing community, with a strong party political system of leadership in the form of the Bhambayi Reconstructive and Development Committee (BRDC).

- **BRDC leaders**

The BRDC was the only recognized community organization that had led the community in its development.

“.....the BRDC has been leading this community for many years....”

- **Appointment criteria for leaders**

Leaders were appointed according to a set of criteria including a commitment to development, understanding community dynamics, self motivation and communication skills.

“.....members are nominated according to their involvement and commitment in development activities, negotiation and communication skills and their willingness for self development.”

- **BRDC structure**

The BRDC was comprised of 10 members: five executive members who were elected by popular vote and ten associate members who were randomly selected by the community. The executive members were appointed to serve a three year term of office.

“.....nominations for the executive seats are put forward by the community. We then vote by show of hands. The members have to serve a minimum of three years on the committee. The associate members are appointed by the executive committee. They should be representative of all sectors of the community.”

- **Community leaders engage in capacity building activities**

As a young developing community the committee members were engaged in capacity building workshops facilitated by non governmental organizations and the eThekweni Metro Council. The committee had formed sub committees and forums to address various development projects and community concerns. The committee had also participated in a community needs analysis process conducted by the eThekweni Metro Council.

“.....PDI (Participative Development Initiative) has conducted many workshops on communication skills and conflict resolution amongst other things over the years....Metro Council has conducted capacity building workshops for the housing projectwe have worked with University of Natal on Social Welfare issues that their student have identified for their studies....we have assisted in collecting data for a study done by eThekweni Council and we are presently working with DIT on the home based care project.”

Although the committee had engaged in the above-mentioned capacity building activities, they believed that they lacked financial management skills and were therefore not in control of their destiny as a community.

“.....we have all these skills but we do not have financial management skillswe can never be in control of our development without this.”

They were also involved with other organizations such as the local police services, the neighboring Phoenix township community and tertiary institutions that were engaged in community development programs in Bhambayi.

“.....we have worked with the local SAPS and the Phoenix community and have formed a Community Policing Forum in order to reduce crime in our area.”

“....we have worked with University of Natal for many years on Social Welfare issues that their students have identified for their studies....we have assisted in collecting data

for a study done by eThekweni Council and we are presently working with DIT on the home based care project.”

The participants expressed several concerns including that community members acquired skills and left for other employment opportunities that resulted in a shortage of skilled committee members which hindered development and that there was ongoing training but very little action to implement the acquired skills.

“.....all the committee members are volunteers....they get the skills and leave for proper employment....then we have a problem of skilled people to continue with development projects.”

“.....there is lots of training but not enough action.”

- **Community leaders responsibilities**

The responsibilities of the community leaders included community development, security and cultural issues and human rights issues.

Community development

A housing development committee was formed to facilitate the development process and create employment opportunities for the community.

“.....a housing development committee was formed to assist the developers and the community to understand the process. We have also created employment opportunities for our people. We have negotiated with the developers so that skilled and semi skilled labor is drawn from the community.”

A youth forum was formed in order to address issues related to development of the youth of Bhambayi.

“.....the youth forum was formed to help our youth to express their concerns and to try and get them skills so that they do not turn to crime from being frustrated.”

Security

A need to form a community policing forum was necessitated by the high crime rate in Bhambayi. The committee was successful in this initiative that was collaboration between the local SAPS, the BRDC and the Phoenix community. The crime rate was reported to have reduced significantly since its formation. This initiative was designed to make Bhambayi a safer place in order to encourage development.

“.....we have been successful in reducing the level of crime in Bhambayi by forming the community policing forum....we had to do this because we need to encourage development in the area. The crime rate has come down and developers can now feel safe in the area.”

Cultural issues

The committee encouraged inter-racial tolerance and respect of all cultures amongst its people. Any persons found guilty of cultural intolerance were severely dealt with by the community. They were forced to leave the settlement.

“.....no person in Bhambayi will be allowed to live here if they practice racial intolerance or if they object to cultural practices of another ethnic group. We make it our duty to encourage our community members to respect one another.”

- **Considered unsuitable by some**

The present leaders were considered to be unsuitable by some but were recognized and accepted by the greater community. One community leader was of the opinion the manner of selection of the present leaders was not entirely acceptable by the elders of the community. They were disturbed by the fact that mainly younger people without acceptable values were selected to lead the community.

“....the older members of the community do not agree entirely with the process of selection of BRDC members...how can these young people with poor moral values...some with criminal records from the apartheid days and not even married...lead such a community....nobody would listen to such people.”

This community leader was of the view that in the most recent 2003 elections, many recognized elders were not considered.

“.... moreover these elder members in the community were completely overlooked in the 2003 elections....”

Theme 2: Major health concerns

There were numerous health concerns expressed by the community leaders including HIV/AIDS, TB, sexually transmitted diseases (STD's), child health, nutrition and sanitation. Actual issues related to these concerns will be discussed.

- **HIV/AIDS**

The participants were very concerned about the many lives being lost due to AIDS. They believed that non-disclosure was mainly due to the fact that AIDS was a sensitive, secretive issue. Failure to seek medical care and support was attributed to people being in denial of the seriousness of the disease.

“.....too many lives are being lost to AIDS.....our community can be wiped out if people do not go for help in the early stages.....the problem is that people do not disclose their illness because AIDS is a sensitive issue and people are secretive about it.”

“....the problem is that even though people are aware of the disease, the people are in denial....until they accept that AIDS will not go away on its own, our people will continue to die in great numbers.”

- **TB increasing and non-compliance with treatment**

TB has always been a cause for concern in Bhambayi, given the poor socio-economic and living conditions of the majority of the community.

It was alleged that more people were dying of TB in Bhambayi than 5 years ago. The dual infection of AIDS and TB was a serious problem, as infected individuals never recovered. The community leaders believed that the infection rate was on the increase as there appeared to be infected individuals in almost every household in Bhambayi.

“.....TB has always been a problem in Bhambayi, but more people are dying of TB than five years ago....now we see that when a person has TB and HIV, they never get well.....TB is increasing in Bhambayi.....there is someone with TB in almost every home.”

All the participants believed that infected individuals failed to complete the course of treatment due to the lack of knowledge of the disease and the lack of nutrition. There was therefore an increase in the number of defaulters in the community.

“.....many of our people with TB are so poor and do not have food....and stop their treatment....many also do not understand much about the disease.....”

- **STD's**

The community leaders believed that the community had insufficient information about sexually transmitted diseases and that most people believed that there was no treatment or cure. It was alleged that people were embarrassed to ask for help.

“.....another disease that is killing our people is STD'speople believe that it cannot be treated or cured.....they are also embarrassed to ask for help.....people need more information about STD's.”

- **Child health**

The participants expressed many concerns related to child health in Bhambayi. These included malnutrition, TB infection in children, most children were not immunized and that worm infestation and scabies were common problems in children. These observations were from a community leader who was also running the community crèche.

“.....our children do not grow well and are sickly....it is due to lack of proper food....there is so much of unemployment here...malnutrition and all kinds of disease is common.”

“....there is an increase in the number of children infected with TB....it seems that every other child I know is on TB treatment.”

“.....many of our children are not immunized....yet it is their right....the clinics will not immunize babies who have not been registered at birth....some lose their cards and are afraid to report to the clinic....others have lost the immunization card...it is a big problem in Bhambayi.”

“....this place is so poor....mothers allow their babies to play in the dirt....they do not wash their children well....scabies is so common....every other child has problems with worms that has to be treated.”

- **Nutrition**

The participants reported the problems with chronic food shortage in Bhambayi could be attributed to the inability to acquire food due to the high unemployment rate. It was believed that food aid to the ill and vulnerable sub groups was insufficient. Furthermore hunger was the reason for ill people being non-compliant with taking treatment for chronic conditions that culminated in complications and an untimely death.

“.....ill people need food...there is always a shortage....sick people get more ill and die because treatment cannot be taken on an empty stomach.....food aid is very limited from

the HBC program.....people cannot afford to buy sufficient food....unemployment is a problem.”

- **Sanitation**

Toilets in Bhambayi were of the pit privy system that was shared by as many as 10 families in some instances. The poor standard of hygiene was a breeding ground for flies, especially in the hot summer months. Diarrheal conditions were common in Bhambayi and this problem was attributed to poor sanitation and hygiene. New toilets were not being built due to the housing development.

“.....many families have to share toilets in Bhambayi.....people fail to keep the toilets clean.....flies breed easily and this is a big problem.....many people also suffer with diarrhea from time to time....when toilets are full, new ones cannot be built due to the housing development, so these days more people are sharing toilets....as many as ten families to a toilet.”

- **No health committee**

The community leaders understood that a health committee could play an integral role in addressing community health concerns. However, the community leaders reported that Bhambayi did not have a health committee.

“....Bhambayi does not have a health committee....we know it is important to have one (so that) more can be done for all these health problems.”

A committee was formed in 2003 in collaboration with the local PHC and some community members. The community and the BRDC were not consulted on this issue; therefore the committee was totally rejected.

“....a committee was formed with some community leaders and the (local) clinic...but it could never work, because the BRDC was not consulted....we rejected this committee.”

Theme 3: Home-based care (HBC) for people living with AIDS

This enquiry was to establish whether the community leaders understood the concept of HBC, their awareness of and the activities of an existing program in Bhambayi, whether they considered this program was of any benefit to the community, and their concerns about the program. The participants responded as follows:

- **Understanding the concept of HBC**

The majority of participants understood the concept of HBC.

“.....HBC is care provided for very ill PWA’s by volunteers in their own homes.”

One participant was of the view that home based care was only for educated people.

“.....I did not understand what HBC was all about until the DIT project....I thought HBC was only for educated people.”

- **Awareness of an existing program**

All the participants were aware of the DIT home based care program that was operational in Bhambayi. They were concerned that too few people were being reached and that the program had not met the community’s high expectations. They were of the opinion that basic training and information to the volunteers was inadequate and that there was insufficient material and human resources to meet the increasing need of home care.

“....too few people are being reached by the program....there are many ill people not receiving care....too few volunteers....volunteers need more training and information....they also need more resources to do their work in the community.

- **Range of care provided by HBC community volunteers**

All the participants were aware that care and response to a range of needs was provided by the community volunteers especially to PWA’s living in isolation.

“...the volunteers are caring for people with AIDS in the community. There are many very ill people living on their own....they do not take their treatment....some do not know how.”

The team also attended to activities of daily living such as, bathing, acquiring food and feeding the patient and doing household chores to assist their patient.

“.....patients are helped to bath, some food is prepared and the patient is fed....volunteers also clean the house and do the patient’s washing....they also fetch some water because these people are so weak...they can do nothing for themselves.”

The family of the PWA was counseled and taught how to care for the patient. The team ensured that the prescribed treatment was taken correctly.

“.....the volunteers also teach the family how to care for the sick person....they provide some gloves and soup to the family....they also help with taking treatment correctly.”

The volunteers also assessed the PWA’s needs on each visit and endeavored to meet these needs as best as they could. PWA’s and their families were referred to other helping agencies such as the ward councilor, social welfare agency, health facility and the HBC sister when required.

“.....the volunteers try to help these patients who have many problems....they have some information that can help the patient.... they are referred to the ward councilor for ID applications....the welfare office for grant application.....the clinic or hospital for treatment and to the HBC sister for counseling.”

Very ill patients were assisted to the health facility by the volunteers.

“.....we know that more patients are going for treatment these days....the volunteers help the very sick people to the clinic and hospital.”

- **Community benefits**

The community leaders expressed their appreciation of the program and described the benefits to the community as follows:

Health information encourages early medical intervention

PWA's and their caregivers in the program were provided with the relevant basic health information by the HBC team, which guided the individuals in taking responsibility for their lives. This resulted in infected individuals seeking medical intervention earlier and the distress of being afflicted with a chronic condition was reduced.

“.....PWA's now have more information and they get help earlier...there is less suffering.”

Physical assistance and material and spiritual support offered hope for PWA's

PWA's were able to access physical assistance from the program whereby the volunteers accompanied the individual to the health facility; material resources were accessed from the program; and spiritual support in the form of prayer for the dying was provided to the community. These activities appeared to provide hope to PWA's and their families.

“.....we know that sick people are helped to the clinic by the volunteers....there was nothing of this sort before the program....the community now know that they can get some help from the volunteers.”

“....PWA's can get some soup and bread from the program....many have been helped this way.....if you want some clothes and blankets the families know that they can find some help from the program.”

“.....we also have seen the volunteers have prayer meetings for the dying...all this gives our community hope that somebody does care.”

Families in distress identified and referred

The home visits of affected families enabled the volunteers to identify other problems including socio-economic and psycho-social problems. Vulnerable children who were potential orphans or already orphaned by the loss of parents to AIDS and PWA's in need of a disability grant were referred to NIP and the social welfare agency respectively. The participants were appreciative of this activity as it enabled the community to exercise their right to government assistance from an informed perspective. This finding is consistent with the principles of continuum of care (see 2.6).

“.....the community now have some information about disability grants for PWA's and our orphaned children can get some help from NIP....if they are lucky....we know that some people have received help and they are improvingthey had more hope now.”

- **Program concerns**

The participants expressed their concerns throughout the interview process and the common concerns are discussed below.

Training needs to be ongoing

The participants were of the belief that the current level of training was of volunteers was inadequate to meet the community's expectations. The volunteers and family caregivers needed training in coping with care of the dying patient and with psychological problems associated with the person with AIDS.

“....this training of the volunteers needs to be ongoing.....their knowledge is too limited....we expect more from them.”

More support from government was needed

The participants were of the opinion that greater commitment and support for community based home care programs.

“.....the government needs to be more active in such programswe need their support and commitment.”

More resources were needed

The participants believed that the program required more trained volunteers to meet the community's needs, sponsorship for food aid in order to meet the most basic need of ill people and essential equipment such as wheelchairs and patient stretchers.

“.....there are too few committed volunteers at present.....we need more people to be trained to cover Bhambayithere are many sick people not being cared for.....we need sponsors for food aid....many sick people are dying of hunger.”

“.....we need proper wheelchairs and stretchers so that the patients can be taken to the clinic in dignity....wheelbarrows should never be used.

Figure 4.12 illustrates community capacity for present and future support for PWA's.

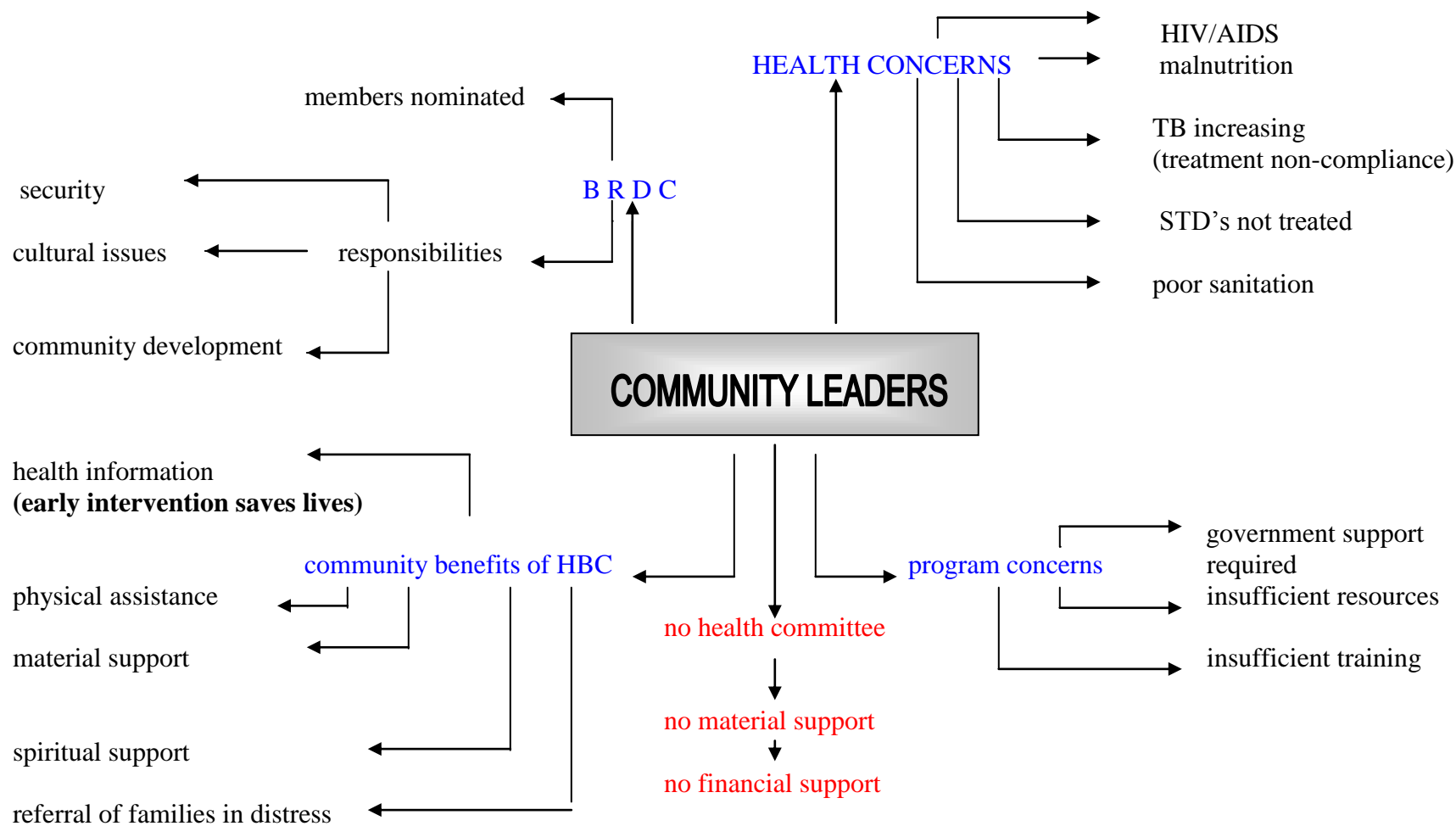


Figure 4.12: Community capacity for present and future support of PWA's

Conclusion

All communities have a system of governance, whether traditional or political, in order to facilitate leadership and development of their members. Although the community leaders had received ongoing capacity building skills training, they were of the opinion that the Bhambayi community required financial management skills in order to take control of their development.

The BRDC was committed to development and cooperated with all role players engaged in development activities in the area. They attempted to maintain a safe environment for its residents and visitors alike by forming the community policing forum. All inter-racial and inter-ethnic conflict was successfully addressed by the BRDC. The Bhambayi community was much politicized and well informed of their rights. All community decisions were taken observing the people's rights. The BRDC was therefore in a strong position to assist any helping agency to improve the quality of life of its people.

Despite being aware of numerous health problems in the community, the BRDC had failed to form a health committee. The single attempt to do so in 2003 was dissolved as the committee was appointed without community consultation. There is an urgent need for a health committee without political undertones, in Bhambayi.

All the participants were aware of the existing program in Bhambayi but were of the opinion that basic information and training of volunteers did not necessarily meet the growing need for home care in Bhambayi. The physical, material and spiritual support rendered by the volunteers offered hope to people living with AIDS in Bhambayi. Despite being appreciative of the existing program, there were concerns that the program did not reach the growing number of people needing care and the chronic shortage of manpower and material resources needed attention.

4.4.4. COMMUNITY LEVEL: COMMUNITY VOLUNTEERS

This assessment was intended to determine the motivation that drove community members to volunteer, the benefits achieved by the volunteers and their perceptions of the community's response to HBC for AIDS in Bhambayi.

Four themes emerged from this enquiry including motivation to volunteer, perceptions of community response to home-care for people living with AIDS, personal benefits of being a community volunteer and actual care provision. These themes are discussed below.

Theme 1: Motivation to volunteer

The desire to assist and care for the very ill and dying people, especially those living in isolation, was the principal reason for members of the Bhambayi community wanting to become community health volunteers.

- **Fulfilling the ambition to nurse sick people**

One volunteer in particular, whose ambition to become a nurse was not realized, found a degree of fulfillment instead, in caring for the ill and vulnerable in their homes.

“..... I became a volunteer because I thought to myself that I will be a nurse, but I was unsuccessful to pass my matric because of the death of my parents. But here in the community I have availed myself because I want to help our community by helping those patients in their homes in every way.”

- **The desire to help the growing number of sick community members**

Another volunteer, who was also an active community leader for a number of years expressed the intent to assist the growing number of sick, lonely people.

“..... I became a volunteer to help the very sick people in my community many sick people do not have anyone to help them. It has become a good way to go out and see how

the community is doing, what do they need. I like helping people. If I do not go into the field, I feel sick, because I am used to this now.”

- **A calling from God**

A special calling from God to assist those in need was considered a challenge, by another volunteer.

“.....what made me to be a volunteer is that one day I was doing my washing in my yard. My house is nearby the road and that is where people are going up and down. I saw a very sick person walking on her own, sometimes sitting down to rest and then moving slowly again. That hurt me a lot such that I found myself asking her where she was going. She was on her way to the clinic. I just thought when I took my washing out: God wanted me to see that life to other people was not the same. Someone needed my hand. From that day I had that feeling to ask my family that I need to volunteer. Sometimes you hear from the neighbors that there may be a dead person in a certain cottage. The person could be dead for as long as a week before being found. I thought this is a challenge that I have to be a volunteer and help those dying alone.”

Theme 2: Perception of community response to home care for PWA's.

- **Range of response**

The volunteers perceived that the response to HBC for PWA's differed widely in Bhambayi. People who had received assistance appreciated the work being done, whilst other people were unaware of the usefulness of the work, as they did not recognize the nature of the work.

“.....people have different ways; some people do love us such that they wish we can get something (money). Those whom we have helped speak well of us, appreciating our work.”

“.... And there are others who have not needed our help as they do not have sick people needing care, say that they do not know the use of volunteers. But the majority of people like the work being done by the volunteers, as they are hard working.”

- **Appreciation of the work**

The community generally appreciated the work being done as they realize that this is done out of the love for the people.

“.....the community is very happy (and) they appreciate everything and also that we do it out of love for our people. Most people are very happy with our work, and if they do not see us, they become sad, even if it is for a few days.”

- **Recognition as a community source of care**

The volunteer were recognized as a source of care from within the community. This service did not exist previously, as there was no source of assistance from the community for very ill people requiring home care.

“..... some people are very happy to have the community assisting the community, as it is so nice and it was not there before. The community has said that god must help us to get something because what used to happen previously does not happen any more. Sick people had no one assisting them.”

- **Community confidence**

The volunteer was usually the first contact for most people who were ill in Bhambayi and the wellbeing of the community was reported to be entrusted in the hands of the volunteers.

“.....the volunteers have made a difference in the Bhambayi area because the community believes that their lives are in the hands of the volunteers as the volunteers first see them when they get sick.

- **Acknowledgement by other communities**

The work being done by the community health volunteers was also observed and acknowledged by communities in other areas.

“..... the volunteers going house to house has helped a lot and the committees in other places are calling us nurses....”

- **Attempting to trace PWA's family**

The HBC team was mindful of the importance of traditional practices that were essential for the wellbeing of a terminally ill person and their families. The volunteers believed that it was important to maintain tradition throughout one's life. They would network with people from a similar clan as the PWA and attempt to gather some information. This was not always successful as the community lacked a sense of cohesiveness when it came to such matters. The volunteers also found this activity time consuming and created frustration amongst the team members.

Furthermore, the PWA needed to be taken back to the place of his birth whilst they were well enough to travel, as it was extremely expensive for the families to transport a deceased person. The attending volunteer was also expected to furnish this information to the police services, on the death of the individual.

.” As a volunteer you know that a person needs to be taken home, because when this person dies, the police will ask the volunteer who had taken care of the patient, the whereabouts of the family”.

- **Overcoming inequity at the local health facility**

Community members in the HBC program expressed their fear of identification by the health personnel at the local PHC. Some personnel knew the PWA's as they lived in the same area. They were embarrassed and afraid of possible recognition. The volunteers would then encourage the patients to seek medical attention at any other health facility. It

was found that patients preferred visiting other health facilities for AIDS related care and treatment where they would not be identified.

“...some people are so scared to go to the local clinic because the nurses know them. Then we suggest that they can go to any other clinic”.

Theme 3: Personal benefits of being a community volunteer

The community volunteers had used their personal motivation, the training and support received during the project process, which had helped them with personal growth and the understanding of human needs.

The participants' responses are discussed as follows.

- **Unconditional acceptance of people**

The volunteers had learnt to accept all people unconditionally, and appreciated that it was important to be kind to all, whether they were ill or not.

“..... I have learnt a lot, especially that I have to be kind to every person, whether sick or not. Sometimes if a person is sick, people do not love them. As a volunteer I need to have love.”

- **Self improvement**

Volunteers utilized health information acquired during the project process, which had assisted them in improving their lifestyles. They benefited by being able to prepare nutritious meals for their families.

“..... I have learnt a lot as a volunteer, because even in my own house, I used to cook any how, saying as long as I have something. Now I know how to cook nutritious food and that is what I tell people out there, what they should eat.”

- **Overcoming the fear of death**

The nature of caring for the very ill and dying patient in their homes assisted the volunteers to overcome the fear of death. This enabled them to attend to the dying patient with more confidence.

“..... I used to be scared of a very sick person, but now I can go to any sick person in the community who may have died. I could not even close her eyes. I was a coward, but now I know that when a person dies, that is nothing, it’s just like a chicken. That is also learning. I have learnt a lot.”

- **Improved understanding**

Disclosure, a matter of choice

The volunteers appreciated and accepted that it was human nature for some people to willingly disclose their HIV positive status, whilst others may conceal their condition until death.

“..... I’ve also learnt that other people can disclose their sickness (AIDS) while others hide it until death.”

Counseling plays an integral role

Volunteers experienced and appreciated the outcomes of counseling skills in the role as care givers. They understood that it was the individual’s decision that was important, and that a patient was not to be coerced into doing anything against their will. The patient’s view need to be considered prior to any offer of assistance.

“..... I have learnt that you do not take decisions for the patient. Now I know that I have to ask her what she needs (and) then do as she wishes. I do not have to force the patient to go to the clinic, whereas she does not want to do that. I do not have to force the patient to visit the traditional healer, whereas she does not like that. I have learnt to hear from her, and ask what she thinks, get her view, and assist from there.”

- **Community support**

Given that Bhambayi was an under-resourced community, with the high rate of unemployment, the poverty in this community precluded the availability of material and financial support. However, the community was mainly appreciative of the value of the work being done by the volunteers and appeared to hold them in high esteem. The community was reported to have recommended stipends for the volunteers.

“....some people do love us such that they wish we could get something (money) ...others even think of buying you a present when they get paid. ... but the majority of people like the work being done by the volunteers , as they are hard working.”

“..... people appreciate a lot the way we treat them, such that they even ask if we do get something for our work. We have told them that we do not get paid for our work. The community has said that God must help us to get something because what used to happen previously does not happen anymore. Sick people had no one assisting them.”

Theme 4: Actual care provision

The following discussion demonstrates that the volunteers had sufficient knowledge and commitment to provide home care to PWA's in Bhambayi.

- **Community education**

The community was offered health information including personal and environmental hygiene, food preparation and the importance of regular clinic visits, during home visits by the volunteers.

“..... they are visited by the volunteers in their homes and are taught to clean taught to clean their homes, open their windows in the morning, what foods to prepare and the importance of clinic visits.”

- **Restoring the dignity of frail PWA's**

It was reported that very ill PWA's who were unable to adequately attend to their personal hygiene, were neglected by some staff members, during clinic visits at the local PHC. However, the special attention that was paid by the volunteers to personal hygiene of these very ill patients, helped to restore their dignity prior to a clinic visit.

“.....previously people used to go to the clinic not having bathed, and now the patient is bathed and cleaned, with the help of the volunteer before going to the clinic.”

- **The ability to improvise**

The lack of funding for transport and equipment such as wheelchairs and patient stretchers did not deter the volunteers from assisting their patients to access health care. They improvised by using wheelbarrows to transport their very ill, immobile patients to the local health facility.

“ If the sick person cannot wake up, as a volunteer you do not always have money to hire a cat to take her to the clinic if need be. She may not be able to walk. You end up asking some people to help you take her. Even if they agree, you do not have a stretcher, you cannot manage to carry her, you at least think of a wheelbarrow and it will hurt her also.”

- **Assessment**

PWA's were identified by the volunteers during home visits. Needs were assessed through a basic interview process. the volunteer would then attempt to formulate a care plan based on the findings. Most households lacked the availability of food. Some PWA's were found living in isolation in total neglect.

“.....as we all know our job is home visits and this is how we find people who have AIDS. I simply sit down and talk and sympathize, *giving the person hope that she can still live.*”

“.....the main problem people have is that they do not have food. Sometimes you find that she does not have clothes, not to mention something to eat. You find that she has not eaten in 3-4 days, not until we get soup from Sister Benjamin.”

- **Attending to activities of daily living**

The community was mainly reliant on the HBC team to assist with the provision of care and support to PWA's in Bhambayi.

The volunteers would bath the PWA whilst observing universal precautions, by wearing gloves.

“yes, here within the community, if there is a person with AIDS, they just give their hope to me as a volunteer, such that I have some knowledge on like if I bath a patient, I need to put on gloves.”

The volunteers would also clean a patient's home, when necessary.

“.....maybe this person has passed urine the night before, so we as volunteers have to help change her and clean everything.”

On occasion, the volunteers would share their own food in order to meet the needs of the PWA.

“.....because it is not nice to eat whereas you know that there is a person who is sick and does not have food. We take from our families and try and cook for them, and that makes it better.”

Patients were bathed before a visit to the health facility.

“.....I know the night before if I have to take a patient to the hospital and check when her appointment is and if she has taken a bath. If not I have to bath her quickly and then take her to the doctor.”

They would also ensure that hospital appointments were kept and that treatment was taken as prescribed.

“.....and I make sure she’s got her treatment in the right way and she takes it and I take her back home (after a clinic visit).”

- **Assisting with symptom control**

Chronic diarrhea was a common, troublesome AIDS-related opportunistic condition that the volunteers had to deal with. The volunteers would make ORS (oral rehydrate solution) in order to prevent dehydration.

“.....if a patient has diarrhea, I mix glucose (ORS) for him.”

- **Treatment compliance**

The volunteers ensured that their patients needed to take their medication as prescribed.

“..... and I make sure she’s got her treatment in the right way and she takes it and I take her home.”

- **Counseling**

The volunteers believed that counseling skills enabled people to seek medical attention earlier by agreeing to take an HIV blood test. Furthermore disclosure of a positive result to the family was also facilitated by proper counseling and support both from the health facility and the HBC team.

“..... OK, the way you have counseled the patient may have assisted her in getting help. They like going to other clinics and tell their families and you that they have tested positive.”

- **Emotional support**

There were many PWA's in the program living in isolation, having been abandoned by their families. The volunteers made every effort to provide emotional support, to this vulnerable sub-group by utilizing their counseling skills, their understanding of community dynamics and their knowledge of home care.

“.....I simply sit down and talk and sympathize, giving the person hope that she can still live.”

“..... sometimes the main problem is that as the people are sick in the community, they've got TB or HIV, the family members do not love them any longer. So we, as volunteers have to take care of that patient, bath her, because that patient is on his own in the house. There is no one who can comfort her to do anything for her.”

“..... then the patient may ask you to stay awhile and now she wants to tell you everything because she needs to talk and cannot trust anyone else. She feels that you are the only one who understands her.”

The volunteers have given PWA's hope by caring for this neglected subgroup within the Bhambayi community. The community was reliant on the volunteers essentially for their knowledge on AIDS care.

“.....yes, here within the community, if there is someone with AIDS, they just give their hope to me such that I've got some knowledge.”

- **Assisting the PWA to the health facilities**

Clinic visits formed an integral part of AIDS medical care. Volunteers ensured that any PWA requiring medical intervention was taken to the clinic. Very ill immobile patients are transported to the local PHC by wheelbarrow as it cost R100 to hire a car. Patients referred to the hospital were accompanied by the volunteer at their personal expense. Despite financial and transport problems every PWA needing medical care received attention with the assistance of the HBC team.

“..... but to those who are very sick, who cannot even swallow tablets, we try to get them to the clinic. We have to use a wheelbarrow to get the patient home. Sometimes the clinic refers the patient to the hospital and you have to go with her. The hospital may not admit the patient and you have to take the patient back home. You are using your own money for both of you. It is so difficult; it is not easy, very difficult.”

- **Preparing a PWA for a visit to the health facility**

Volunteers also ensured that their patients were bathed and tidied before a hospital or clinic visit. This activity has earned them the respect of communities outside Bhambayi.

“..... firstly I know the night before if I have to take a patient to hospital and check when her appointment is and if she has taken a bath, if not I have to bath her quickly and then take her to the doctor.”

“.....the volunteers going house to house has helped a lot and the committees in other places are calling us nurses, because previously people used to go to the clinic not having bathed, and now the patient is bathed and cleaned with the volunteer’s help before going to the clinic.”

- **Understanding the need for referral**

The volunteers could identify a patient’s deteriorating condition that warranted medical intervention and would encourage the patient to seek assistance at the health facility.

“....if a patient does not get any better on treatment and is still losing weight and power, I would encourage her to have her blood tested for the virus.”

All PWA’s who needed further assessment were referred to the HBC sister. The volunteers regularly encountered social problems associated with AIDS in the field.

“.....others do not tell you the truth and we do not just leave her alone, but have to think of her life and how can we help her. We look at the her treatment from the clinic and then tell our sister in charge that there is a sick person in a certain house and give sister the report. The sister makes a home visit and the patient may tell the sister her problem.”

- **Social welfare aid**

The volunteers were well informed of the process and requirements to access social welfare aid for PWA's. They were able to inform their patients and provided support through the process.

“....maybe the person is sick, at the same time she does not have an ID or anything. She has children and no food. Maybe even the husband passed away, she does not have a death certificate, she's got nothing, maybe we try to get her help, and maybe she will not even get that help, because she does not have anything.”

Figure 4. 13 below illustrates the community volunteers' ability to provide home care.

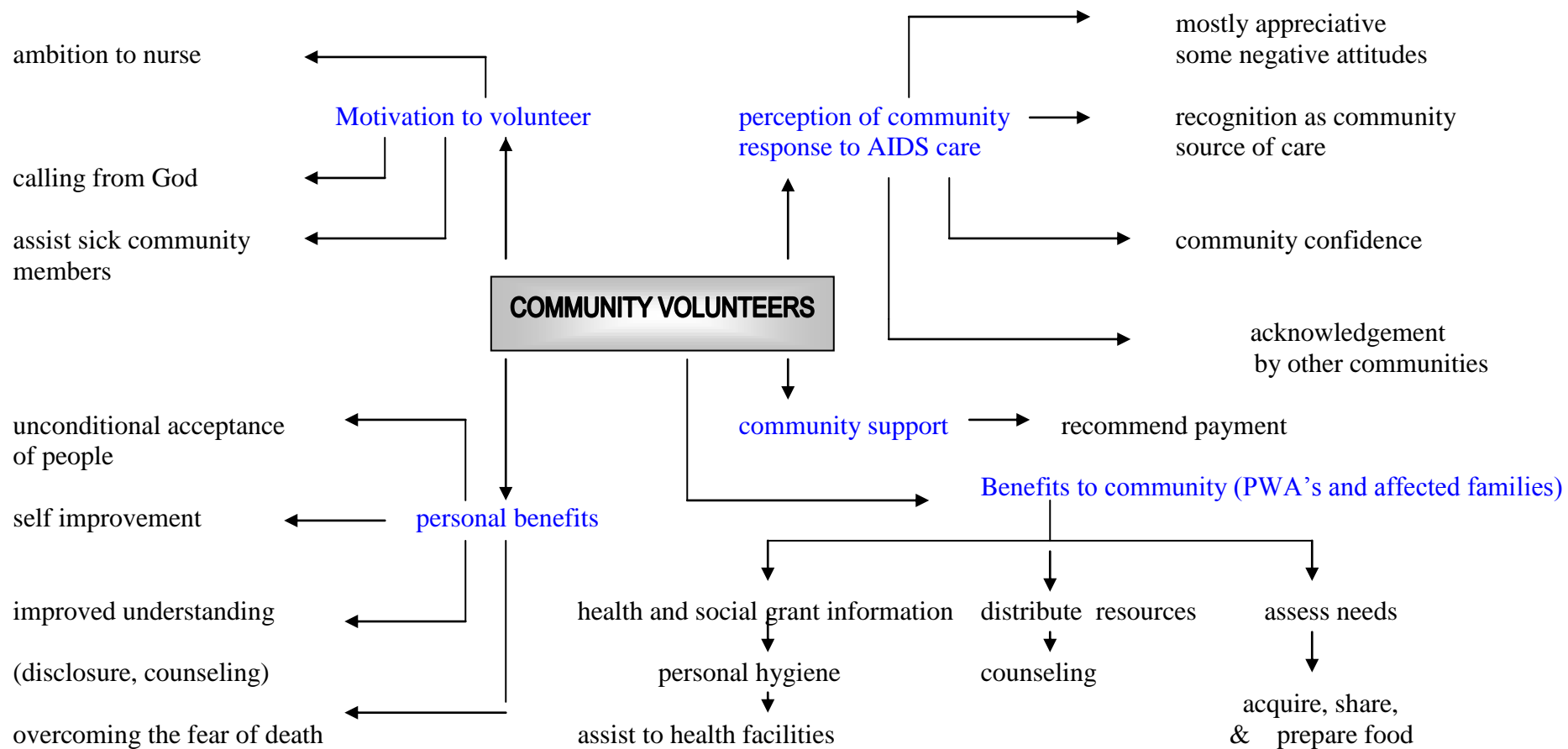


Figure 4.13: Community volunteers ability to provide home care for PWA's

Conclusion

All the volunteers expressed their willingness to care for the ill and helpless in their community. They worked on a premise of trust observing customs and norms amongst their people. They understood the significance of their work and used every opportunity to improve their skills, thereby benefiting themselves and the community. Although it would appear that they perceived that some community members did not understand the nature of voluntary service, the volunteers had the courage to persevere with home care for PWA's in Bhambayi.

The community however generally appreciated the work being done by the volunteers as they realized that this was done out of love for the people. HBC was a community source of care that had not previously existed and the volunteers were often the first source of contact for ill people in the community. The work being done by the volunteers was also acknowledged by communities in other areas which added to their confidence and further inspired them to serve.

It can therefore be concluded that the community volunteers were a valuable resource to the Bhambayi community who brought hope to people infected with and affected by AIDS.

4.4.5 OUTCOME FOR OBJECTIVE 3

Four themes emerged in response to the enquiry, and all the participants expressed their participation in home care for AIDS in Bhambayi. This section summarizes the findings and presents their commonalities and differences between the levels.

Table 4.3 below shows the comparison of themes and categories in relation to the level of the community. It highlights the commonalities and differences in each category. Themes and categories are listed on the left hand column. To the right of this, the actual expressions are aligned with the category of each level of the community studied. In places there is an absence of a comment which shows differences between the levels.

Table 4.3: summary and comparison of themes and categories for Objective 3 in relation to the level of the community

Themes and Categories	Level of the community			
	PWA	Caregiver	Community leader	Community volunteer
Day to day care	able to attend to personal hygiene, light personal laundry, feeding self, caring for young infants for as long as condition permits	acquire and prepare food, fetch water, environmental hygiene, caring for children, heavy laundry	no active involvement	assist with personal and environmental hygiene, emotional support, distribute resources assist to health facilities
Symptom control source of advice treatment	family caregiver, volunteer, health professional traditional medicine, home remedies	volunteer, HBC sister	no involvement	prevention of dehydration
Resources Community leaders	no specific support	no specific support	no material, financial support no health committee	no specific support
CHW	no support, lack of confidence	no support, lack of confidence	lack of confidence	
community volunteer	material resources, emotional support, assist to health facility	emotional and nutritional support, health and social grant information, assist to health facility and with chores	emotional and nutritional support, health and social grant information, assist to health facility and with chores	emotional and nutritional support, health and social grant information, assist to health facility and with chores
HBC program benefits	Basic nursing care, assistance to Health facility, distribution of food, Clothing, counseling,	gloves, food, psychological support , health information	early intervention saves lives physical, material , spiritual support, referral of families in distress	recognition as a community source of care
concerns	Insufficient nutritional support	insufficient nutritional support	insufficient resources, training lack of government support	insufficient resources, training lack of government support

Theme 1: Day to day care

The study found that all the participants were able to attend to the activities of daily living. These included personal hygiene, feeding self, light personal laundry, and caring for their young infants for as long as their condition would permit. Family caregivers attended to all heavy chores including heavy laundry, fetching water and environmental hygiene. They also acquired and prepared the food for the family and cared for the children. The community volunteers assisted with personal and environmental hygiene needs of the PWA, provided emotional support and health information, distributed resources and assisted the frail PWA's to the health facilities. They also supported PWA's in treatment compliance. There was an absence of active participation in AIDS care by the community leaders. The community health worker was not consulted on AIDS issues by PWA's or their families as the community appeared to lack confidence in her.

Theme 2: Symptom control

The PWA's in the study sought advice from the caregiver, volunteer and the health professional for symptom management in the home. The caregivers consulted with the HBC sister for guidance and support on AIDS related problems. The PWA's used traditional medicines and home remedies regularly to control common symptoms of opportunistic conditions. The volunteers taught the families how to prevent dehydration in patients with home made oral rehydration solution and the recommended food preparation methods for PWA's.

The PWA's in the study sought advice from the caregiver, volunteer and the health professional for symptom management in the home. The caregivers consulted with the HBC sister for guidance and support on AIDS related problems. The PWA's used traditional medicines and home remedies regularly to control common symptoms of opportunistic conditions. The volunteers taught the families how to prevent dehydration in patients with home made oral rehydration solution and the recommended food preparation methods for PWA's.

Theme 3: Community Resources

An attempt to form a health committee in Bhambayi failed due to the lack of community consultation by the facilitators. Community leaders were unable to facilitate material or financial support for AIDS care. The CHW did not provide any support to the participants. The PWA's and affected families alike had no confidence in her and refrained from discussing AIDS issues with her. The HBC volunteer team was the only active group engaged in AIDS care. The recipients of this care expressed confidence in the team's ability to provide care.

Theme 4: The HBC program

The community appeared to appreciate the work done by the volunteers. They were recognized as a community source of care and the community leaders appreciated that more lives were being saved with early intervention care and support. However there were concerns about the insufficient HBC resources, training and the lack of government support for community-based AIDS care. The family caregivers required adequate material support.

4.4.5.1 Summary of community capability

- The day to day care of PWA's was done by the family caregivers with support from the HBC team. Symptom control in the home was mainly with traditional medicines and home remedies. The family caregiver sought advice from the HBC sister when necessary.
- There was no health committee in Bhambayi. The community leaders did not have the capacity to support AIDS care in Bhambayi. The CHW was an under-utilized resource. The volunteers were a valuable community resource that needed to be nurtured.

- The HBC program had its merits but was under-resourced. The lack of government involvement in community-based AIDS care was a general concern expressed by the leaders and the volunteers alike.

4.5. DATA ANALYSIS FOR OBJECTIVE 4

To examine the ability of the health and social system to provide support and services to people with AIDS

This objective was intended to determine whether the health system was indeed providing minimum services required by PWA's and whether the health system was able to reach out in support of PWA's at community level. PWA's cannot be taken care of in isolation; therefore the ability of the social system to render support was also examined. This included the community, the social welfare agency, the church and other organizations.

4.5.1. INDIVIDUAL LEVEL: PEOPLE LIVING WITH AIDS

Three themes emerged from this enquiry including the health system, social welfare support and support from other organizations. These themes are discussed below

Theme 1: The health system

The purpose of this enquiry was to determine the quality of care and support at the public health facilities that people with AIDS attended. The participants responded as follows:

Although the Bhambayi community was less than a kilometer from the nearest primary health clinic (PHC), it was reported to the researcher that the majority of people requiring AIDS care preferred to attend other health facilities. As medical intervention and support could only be found at a health facility, the enquiry initially set out to

establish the reasons for this situation. Other sources of health care accessed by the participants included AIDS clinics at a tertiary hospital and the AIDS clinic at a neighbouring suburb. The traditional healer was also regularly visited for consultation on AIDS related health problems.

- **Attitudes, medical management and support**

The quality of care for PWA's appeared to differ at the various public health facilities. The participants' responses are discussed below.

The local PHC

The participants attending the local PHC alleged that the service was discriminatory to PWA's as they were attended to in a department known as Room 8 that was located in the general public waiting area. PWA's reported being embarrassed as they were subjected to public scrutiny when attending the AIDS clinic.

".... everybody knows you have AIDS....Room 8 is right where the other sick people wait...it is so hard to be sick with AIDS."

They also reported that some clinic staff members showed little empathy as only some concerns were addressed and treatment was prescribed selectively

"....the nurses are rude to us...they do not even hear our problems....they do not give treatment like other clinics."

They were adamant that they did not feel comfortable about attending the local PHC.

"....I do not like to go this (local) clinic...."

Some participants reported that they had defaulted on TB treatment because the explanations for the lost record card were not accepted by the clinic staff.

“....I lost my clinic card....the nurses shouted at me....they were cross with me.... (therefore) I stopped taking my treatment.”

The tertiary hospital

The two participants attending the AIDS clinic at the tertiary hospital found that all their concerns were addressed.

“....I like attending the clinic t the hospital...they listen to your problems and care about you.”

They reported that they received regular counseling and support on each visit and that the caregiver was also sometimes counseled by the doctor.

“....the staff always counsel me each time I visit the clinic....the doctor has spoken to my cousin (caregiver) many times.... she knows everything about my illness.”

They were satisfied with the medical treatment received.

“....the treatment (medicines) I get helps me a lot.”

Furthermore these participants felt comfortable about attending the clinic because they felt that the staff was kind and respectful to them at all times.

“....everyone...the doctors and nurses are so kind to me....I am lucky... (because) it is bad in other places.”

The neighbouring PHC

Two participants attended the PHC in the neighbouring suburb. They reported that they preferred this particular clinic as they were treated with respect and the staff was kind.

“....I like this clinic because the treat a person well....the nurses are kind and they do not shout at you like some other places.”

They felt that all their concerns were adequately addressed and that the medical treatment prescribed was helpful.

“....I can ask the nurses anything and they try to help me....the treatment (medicines) they give me helps me a lot...they can explain everything to me...I am now feeling better....”

They further reported that their caregivers were also summoned by the clinic staff for counseling and the PWA was therefore confident of the support from the caregiver.

“....the nurses sometimes want to talk to my mother....I am happy now because she also knows what is happening and what she can do me....”

- **Counseling and support**

Counseling is important aspects of AIDS care in order to assist the patient in dealing with feelings of rejection, guilt, shame and blame in a relationship. PWA's are living with uncertainty and there are many unanswered questions that need to be addressed during counseling, in order to allay anxiety and prevent depression and are often subjected to discrimination and rejection by society including their family, partners and friends. It is also important to counsel patients and help them cope with loss. People with HIV suffer many losses including their health, their independence and many years of life. Many lose their financial security and their usual life and lifestyle (Evian, 2000).

Inadequate support

It was alleged that PWA's did not receive the necessary counseling and support from the local PHC. The PWA's found the attending health personnel to be impatient.

“.....the nurses at the local clinic do not care to listen to my problems....they are busy talking about their own things to each other....they don't care about people with AIDS.”

Satisfactory support

Therefore it was reported that PWA's preferred to seek treatment and support at a PHC outside the area. Although this was physically more taxing on the PWA's as the facility was some distance away, they persisted as they felt that they were well cared for.

".....the nurses at the other clinics are better. They are kind and take good care of me. ...I now feel happy to go to the clinic."

Some PWA's had been on AIDS programs at a tertiary hospital and reported that they were satisfied as all their concerns were addressed.

".....I am happy that I can get good care from the hospital. The nurses and doctors treat me like I am special."

- **Health information**

According to Evian (2000), patients on chronic medication may experience difficulties in taking medication every day which need to be dealt with at counseling sessions. Furthermore, a PWA needs to understand the nature of the AIDS condition and have relevant information and support in order to cope with the disease. Some PWA's expressed exasperation at their lack of information from certain health facilities.

".....what is the use of going to the clinic....they don't tell you anything....there is no cure."

Other PWA's appeared to cope with their condition and reported to have received information on the disease process, nutrition and the directions on how to take the prescribed medication as on each visit to the health facility.

"....the sister explains what is wrong and how I should take my treatment and what I should do to take care of myself....I am getting better and I am not frightened anymore"

- **Accessing health care**

Physical difficulties

Although the local health facility was less than a kilometer away from Bhambayi, it was reported that some participants experienced great physical difficulty in accessing the local PHC due to their deteriorating physical state.

“.....I walk to the clinic, very slowlyI feel weak and have to stop now and then to rest.”

These frail participants were assisted to the health facility by the volunteer.

“....the volunteer helps me to the clinic”.

Financial cost of accessibility

One participant reported that her family hired a car at enormous cost to get her to the health facility for medical treatment. The family borrowed the money from a money lender, as they did not have the budget to meet this cost. The PWA, being aware of the financial constraints on the family, expressed her distress at incurring this cost.

“....when I was very sick, my cousin borrowed some money and hired a car....it cost R100....she has helped me, but it is too expensive....I must try to walk.”

The researcher had observed that some people simply did not seek health care as their physical strength failed them. Attempts to negotiate transport for these patients with the local taxi association by the researcher during the project process had failed.

Theme 2: Social welfare support

As all the participants were PWA's with full blown AIDS with no disability benefits, some had opted to seek social welfare assistance. This enquiry was intended to elicit the experiences of PWA's attempting to seek financial aid. The participants responded as follows:

- **The distress of awaiting a response**

It was reported that PWA's who qualified for the much needed government disability grant were often found to be in despair. Many PWA's had applied for this grant and were awaiting a response from the welfare agency. The PWA's expressed frustration at the length of time taken to process these applications.

“.....it is taking too long....I is suffering...there is nothing in my home....no food for my children....maybe it will come when I die...”

Their concern was expressed from witnessing distressing incidents within the community.

“....like it happened to another lady I know...her children are suffering more now....they do not stay together...the older ones have run away.”

- **Problems experienced at welfare agencies**

It was reported that PWA's had experienced many difficulties when accessing social welfare assistance. This enquiry was therefore necessary to determine the type of problems experienced by PWA's attending the welfare agencies. The participants responded as follows:

Lack of empathy from agency staff

In addition to the stress of coping with the disease itself, PWA's were subjected to humiliation at the welfare agency. PWA's had reported the alleged discourtesy shown to them by welfare agency staff.

“....those social workers say we are too many AIDS people coming here...they say I am fit to work and that I am lazy.”

Long delays

PWA's have also reported long delays in being attended to. Some had given up and never returned.

“...it is uselesswe just wait the whole day...sometimes without any food or anything...it is better not to go to this place at all.”

Theme 3: Support from other organizations

- **Church organizations**

The study found that Church groups were not active in any AIDS care in Bhambayi.

“.....church members do not visit me since I am sick...when I feel well, I sometimes go to church.”

However, one participant who sometimes visited her family in the rural area did receive visits from her church members. She appeared to look forward to these visits when she would join the members in prayer.

“.....I like going home. The people from my church visit and we pray together.”

- **Other organizations**

The participants reported receiving assistance from the HBC program, and the Hospice day care centre at the local clinic.

HBC program

The only organization that was actively engaged in HBC for people with AIDS was the program facilitated by the Durban Institute of Technology (DIT).

“....I have only been visited by the sister from the HBC program.”

All the PWA's in the study received soup powder weekly and occasional small food parcels from the project donations.

“....I get some soup from the volunteer....it is very little....but it is something.”

In exceptional cases, the volunteers shared their own food with PWA's living in isolation.

“....the volunteer helps me with food from her own home sometimes.”

The National Integrated Plan

The researcher found that towards the end of the DIT project, caregivers engaged by National Integrated Plan, had commenced with data collection to address the needs of vulnerable children affected by HIV/AIDS.

Hospice day care

Two participants reported that they attended the Hospice day care support group. They were engaged in income generating activities and their shared experiences with other AIDS sufferers appeared to restore their self esteem.

“....every week I go to the Hospice AIDS support group....I like going there....we talk about many things....and I am now doing some knitting and bead work...this is helping me so much....I am not alone anymore....there are many people like me....”

• **Other persons**

It was reported that PWA's had experienced the problem of chronic food shortage in the majority of households. Some patients had occasional assistance from other family members.

“.....my grandmother (a pensioner) helps me with some food sometimes”.

“.....my father buys some food, when he is working”.

Figure 4.14 below illustrates the ability of the health and social systems to support PWA's within a community.

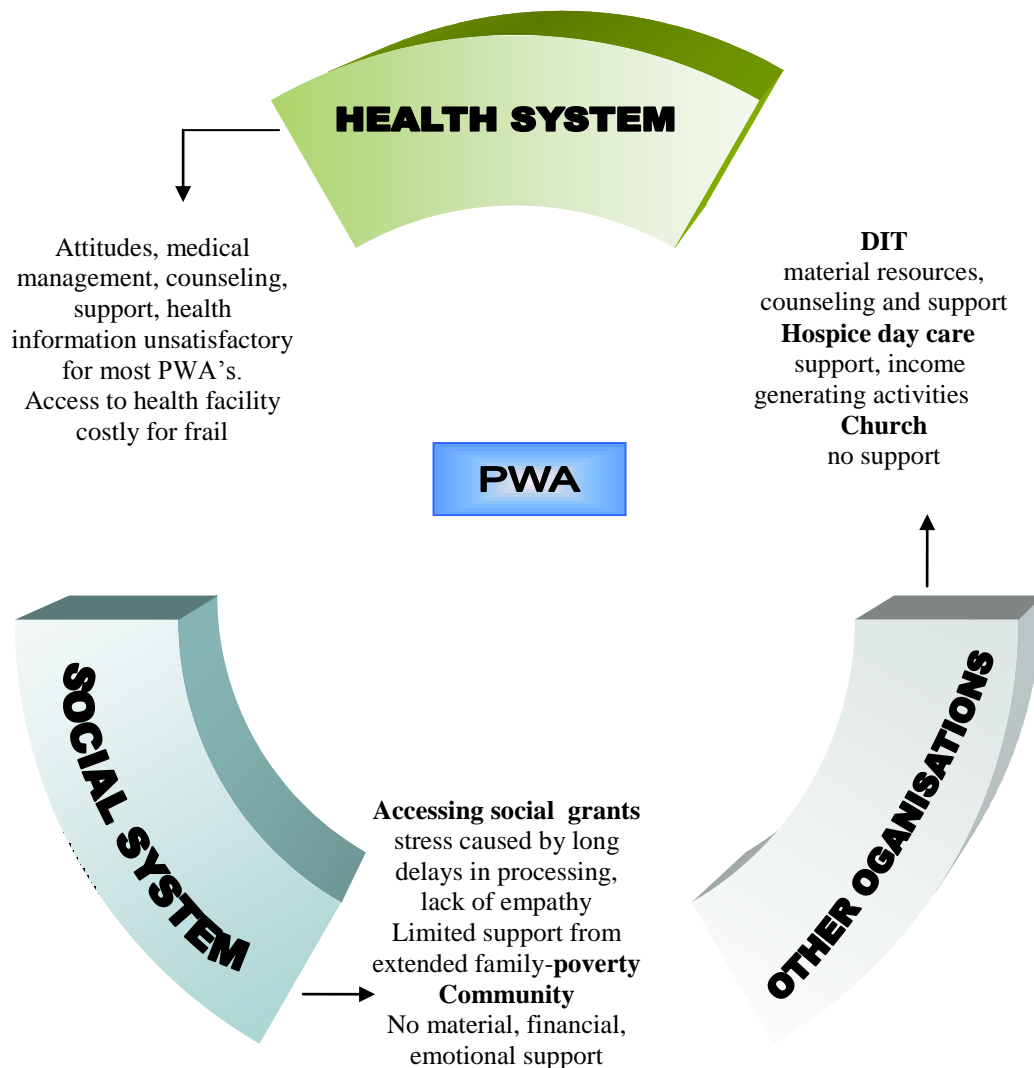


Figure 4.14: Health and social systems ability to support PWA's within the community

Conclusion

It would be prudent to note that the PWA's in the study were people with full blown AIDS whose condition had deteriorated manifesting in reduced body strength due to HIV wasting syndrome, dyspnoea on exertion, chest pain and dizziness. Some patients had presented with behavior changes and required close supervision by the caregiver. It was critical that these patients received medical attention as recommended.

The study found that only a small percentage of people were receiving adequate counseling and support at the health facilities. PWA's who attended the tertiary hospital and alternate PHC's reported receiving essential treatment, counseling and support for AIDS. All the PWA's who attended the local PHC reported that they did not receive satisfactory medical treatment, counseling and support at the facility. Some PWA's reportedly experienced discourtesy from some health care staff at the local PHC. This behavior was reported to be the main factor that discouraged the Bhambayi community from seeking health care for AIDS at this facility. Transport to the local clinic was hired by the families for immobile patients, if funds were available. Most families could not afford the cost and sometimes money was borrowed from unscrupulous money lenders at an interest rate of 100-200%. The volunteers accompanied their sick charges and ensured their safety.

The PWA's in the study were people living with full blown AIDS and had ceased working due to their deteriorating health. They had recently learnt of the government disability grant for people living with AIDS. They therefore sought and received further information from the HBC team. All the PWA's expressed their frustration at the long delays in being attended to and the alleged discourtesy shown to them by some welfare agency staff. Some PWA's had pledged never to return to the agency, consequently giving up all hope of accessing the much needed government aid.

Concerned individuals within the HBC team assisted their patients with food when required. All the participants regularly received food aid in the form of soya soup

powder and occasional small food parcels from the HBC program. Promises of assistance from the government NIP program was not forthcoming as it was reported that the program had failed to reach the majority of affected families.

All the participants said that they had not received any visits from their church members.

The study found that Church groups were not active in any AIDS care in Bhambayi. The only organization that was actively engaged in HBC for people with AIDS in Bhambayi, was the program facilitated by the Durban Institute of Technology (DIT).

It can therefore be concluded that the majority of PWA's in Bhambayi were not receiving adequate support from the health and social system.

4.5.2. HOUSEHOLD LEVEL: FAMILY CAREGIVER

The individual caregivers need support so that they do not succumb to fatigue and despair. They need information and training on what to expect from AIDS, how to care for a patient and access food support and where to receive counseling for their own emotional needs. Therefore the family caregivers are a vital link in the chain of the continuum of community-based care (UNAIDS, 2004).

The purpose of this enquiry was to determine the support from the health and social systems to families caring for a family member living with AIDS in the home. All the family caregivers in this study were women who were also the producers and guardians of family life. Therefore they bore the largest AIDS burden. Some participants were older women who were carrying the burden of care for their ill adult children.

Three themes emerged from this enquiry including the health system, social welfare and support for caregivers. These themes are discussed below.

Theme 1: The health system

The response to the needs of PWA's and their caregivers differed at the various health facilities.

- **Response to AIDS care at the local health facility**

The majority of the participants attended the local PHC. They expressed their frustration at the apparent lack of communication by the nursing staff at this facility.

Caregivers excluded

The caregivers alleged that the staff at the local clinic was not attentive as the caregiver was not included in the management of the PWA. Furthermore all the PWA's problems were not addressed by these staff members.

“...the nurses at the local clinic are not good... I take my sister every now and then to the clinic but they have never spoken to me about her illness...”

PWA's who were very ill and had difficulty with concentration, were unable to communicate their concerns to the attending staff member.

“...sometimes my sister forgot to ask about something serious that is troubling her....she can come away with nothing new to help her....what can I do?”

They also appeared not to remember the outcome of the consultation and consequently were unable to keep their caregiver informed of any changes in treatment and management of the condition. Therefore the caregiver appeared not to understand how to care for the PWA.

“...I don't know what is happening to my sister...she cannot remember anything sometimes....I don't know what to do for her.”

Medical response

The caregivers reported that medical care at the local primary health clinic was unsatisfactory as AIDS related problems were addressed and treated selectively.

“....the nurses cannot even examine the patient and give some treatment....they just say you know you got this disease, there is nothing you can do.”

This was a source of frustration to the caregivers, as the clinic did not provide sufficient medication for symptom control including pain and chronic diarrhea.

“....my sister has too much pain....they do not give pain tablets.”

“....my sister has diarrhea now and then....they do not give anything for this at the clinic.”

- **Response at the other health facilities**

Caregiver inclusive of care plan

In families where the PWA's attended the AIDS clinic at the tertiary hospital and other primary health clinics, the caregiver was included in the active management of the patient. The caregiver was periodically summoned by the health facility for consultation by the staff.

“....the hospital called for me when my daughter was HIV positive. The doctor explained everything to me. Everyone is kind at the hospital. They call me now and then and tell me what is going on.”

These caregivers were therefore well informed and were able to take care of the PWA with confidence. The caregivers reported that the staff was kind and helpful, and that all their concerns were addressed.

“....I know everything about my cousin’s illness. They explained how to look after her at the hospital and what will happen when the baby is born. I go whenever I am called...it is good to know what to do for a sick person”

Medical response

It was reported that all health problems and concerns were addressed and treated at the tertiary hospital and the other primary health clinics. Medication for symptom control was provided and these were reported to be effective.

“....my daughter is lucky because she gets good treatment that helps her from the hospital.”

“....my cousin has many problems but the hospital treatment has been good.....”

- **Health information**

The disease process

All the relevant information was given to the caregiver at the AIDS clinic at the tertiary hospital and the other primary health clinics, as the caregiver was integral to the continuum of care of the PWA.

“...I have been told everything about the disease at the clinic. The nurses say that I must know what to do if my sister gets sick.”

The caregivers did not receive any information on the disease process from the local primary health clinic.

“....nobody at the clinic has explained anything to me.”

The management of opportunistic conditions.

Caregivers were well informed on the management of opportunistic conditions in the home at the AIDS clinic and the other primary health clinics.

“...I know what to do for my cousinthe doctor has explained everything to me.”

However, caregivers received no information at the local primary health clinic.

“...I do not know what is happening to my sister...I don't know what to do to help her when she is very sick.”

Universal precautions

Caregivers received the relevant information from the AIDS clinic at the tertiary hospital and the other primary health clinics on universal precautions to be observed whilst caring for a person with AIDS.

“....the nurses at the hospital have taught me that I must wear some gloves when washing the patient....and that I must wash the clothes separately....maybe (if) there is some blood in (on) the clothes.”

Most caregivers did not receive any information from the local primary health clinic.

“....the nurses at the local clinic do not tell you anything.....you just hear from the volunteers what to do when looking after the patient.”

Nutrition

The caregivers received health information on nutrition for people with AIDS from the tertiary institution and the other primary health clinics, but no education was forthcoming from the local primary health clinic.

“.....before my cousin was discharged from hospital, the nurses talked to me about many things....what food to give my cousin and how to cook this food.”

“....they don't tell you anything at the (local) clinic....I just hear what the volunteer has told me.”

Theme 2: Social welfare

The government disability grant was designed to assist people with AIDS financially in order that they could take care of themselves. The community was well informed about the availability of this grant through the media, the health facilities, and the HBC program and by hearsay. The PWA's with full blown AIDS who met a specific criteria, which included a CD4 cell count of less than 200mm and correct identity documents, supported by a medical report were assisted to apply for this financial assistance. These patients had no source of income as their deteriorating condition prevented them from maintaining their employment. The majority of PWA's in the program were unskilled workers who did not enjoy any employment or sick benefits.

- **Problems experienced in accessing social grants**

The PWA's and their caregivers experienced several problems in attempting to apply for the disability grant including additional traveling costs to the welfare agency office, the endless wait to be attended, the processing of applications took several months, the frustrations of the PWA's documentation not being in order and the negative attitudes of agency staff towards PWA's.

The following quotations illustrate the participants despair and frustration.

Additional financial burden

“....I have no money...I went too many times to the welfare...still nothing is happening.”

Long delays in being attended

“....they say to come the next day...the person is sick and hungry the whole day...”

Long delays in processing applications

“....my sister appliedwe are still waiting....it is many months...”

Incorrect documentation

“....there are many papers to be filled....sometimes the name is wrong and we have to go and apply for a new ID....”

Slow response at health facilities

“....we waited very long for the clinic doctor to sign the form...it is not right....we are suffering.”

Poor attitudes by some welfare agency staff members

“....the social workers do not like to help the people with AIDS...they say we are too many people applying for this grant...if you are clean and look OK, they say you must go and work.”

Theme 3: Support for caregivers

• Support from the Church

There were many church groups of different denominations that existed in Bhambayi. However none of the groups were actively engaged in AIDS care in the community. Therefore none of the families in the study received any support from any church organizations.

“....the church does not know about my problems. Nobody can visit (visits) me.”

However, one PWA did receive spiritual support from a rural church in the village of her birth.

“....many people are praying for me at church in my home.... it makes me strong to look after my cousin...”

- **Support from other organizations**

It was essential to determine the organizations that were active in Bhambayi and the role that they purported to play in the provision of support and care to people with AIDS and their families at community level. This support would be critical for sustainable HBC, particularly in under resourced communities such as Bhambayi. The support that would be considered essential included psychological support, material support and addressing the care of AIDS orphans.

Psychological support

Counseling was received from the HBC project team at the drop-in centre at the site and during home visits. This facilitated the opportunity to build relationship of trust with people infected with and affected by AIDS. The team was enabled to assess the needs of families affected and initiate an appropriate care plan for the PWA in consultation with the family caregiver. The team was also easily accessible to the community.

“....at first I did not trust the sister...then she began to help me in other ways with some soup and clothes....sometimes this soup is the only food in my home....later I could talk to her about other problems...my daughter who is HIV positive then visited the sistershe gets some advice that gives her some hope in her life.”

“....the volunteer visited me many times before I decided to listen to her and get some help from the sister...she visits me when I send a message that I have a problem....I can trust her....she does not discuss my problems in front of others.”

Material support

The affected families were able to access material support from the HBC project in the form of soup, occasional small food parcels, protective equipment and clothing. The families found this helpful although the assistance was limited compared to the need.

“....we get some soup from the volunteer...it is small (very little) but we get some every week....sometimes we get some groceries and some bread if we are lucky.”

- **Support for AIDS orphans**

The HBC project did not have the capacity to address the increasing need to care for children orphaned by AIDS in a realistic manner. These problems were initially referred to the Department of Social Development for management and more recently to the National Integrated Plan. The families of these children were to receive regular food parcels on a monthly basis. The program had many requirements that needed to be fulfilled in order that a family could qualify for assistance (Department of Social Development, 2005).

The plan failed to meet the community's high expectations of material assistance and this was a source of frustration to several families. The participants expressed their concerns as follows:

High expectations not met

“....I tried to get some help from NIP but I failed....they want many things....I do not know where to find the father of these children....my sister does not have an ID...the children do not have any birth certificate...this NIP cannot help us.”

“....I gave them everything they wanted....but still no help....I got some food parcel only once....they promised us food every month.”

The lack of understanding

“....we are frightened to talk to the sister....they say she can shout at people...”

Figure 4.15 below illustrates the ability of the health and social system to support family caregiver of people living with AIDS.

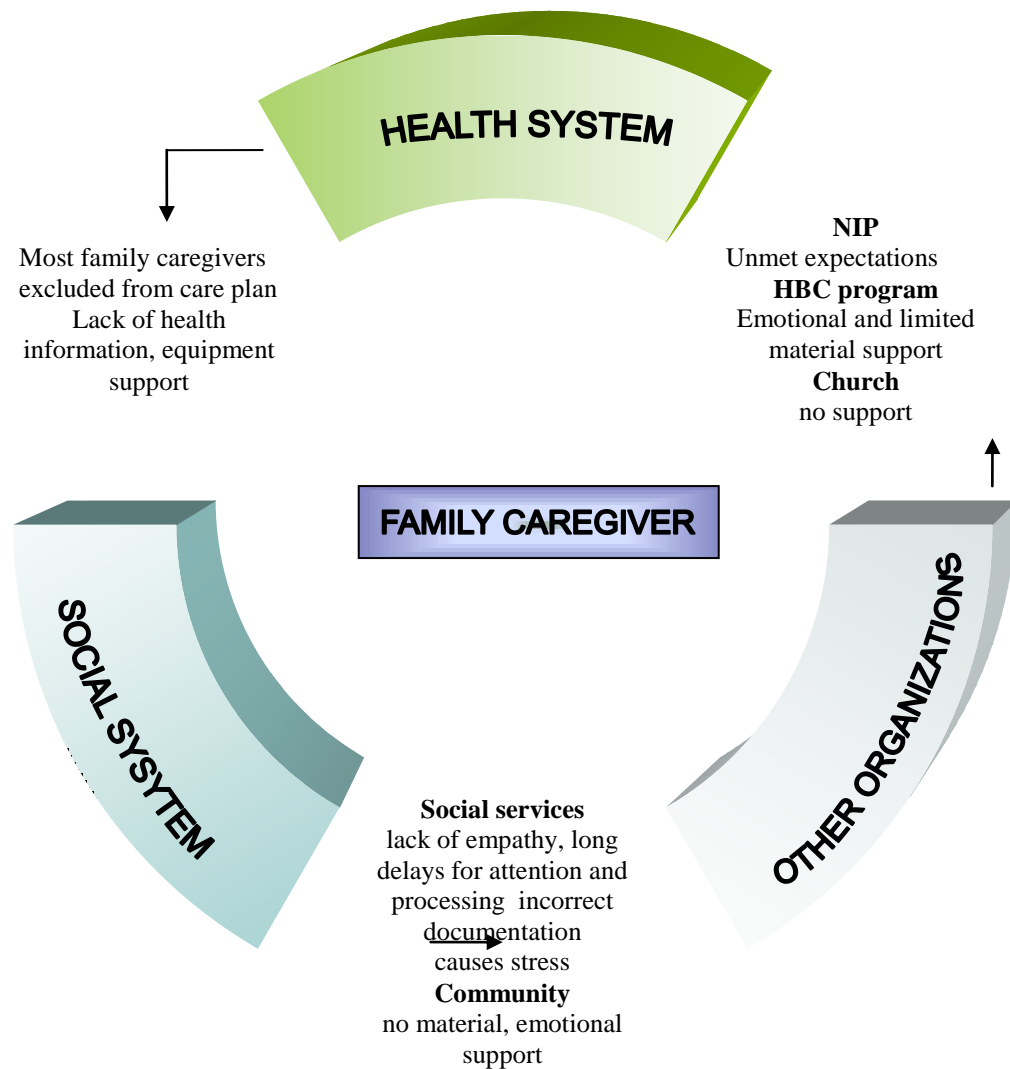


Figure 4.15: Health and social systems ability to support family caregivers of PWA's

Conclusion

AIDS home care is very time-consuming and stressful to caregivers. Therefore the care of the caregiver is important in order to prevent stress and burnout. This assessment found that caregivers, who were included in the PWA's care plan by health facilities, appeared to cope with care of the patient in the home with confidence. Conversely, caregivers who were excluded from the care plan process lacked the confidence and appeared not to cope with caring for the PWA.

All the caregivers appeared to experience several problems in attempting to apply for the essential disability grant that could provide vital resources such as correct nutrition for the PWA. All these problems created despair with community members. The delays in processing applications impacted adversely on the entire family. Some PWA's died awaiting approval of their applications. Some PWA's were unable to pursue the process due to their failing health, and simply gave up in despair. Caregivers who lacked empathy from some health workers and social welfare agency personnel compounded the problems of caregivers.

The absence of church involvement in AIDS care in Bhambayi denied the essential spiritual and possibly material support, which would have reduced the high levels of stress that is synonymous with AIDS care.

Counseling and material support from the HBC team, built on the basis of trust, was beneficial to the families. The high expectations of the community were thwarted by the lack of delivery by NIP to assist families affected by AIDS in Bhambayi.

It can therefore concluded that despite the important role that the family caregiver is expected to play in AIDS HBC, support and care from the health and social system was inadequate.

4.5.3. COMMUNITY LEVEL: COMMUNITY LEADERS

This objective was intended to determine whether the health and social systems were indeed providing minimum services required for home based care for PWA's and whether the health system was able to reach out into the community in support of the PWA's families.

Three themes emerged from this enquiry including the health system, the social system and support from other organizations. These themes are discussed below.

Theme 1: The health system

- **No support from DOH**

There was no material or psychosocial support from the health facilities for AIDS home care during the project process. PWA's received medical intervention only and were sent home to be cared for by their families.

“.....a patient is seen at the clinic and receives some medication only....nobody cares about other problems they may have.....such as food, the needs of their children or the need to apply for a grant.”

Theme 2: Social system

Although many people had attempted to access the government disability grants, the community leaders expressed their concerns at the lack of support from the social welfare agencies. These concerns will be discussed.

The success rate at acquiring a disability grant was poor due to inadequate documentation, an unsympathetic attitude from welfare agency staff and the waiting period to be processed. Some applicants had died awaiting approval of this aid.

- **Social services**

Poor success rate in disability grant applications

According to the participants, the Bhambayi community had a poor success rate of its members attempting to access disability social grants.

“.....there are many problems...people wait very long to be seen....some are tuned away....then they get fed up...these are sick peoplesome never return... (to the agency).”

The community leaders were of the belief that many people had died whilst awaiting their applications to be processed.

“.....others have died before the grants are through.”

Common problems encountered

The most common problem experienced by PWA's was that identity documentation were incorrect or not available. The Bhambayi population was mainly transient in nature, and some individuals did not know their place of birth or their origins. Furthermore some adults were not registered at birth. These problems were difficulties encountered when attempting to apply for a social grant.

“....people come from different places and they do not have ID'ssome people were never registered at birth.”

It was alleged that most deaths in the community were not registered. This created problems for families when attempting to apply for a social grant for AIDS orphans. Furthermore all babies were not registered at birth and social welfare assistance could not be accessed on the death of a parent.

“.....most of our people are just buried without a death certificate.....you need a death certificate when applying for a grant for an orphaned child....these babies are not even registered at birth....you cannot do anything without these documents.”

- **Community support**

According to a report by World Bank (1999) cited in UNAIDS, (2004), families often spend more on funerals and memorials than on medical care and other AIDS-related needs in South Africa. Community advocacy and assistance with funeral costs would assist the families of people with AIDS. The response to this enquiry is discussed.

No financial assistance with funerals

There was no financial assistance with funerals according to one community leader as funerals were perceived to be the responsibility of families.

“....there is no such thing in Bhambayi; funerals are the responsibility of families.”

Burial society failed

One participant reported that attempts to establish a burial society in Bhambayi had failed due to mismanagement of funds.

“...a burial society was started several years ago, but failed due to mismanagement of funds.”

Assistance with minor funeral costs

Despite the level of poverty, another participant reported that community members in one section of Bhambayi, that appeared to have greater cohesiveness, assisted a grieving family by raising funds through small donations that assisted with some funeral costs.

“.....in this section (where she resided) we try to collect some money to help the family....although it is not much, it does help to pay for some funeral costs.”

Theme 3: Support from other organizations

- **The church**

No support for AIDS-related care

The participants alleged that church organizations were not active in AIDS care and support in Bhambayi. According to the participants, there was no support from the Church leadership as AIDS was considered to be a moral issue. AIDS was perceived by the Church as some affliction acquired due to immoral conduct by the infected individuals.

“.....the Church is not active in AIDS care and support in Bhambayi.....there is no commitment from the Church leadership.....AIDS is seen as a disease that people get due to bad moral behavior.”

Visits made by concerned individuals

However some church members did visit the sick in their private capacity.

“.....but we do visit the sick and pray with them as individuals, not representing the church.”

Tertiary institutions

Tertiary institutions, such as the University of KZN was engaged in counseling, support and referral of individuals and families in need of social welfare support. The Durban Institute of Technology was engaged in community development, education and training. The National Integrated program had commenced a project for AIDS orphans and children in distress.

Figure 4.16 below illustrates the ability of the health and social systems to support communities in HBC for people with AIDS.

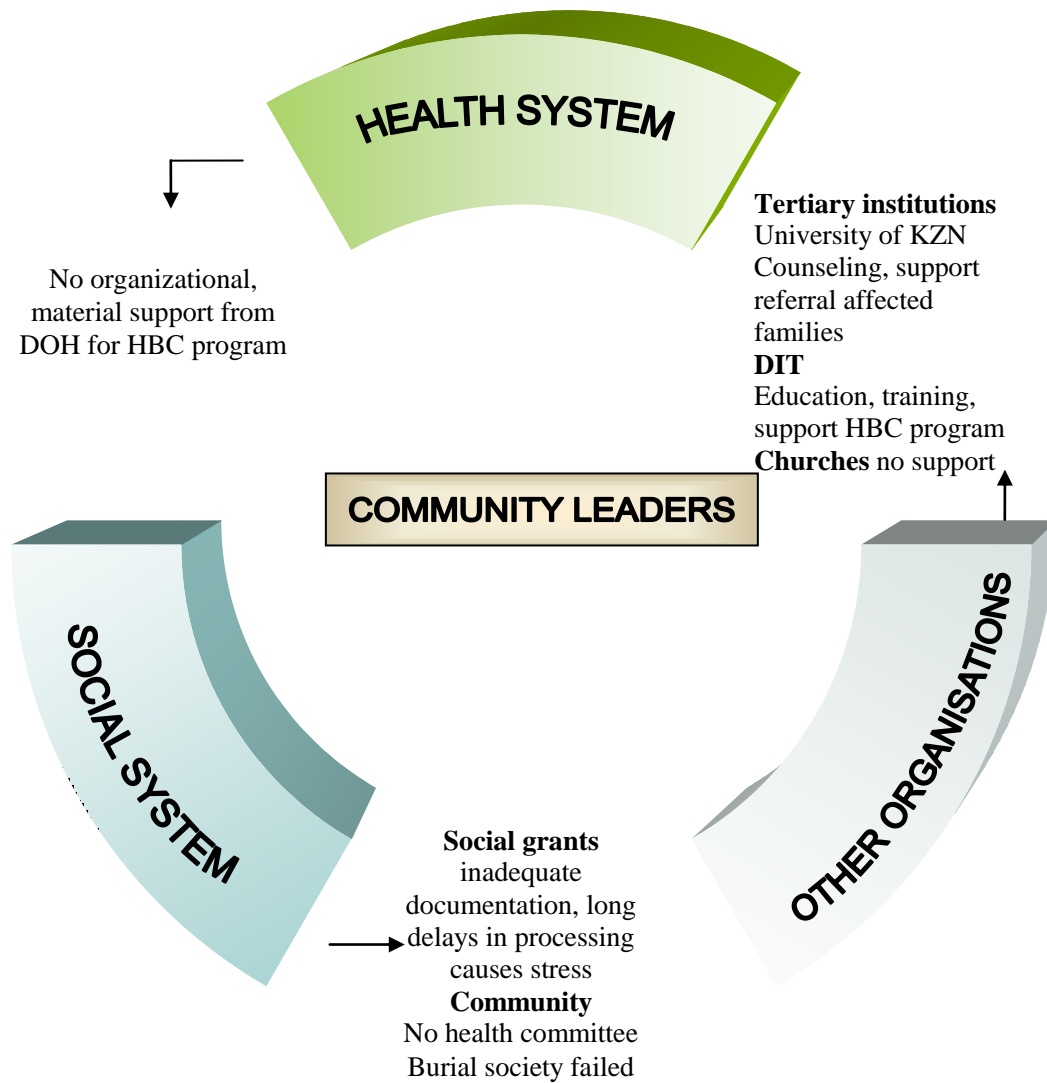


Figure 4.16: Health and social systems' ability to support communities in HBC for PWA's

Conclusion

Communities cannot be expected to provide care for PWA's in isolation; They would require the continued support from the health and social system in order for care provision to be meaningful.

There was no evidence of assistance or support from the Department of Health for the people of Bhambayi. All attempts by the CHW, the community leaders and the researcher, to engage the local PHC in a working relationship to address health issues, including AIDS, had failed. Hence a referral system could not be developed for the area.

The hope of financial aid for PWA's was thwarted by the tedious application process and some unsympathetic welfare agency staff. It was impossible to reassure the applicants who were frail and desperate for this aid, that all will be well.

The cost of funerals was borne by the families. It was reported that many people simply buried their family members in an illegal burial site in Bhambayi without any documentation. A burial society had failed, due to the mismanagement of funds.

The church organizations in Bhambayi were not active in AIDS care, due to the apparent absence of commitment from the church leadership. However, church members visited the ill in their personal capacity.

It was reported that the community had benefited from the activities of service providers engaged in AIDS care in Bhambayi. The University of KZN, Department of Social Sciences; the Durban Institute of Technology and the National Integrated Plan were engaged in counseling, support and referral of families affected by AIDS, community development, education and training and the care of AIDS orphans respectively.

It can therefore be concluded that Bhambayi as a community, did not receive sufficient support for people with AIDS who needed home care. Furthermore the community itself, made little effort to support its community members living with AIDS.

4.5.4. COMMUNITY LEVEL: COMMUNITY VOLUNTEERS

The purpose of this objective was to determine whether the formal health and external social systems were able to support the volunteer caregivers in their provision of HBC for PWA's in the Bhambayi community. The volunteers were part of the informal community system, especially that they were not paid or recognized by the health system.

The volunteer caregivers were the first point of contact for the frail in the community. Therefore support for their work would be essential in order to sustain their valuable services within their community.

Theme 1: Support for volunteers

- **The Government**

The volunteers believed that the Government needed to play a more active role in community based care for people living with AIDS. They felt that greater community education by health and social welfare development agency workers could assist the community in dealing with the wide range of health and social problems associated with AIDS. The current burden of care fell on the community as evidenced by the role that community volunteers assumed in AIDS home care.

“...yes, the volunteers do take a role, but the government must also have a role by sending welfare workers or health workers to teach the community.”

- **The health system**

The lack of support

The HBC program in Bhambayi did not receive any direct support from the local health facilities. The absence of any comment by the volunteers indicates the complete lack of support in terms of several issues including: referral, the use of an existing community based program and the provision of equipment.

The ability to improvise

The lack of funding for transport and equipment such as wheelchairs and patient stretchers did not deter the volunteers from assisting their patients to access health care. They improvised by using wheelbarrows to transport their very ill, immobile patients to the local health facility.

“If the sick person cannot wake up, as a volunteer you do not always have money to hire a cat to take her to the clinic if need be. She may not be able to walk. You end up asking some people to help you take her. Even if they agree, you do not have a stretcher, you cannot manage to carry her, you at least think of a wheelbarrow and it will hurt her also.”

- **Other organizations**

The principle early source of support for the program was from the Durban Institute of Technology (DIT) that initiated the program. The researcher, who also facilitated the program, was supported by the institution. Material resources were provided through donations from the institution and religious organizations. Education and training of the volunteers was also provided by DIT.

It would be prudent to note that the volunteers did not mention DIT at any stage of the discussion. This could be indicative of the fact that, all attempts at meaningful engagement with the Institution’s management by the community, had failed. The team

and the community leadership had expressed their disappointment during the project process.

Theme 2: The willingness to serve

- **Commitment**

The volunteers did not receive any stipends or remuneration for their work. They were a committed group of individuals, who despite being poor themselves, would share their meager personal funds in order to meet transport costs of their charges to the health facility and to purchase fuel for their patients when necessary.

“... the hospital may not admit the patient and you have to take her back home. You are using your own money for both of you.”

“.... if she does not have paraffin, we buy her paraffin.”

They would also share their own food in order to provide nutrition for their very ill patients living in isolation.

“....and it is so difficult, we end up bringing from our home what was for our families. Because it is not nice to eat whereas there is someone who is sick and does not have food. We take from our families and try and cook for them and this makes it better”

Theme 3: Displaying resilience

It was reported that the volunteers experienced tremendous difficulties in their attempts to provide home-based care for PWA's. However, their toughness as discussed below helped them to overcome these odds.

- **Food aid**

The chronic shortage of food for the PWA was a regular problem encountered by the volunteers. The volunteers found that a PWA may not comply with treatment mainly

due to the inability to acquire food. Furthermore, some prescribed medication needed to be taken after meals. The volunteers made every attempt to prepare some food for the patient: soup obtained from the HBC program or, in some instances the volunteers share their own food with the patient at a tremendous cost to themselves.

“....the big problem is that the patient does not have food but needs to take treatment after meals. We end up bringing from our home that was for our families. We take from our families and try and cook for them and that makes it better.”

- **Motivating people to seek health care**

Some patients had difficulty in discussing their health problems with the volunteers, especially if it was HIV related, or if there was a history of prolonged deteriorating ill health. The patient would not be abandoned by the volunteer; instead the patient would be referred to the HBC sister for further assessment.

“....a patient may tell you that they do not know what sickness they have and they have been sick for along time. Some do not go to the clinic at all.”

“....others do not tell you the truth and we do not just leave her alone, but have to think of her life and how we can help her. We look at the treatment from the clinic and then tell our sister in charge that there is a certain sick person in a certain house and give sister the report. The sister makes a home visit and the patient may tell the sister her problem.”

- **Caring for people living in isolation**

PWA's were often abandoned and neglected by their families. They could also be easily evicted from their homes by an unsympathetic landlord, as they had no source of income since their illness. PWA's found them homeless and resorted to living on the streets. PWA's living in isolation was cared for by the team of HBC volunteers. They

would assist the patient with activities of daily living such as personal hygiene, food preparation and feeding.

“.....some of them are staying on the streets as they do not have a place to live, because where they used to live, the owner has chased her away when she became ill and now she does not have money to pay the rent and now she sleeps anywhere.”

“.... Maybe she stays with a partner. The partner just leaves her like that very sick in bed.”

“.....as volunteers we have to take care of that patient, bath her because you find that patient is on her own in that house. There is no one that can comfort her or do anything for her.”

Figure 4.17 below illustrates the ability of the health and social system to support community volunteers in the provision of AIDS home care.

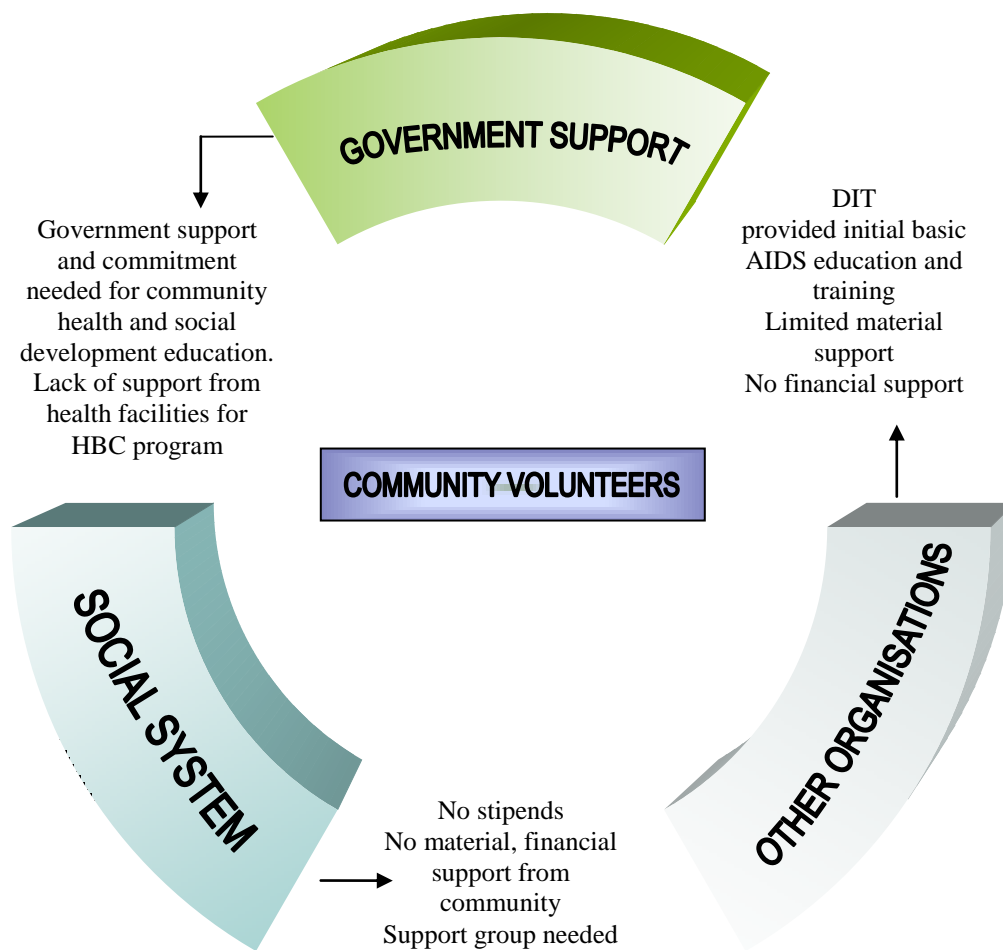


Figure 4.17: Health and social systems' ability to support community volunteers in HBC for PWA's

Conclusion

Caring for people with AIDS requires support from the health and social system. In the absence of such support, it would be difficult for any CBO to independently provide quality care to PWA's. This assessment found that the HBC team did not receive any support from the health system in their work.

The principal early source of support for the program was from the Durban Institute of Technology (DIT) that initiated the program. The researcher, who also facilitated the program, was supported by the institution. Material resources were provided through donations from the institution and religious organizations. Education and training of the volunteers was also provided by DIT.

There was no material or financial support from the community that was under-resourced. However they received community support by show of appreciation of its members who recommended that the volunteers deserve stipends for their efforts.

It can therefore be concluded that given sufficient education and training, community volunteers in any setting, including those similar to Bhambayi, are able to provide an essential home-based care for people living with AIDS. The determination and courage of the Bhambayi volunteers has played an important role in assisting their community to cope with the disease. However, the lack of support from the health and social system could destroy this valuable community resource.

Table 4.4 : Summary and comparison of themes and categories for objective 4 in relation to levels of the community

Themes and Categories	Level of the community			
	PWA	Caregiver	Community leader	Community volunteer
Health system quality of care local PHC other health facilities	lack of empathy, poor medical care, insufficient information	excluded from care plan	no support from health system	no support from health system lack of referral system
	treated with dignity, adequate medical care and health information	included in care plan caring with confidence		
Social system social services	lack of empathy, long delays in being attended, application processing	frustration caused by lack of and incorrect documentation	unregistered deaths and births a source of frustration	unable to assist effectively without correct documentation
community	no material, financial support	no material, financial support	burial society failed, communal garden being planned no income generating activities	no material, financial support
Other organizations the church	no support from local churches support from one rural church	no support from local churches support from one rural church	lack of commitment from local church leadership for AIDS care	no support
tertiary institutions	visits by HBC sister	visits by HBC sister	DIT- education and training for HBC- resources and support NIP - assisting AIDS orphans University of KZN- counseling and referral	DIT- limited resources HBC training and support

4.5.5 OUTCOMES FOR OBJECTIVE 4

Three themes emerged in response to the enquiry, and all the participants expressed the response of the health and social systems to the needs of PWA's. This section summarizes the findings and presents their commonalities and differences between the levels.

Table 4.4 below shows the comparison of themes and categories in relation to the level of the community. It highlights the commonalities and differences in each category. Themes and categories are listed on the left hand column. To the right of this, the actual expressions are aligned with the category of each level of the community studied. In places there is an absence of a comment which shows differences between the levels.

Theme 1: The health system

The attention to PWA's appeared to differ at public health facilities that the participants attended. The majority of the participants were dissatisfied with all aspects of care at the local health facility. They reported that some health personnel lacked empathy and all their concerns were inadequately addressed. There appeared to be a lack of appropriate medical care and support. Furthermore family caregivers were excluded from the care plan of the PWA. The volunteers were not supported in their provision of HBC. All attempts to form a referral system during the project process had failed.

Conversely PWA's attending other health facilities appeared to be satisfied with the care and support received. Family caregivers were included in the care plan that enabled them to provide care with a degree of confidence.

Theme 2: The social system

All the participants reported the poor service at the social service agency that was the only agency dealing with disability grants for PWA's. They reported the lack of empathy, long delays in being attended and processing of applications. There was no assistance in sourcing correct identity documentation. The tardy response of the agency,

compounded by the knowledge of some applicants in the community dying whilst awaiting a response, was reason for many participants failing to pursue this much needed source of financial aid.

The absence of material, financial and physical support from the community for PWA's, affected families and volunteers was reported by all participants. The failed attempt at forming a burial society was indicative of the lack of financial management skills of the community leaders.

Theme 3: Support from other organizations

All the participants reported that the local church organizations were not active in AIDS care in Bhambayi. This was attributed to the lack of commitment from the church leadership. Tertiary institutions engaged in the area provided some support in HBC and counseling, support and referral of affected and infected individuals.

4.5.5.1 Summary of the ability of the health and social system to provide minimal care and support for PWA's

- the majority of PWA's did not receive adequate care and support at the local health facility. However care and support was adequate at other health facilities.
- the service was poor at the social service agency and was a source of grave concern to all the participants. The lack of correct identity documentation was reported as a serious concern. The community lacked the ability to support PWA's in any significant way.
- no support was forthcoming from church organizations in Bhambayi. Tertiary institutions were able to provide only minimal support for AIDS care within an academic year.

CHAPTER FIVE

CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

It would be incorrect to assume that home care for people living with AIDS is the best care. Communities are different, so do their strengths and weaknesses differ. Therefore each community needs to be systematically assessed in order that appropriate interventions can be planned and implemented. This chapter provides the action plan, the setting of priorities in terms of the assessment discusses and the merit of the theoretical framework used in the study and provides recommendations for further research.

5.2 ACTION PLAN

In this section, an action plan for the three levels of the study, based on the outcomes of the data analysis, is discussed. These include an individual care plan for people with AIDS, a household support plan for families engaged in home-care and a community support plan for community-based home care for HIV/AIDS.

5.2.1 Individual care plan

- Food security

The critical need for food security was identified by all the participants. Regular food parcels for PWA's could be an interim measure of relief from hunger. A communal garden could be a medium to long term measure in addressing food insecurity.

- A program to de-stigmatize AIDS

A program to de-stigmatize AIDS at community level, facilitated by trained community members is paramount to the success of any other forms of community support. PWA's must be part of this program that should be culture sensitive with the primary focus on

the dissemination of accurate information on the disease transmission, prevention of spread and the care of infected people.

- Support groups for PWA's

Support groups need to be established for PWA's. The activities could facilitate early disclosure and engage family support. The support group could further serve as a resource centre for networking with other helping agencies. Life skills could also be acquired that would enable the individual to cope with the disease.

- Education on self-care

Specific education on individual self care such as prevention of infection, personal hygiene, nutritional adjustments to accommodate the changing nature of the AIDS condition and symptom control would improve self care. This could prevent the individual from acquiring further infections.

- Income generating activities

Income generating activities are needed to stimulate financial independence especially for people who are too ill to continue working at their usual jobs. This could assist the PWA to maintain his caring role and thereby his self-esteem. The income generated could augment any other source of income such as a disability grant.

- Improve health service delivery

The health services need to train and support staff to provide more compassionate care for PWA's at all health facilities. The training program for staff may require re-evaluation in order to accommodate the changing needs of people with AIDS. The actual health care provision needs to be evaluated by communities that they serve. This process could assist the health system to identify and correct gaps in the system that could improve the quality of care.

- Improve social service delivery

The training and support of agency staff needs to be re-visited. Attending to the social needs of PWA's requires special skills that when correctly used, could improve the quality of service. The social services agency needs to be engaged in actively assisting the frail to access identity documentation for themselves and the registration of all children by bringing the service to the homes of the people. This would assist the affected families enormously in accessing government aid and other support services.

5.2.2 Household support plan

- Food security

Affected households had serious problems with acquiring food. Food parcels could be an interim measure to assist these families. The community needs to give affected families priority of participating in a communal garden.

- Skills development

Programs are needed so that affected families could equip themselves to participate in income generating activities. This is necessary for the financial security of caregivers. Life skills programs could serve to empower caregivers with accurate information on behaviour change, home nursing skills and health information.

The training and support of agency staff needs to be re-visited. Attending to the social needs of PWA's requires special skills that when correctly used, could improve the quality of service.

- De-stigmatization program

Caregivers need to engage the community elders and leaders to harness community support for AIDS care. A de-stigmatization campaign is necessary. This campaign needs to be culture sensitive and the activities should be aimed at removing any misinformation and misconceptions about HIV/AIDS. The process should focus on positive living and attitudinal change can be achieved with correct information on the transmission of HIV and care requirements of PWA's.

- Health committee

Caregivers must have representation on the health committee so that their concerns can be meaningfully addressed.

- Health services

In order that the caregiver can be well informed and supported in home care, it is vital that they are part of the PWA's care plan at all health facilities. They also need to be supported with all HBC supplies and equipment.

- Social services

Families need to be treated with greater empathy by agency staff, in respect of AIDS related social problems. Social services need to revisit the protocol for foster care support grants for affected children. The caregivers need interim material support whilst awaiting a response to application.

- Caregiver respite

Provision must be made for caregiver respite. Negotiation by the leaders with the neighbouring community that has a faith based hospice could be useful. This would relieve families enormously especially in the terminal stages of the disease.

5.2.3 Community support plan

- Forming a health committee

A health committee needs to be formed with community participation and without a political agenda. This committee could advocate for standards of care at health facilities, acquire HBC resources, training and support for the volunteers from the health facility.

- Income generating activities

These need to be urgently developed for financial security. Part of the income generated could also be channelled into stipends for volunteers and acquiring and maintaining HBC equipment.

- Food security

All food distribution should be supervised and accounted for by the community. The leaders need to actively engage with government departments in the development of a communal garden. The garden must be managed by the community.

- Financial management skills development

The community leaders need to source training in financial management skills from the development agency responsible for capacity building.

- Developing community support for AIDS care

The community has a wealth of knowledge in its elders who could steer the process of community education on traditional beliefs, norms and practices aimed at behaviour change, thus reducing the infection rate. The program should also be designed to encourage the general community on assisting with AIDS care and the tracing of families of PWA's.

- Health services

The health services needs to provide the necessary HBC resources, training and support for volunteers with the community managing and monitoring the process.

- Assistance with alternate accommodation

The community needs to make provision for alternate accommodation for destitute PWA's. This is achievable if the space can be negotiated with some property owners in the area.

- Social services

Social services needed to be brought to the most vulnerable people. The community needs negotiate with the relevant political structures to facilitate this process.

- The community health worker

The role of the CHW needs to be re-visited in consultation with all role players. The CHW has valuable training and skills that could facilitate community education on AIDS home-care.

5.3 SETTING PRIORITIES

Priorities that could assist to set the action plan in motion for a sustainable home-based care program for people living with and affected by AIDS in Bhambayi, will be discussed in this section.

5.3.1 Food security

Food insecurity was identified by all the participants in the study. This problem needs to be urgently addressed by government agencies and other organizations engaged in AIDS care in Bhambayi. The intervention needs to be one that is instituted in consultation with the community whereby the community takes full responsibility for all activities related to cultivating and maintaining a communal garden, identifying and assessing infected individuals and affected families and the distribution of food.

5.3.2 Income generating activities

The Bhambayi community is under-resourced which makes the provision of AIDS home care very difficult. Therefore, income generating activities are essential especially for PWA's who are faced with deteriorating health and are unable to continue with their usual jobs. The income generated from well managed programs could assist with augmenting any other source of income such as a disability grant and partly finance other home care costs such as transport and stipends for volunteers.

5.3.3 Support groups for PWA's

Support groups need to be established for PWA's. The activities could facilitate early disclosure and engage family support. The support group could further serve as a resource centre for networking with other helping agencies. Life skills could also be acquired that would enable the individual to cope with the disease.

5.3.4 Forming a health committee

A health committee needs to be formed with community participation and without a political agenda. This committee could advocate for standards of care at health facilities, acquire HBC resources, training and support for the volunteers from the health facility. PWA's and caregivers need to be represented on this committee so that their concerns can be addressed.

5.3.5 Developing community support for AIDS care

The community has a wealth of knowledge in its elders who could steer the process of community education on traditional beliefs, norms and practices aimed at behaviour change, thus reducing the infection rate. The program should also be designed to encourage the general community in assisting with AIDS care and the tracing of families of PWA's.

5.3.6 De-stigmatizing AIDS

A program to de-stigmatize AIDS at community level, facilitated by trained community members is paramount to the success of any other forms of community support. Caregivers need to engage the community elders and leaders to harness community support for AIDS care. PWA's must be part of this program. This program needs to be culture sensitive and the activities should be aimed at removing any misinformation and

misconceptions about HIV/AIDS. The process should focus on positive living and attitudinal change can be achieved with correct information on the transmission of HIV and care requirements of PWA's.

5.3.7 Skills development

Specific education on individual self care such as prevention of infection, personal hygiene, nutritional adjustments to accommodate the changing nature of the AIDS condition and symptom control would improve self care. This could prevent the individual from acquiring further infections. Programs are needed so that affected families could equip themselves to participate in income generating activities. This is necessary for the financial security of caregivers. Life skills programs could serve to empower caregivers with accurate information on behaviour change, home nursing skills and health information. The community leaders need to source training in financial management skills from the development agency responsible for capacity building.

5.4 RECOMMENDATIONS FOR USE OF THE MC DONNELL ET AL. FRAMEWORK

1. The depth of understanding and recording of a phenomenon such as HIV/AIDS requires a researcher to work with the community to be studied in order to build trust and earn the confidence of the people before attempting to assess their needs.
2. The Mc Donnell et al. framework, used in this study can be adapted and used to assess any community in any setting, as it provides the clear guidelines for a holistic assessment. Although the assessment matrix was not used as a rapid assessment tool in this study, as recommended by Mc Donnell et al., it was a good tool for this study.

3. Indicators for similar studies can be developed to suit any community, whether well-resourced or under-resourced.

5.5 RECOMMENDATIONS FOR FURTHER RESEARCH

1. A 'top-down' approach from government or non-governmental organizations is not recommended as these initiatives have been known to fail. The Bhambayi community had shown their reluctance to attend the AIDS support group and the voluntary counselling and testing programs initiated by the Department of Health in 2003. According to the community they were not consulted on their views. Therefore, all community initiatives in HIV/AIDS care need to be evaluated and recognised with community consultation and participation.
2. An evaluation of the delivery of care and support by the health system interfacing with other service providers of community-based AIDS care is urgently required. At the district level, a method of co-ordinating a system of referral between services (CBO, NGO and government) needs attention.
3. Research on indigenous knowledge and traditional healing methods related to HIV/AIDS is required as this can be utilized in the holistic management of people living with AIDS, especially for home-based care. It may also be more cost effective.
4. HIV/AIDS care and support requires special skills from all health care personnel. Therefore, research into the present curriculum for practicing community nurses needs to be evaluated in order to adequately prepare nurses for the multiple needs of the growing number of people living with AIDS that are entrusted to their care. The present shortfall that was identified in this study appeared to be the lack of community outreach by the health personnel.

REFERENCES

AIDS epidemic update, (2004). Available from <http://www.unaids.org> [Accessed in December 2004].

Benjamin, M. (2000). Bhambayi community development project. Health assessment survey. Unpublished report.

Campbell, A. I. & Rader, A. D. (2000). A community development approach to AIDS care, prevention and control. Setting up community health programmes: A practical manual for use in developing countries. 2nd edition. Macmillan Education Ltd: London and Oxford. ISBN: 0-333-67933-4.

Chatora, R. (2003). An overview of the traditional medicine situation in the African region. African health monitor. Traditional medicine our culture our future. 4: 1 (4).

Department of Health, Directorate: HIV/AIDS and TB (2000). Comprehensive home/community based training manual. Pretoria. Department of Health. ISBN: 1-87-5017-8.

Department of Health, Directorate: Chronic diseases, disabilities and geriatrics (2001). National guideline on home-based care & community-based care. Pretoria. Department of Health.

Department of Health, Directorate (2003). National HIV and Syphilis Antenatal Sero-Prevalence Survey in South Africa: 2002. Pretoria. Department of Health.

Department of Social Development, Directorate: You and your grants. (2003). Pretoria. Department of Social Development.

Dorrington, R., Bradshaw, D. & Budlender D. (2002). HIV/AIDS profile of the provinces of South Africa-indicators for 2002. Cape Town: Centre for Actuarial Research, Medical Research Council and Actuarial Society of South Africa.

Evian, C. (2000). Primary AIDS care. 3rd edition. Jacana Education: Houghton. ISBN: 1-874955-53-0.

Green, A. (1999). An Introduction to Health Planning in Developing Countries. 2nd edition. Oxford University Press. ISBN: 0-19 262984 0

Hoeman, S. (1996). Rehabilitation nursing. Process application. 2nd edition. St Louis: Mosby ISBN: 0-8016-77-66-1.

Kalibala, S. & Kaleeba, N. (1997). Participatory evaluation of counselling, Medical and social services of TASO in Uganda. AIDSCARE 9:1 (13-26).

Kindlen, M. (1994). Nursing practical. Hospital and home. The adult. Edited by M. F. Alexander, J. N. Fawcell, & P. J. Runchiman. Churchill Livingstone: Singapore. ISBN O-443-043388.

Lahoud, S. (1997). Home-based care. Continued medical education. 15: (7).

Lankester, T. (2000). Setting up community health programmes: A practical manual for use in developing countries. 2nd edition. Macmillan Education Ltd: London and Oxford. ISBN: 0-333-67933-4.

Mc Donnell, S., Brennan, M., Burnham, G., & Tarantola, D. (1994). Assessing and planning home-based care for persons living with AIDS. Health Policy and Planning; 9:4 (429-437).

Moodley, V. (2003). HIV palliative care course notes. (Unpublished handout). Highway Hospice, Durban.

Pequegnat, W. & Bray, J. H. (1997). Families and HIV/AIDS: Introduction to the Special Section. Journal of family Psychology. 11:1 (3-10) ISBN: 0-8933-200

Polit, F. D., Beck, C. T. & Hungler B. P. (2001). Essentials of nursing research methods, appraisal and utilization. 5th edition. Philadelphia: Lippincott. ISBN: 0-7817-2557-7.

Russell, M. & Schneider, H. (2000). A Rapid Appraisal of community-based HIV/AIDS care and support programmes in South Africa. Johannesburg: Health Systems Trust.

Samba, E.M. (2003). From the Regional Director's desk. (Editorial). African health monitor. Traditional medicine our culture our future. 4:1 (1).

Serovich, J.M. (2000). Helping HIV positive persons to negotiate the disclosure process to partners, family members and friends. Journal of marital and family therapy. 26:3 (362-372).

Swanepoel, H. & de Beer, F. (1996). Community capacity building. A guide for field workers and community leaders. Johannesburg: International Thompson Publishing (Southern Africa) Pty Ltd.

UNAIDS/WHO (2000). Fact sheets on HIV/AIDS. A desktop reference. Geneva: UNAIDS/WHO.

UNAIDS, 2000. Collaboration with traditional healers in HIV/AIDS prevention and care in sub Saharan Africa. Geneva: Switzerland.

UNAIDS, 2004. Report on the global AIDS epidemic. The impact of AIDS on people and societies. Available from <http://www.unaids.org>. [Accessed in September, 2004].

Van Rensburg, H.C.J., Fourie, A. & Pretorius, E. (1992). Health care in South Africa: Structure and dynamics. Pretoria: Academica. ISBN: 0-8687-4471-9.

WHO, 2000. The world health report. Health systems: improving performance. Geneva: Switzerland. ISBN: 92 4 156198 X.

Appendix 1: Development of instrument for data collection according to the objectives and conceptual framework for the study.

OBJECTIVES	CONCEPTUAL FRAMEWORK	METHOD	TOOLS	QUESTIONS
<p>1 To determine the concordance between the prevalence of HIV/AIDS in the community and the community awareness of their susceptibility to HIV infection.</p> <p>Prevalence of HIV/AIDS</p> <p>Awareness</p>	<p>2002 Medical Research Council HIV prevalence data for KZN</p>	<p><i>Comparison of the above data with the data below</i></p> <p>Qualitative- self report</p>	<p>2002 Medical Research Council HIV prevalence data for KZN</p>	<p>Not applicable</p>
				<p>Individual level: Person with AIDS How serious is the AIDS problem in Bhambayi? How susceptible are people to getting AIDS?</p> <p>Household level: Principal caregiver How serious is the AIDS problem in Bhambayi? How susceptible are people to getting AIDS?</p> <p>Community level: Community leaders How many people do you who are living with AIDS in Bhambayi? Is AIDS a serious problem? How susceptible are people to getting AIDS?</p> <p>Community level: community volunteers How serious a problem is AIDS in Bhambayi? How susceptible are people to getting AIDS?</p>

OBJECTIVES	Theoretical Framework: Assessment Matrix by McDonnell et al. (1994)				CONCEPTUAL FRAMEWORK	METHOD	TOOLS	QUESTIONS
2. To determine the perceived needs of individuals, households and the community in order to identify the basic needs that are necessary to care for people with AIDS in the home (continued)					Mc Donnell et al. (1994) and Comprehensive home/ community based training manual (Department of Health, 2001) Adapted to the research setting according to relevancy.	Qualitative - self report	Interview guide and checklist	<p>Community level : Community leaders What are the community's most pressing health concerns in relation to caring for people with AIDS (PWA's) in the home?</p> <p>How are PWA's who are chronically ill people cared for in Bhambayi?</p> <p>Is there an increase in the number of children not attending school due to the AIDS problem?</p> <p>Is there an increase in the number of people who have lost their jobs due to AIDS?</p> <p>Have the income generating activities of people in the community altered in any way due to the problem of the AIDS condition?</p> <p>Have families expressed concern about their present or future ability to care for their relatives living with AIDS?</p> <p>Are family members forced to stop their formal jobs to care for relatives living with AIDS?</p> <p>Are there any other problems in the community related to caring for PWA?</p> <p>Community level: Community volunteers How are chronically ill people (AIDS, TB, stroke) cared for in Bhambayi?</p> <p>Do you have sufficient information to provide care for people with AIDS?</p> <p>What are your problems when caring for patients with AIDS and how do you deal with them?</p> <p>Do you have sufficient equipment to provide care?</p> <p>How do you assist your patient with AIDS?</p>
					Comprehensive home/ community based training manual (Department of Health, 2001) Adapted to the research setting according to relevancy.	Qualitative - self report	Focus group discussion Interview guide and checklist	

OBJECTIVES	Theoretical Framework: A Assessment Matrix by McDonnell et al. (1994)				
	CONCEPTUAL FRAMEWORK	METHOD	TOOLS	QUESTIONS	
3. To examine the community's organizational ability and future Capacity to care for people with AIDS. (contd).		Qualitative- self report	Interview guide and checklist	Community level : Community leaders Are there recognized community leaders in Bhambayi? How were these leaders appointed? What capacity building activities have the community leaders engaged in? What are the responsibilities of the leaders? How is the Bhambayi Reconstruction and Development Committee structured? What are the community's major health concerns? Does Bhambayi have a health committee? What do you understand by a Home-based care program for people with AIDS? Does such a program exist in Bhambayi? Describe the activities of the program? Of what benefit has the program been to the community? What are your concerns about the program? Community level: Community volunteers Why did you become a volunteer? Of what benefit has becoming a volunteer been to you? What are your concerns as a volunteer assisting How does the community feel about your caring for people with AIDS?	

OBJECTIVES	CONCEPTUAL FRAMEWORK	METHOD	TOOLS	QUESTIONS
4. To examine the ability of the health and social system to provide support and services to people with AIDS.	<p>Comprehensive home/community based care training manual (Department of Health, 2001)</p> <p>Adapted to the research setting according to relevancy.</p> <p>Comprehensive home/community based care training manual (Department of Health, 2001)</p> <p>Adapted to the research setting according to relevancy.</p> <p>Mc Donnell et al (1994)</p>	<p>Qualitative - self report</p> <p>Qualitative</p> <p>Qualitative</p>	<p>Interview guide with Checklist</p> <p>Interview guide with checklist</p> <p>Interview guide with checklist</p>	<p>Individual level : Person with AIDS Are you able to get to a hospital, clinic easily?</p> <p>Do you get counselling on every visit to the clinic, hospital?</p> <p>Are you given health information about your condition when needed?</p> <p>Have you applied for a social welfare grant?</p> <p>Did you have any problems when applying for this grant?</p> <p>Have you received any nutritional support from any person or organisation?</p> <p>Do your church members visit you?</p> <p>Do other organisations visit you?</p> <p>Household level : Principal caregiver What has been your experience when seeking assistance from hospital, clinic for your family member with AIDS?</p> <p>Have you received any information on the AIDS condition of your family member?</p> <p>Has your sick family member applied for a social welfare grant?</p> <p>What assistance do you receive from your church?</p> <p>What assistance do you receive from other organisations?</p> <p>Community level: Community leaders What problems do PWA's experience when accessing health care from hospitals and clinics?</p> <p>Do PWA's readily receive AIDS counselling and information from the health facilities?</p> <p>Where do community members get the necessary equipment required to care for PWA's</p>

Theoretical Framework: Assessment Matrix by Mc Donnell et al. (1994)

OBJECTIVES		Theoretical Framework: Assessment Matrix by McDonnell et al. (1994			
CONCEPTUAL FRAMEWORK		METHOD	TOOLS	QUESTIONS	
4. Health and social system ability (contd)	Mc Donnell et.al (1994).	Qualitative - self report	Interview guide with checklist	Community level : Community leaders What is the success rate of community members with AIDS their families accessing social grants? What problems are they likely to encounter? Does the community assist with funerals? Does the community have a communal garden? Do the Churches support the ill and their families? Are PWA's and their families assisted by other groups?	
	Comprehensive home/community based care training manual (Department of Health,2001) Adapted to the research setting according to relevancy	Qualitative - self report	Focus group discussion Interview guide with checklist	Community level : Community volunteers How have you been able to help people with AIDS and their families in Bhambayi? Do you have sufficient information to care for PWA's? What are the common problems experienced in the field and how do you deal with them? Do you have support in your field of work?	

Appendix 2: Use of outcomes from Objectives 1, 2, 3, and 4 in order to achieve Objective 5.

OBJECTIVES	CONCEPTUAL FRAMEWORK	CATEGORY	OUTCOMES
5. To determine the strengths weaknesses and barriers in home-based care that will facilitate the development of an appropriate action plan	Theoretical Framework: Assessment Matrix by McDonnell et al. (1994)	1. Prevalence and Awareness	Prevalence will be compared with the community's perception of risk to HIV infection. Community concern and interest is compared to the actual situation for concordance. Identify barriers: disclosure of HIV status, discrimination.
		2. Perceived needs	The most pressing basic needs and expectations of individuals, families and communities are considered. This will provide information on the minimum intervention that will be considered at each level.
		3. Community capability	Define areas for negotiation between the community and the source of assistance. Define the strengths and weaknesses of the community's capability to respond to the needs and demands: define the gaps.
		4. Health and social system	Define the barriers: political social, cultural resources: available and not used that are non-existent Response to individual and household needs. Response to community needs and link with community resources.
		5. Action plan	Define the gaps and how they can be filled. Define individual care plan, household and community support plan. Define priorities and set targets.

Appendix 3

Interview Schedule with Checklist and Response Sheet

Individual Level : Person Living with AIDS

Objective 1

To determine the community's awareness of their susceptibility to HIV infection

1. How serious is the AIDS problem in Bhambayi?

2. How susceptible are people to contracting AIDS?

Objective 2

To examine the perceived basic needs of individuals living with AIDS

Preamble:

I would like to know how you take care of yourself. There are a few questions I would need to ask you.

2.1 Are you able to take care of yourself?

Indicator	Response	Checklist
1. Nutrition		* acquiring food
		* food preparation
		* feeding self (mouth infections, dysphasia)
Other interesting points		

Indicator	Response	Checklist
2. Water		* carry water (physical ability)
		* availability
		* distance from dwelling
		* quantity required
Other interesting points		

Indicator	Response	Checklist
3 Hygiene		
3.1 Environmental		
Internal		* clean house
External		* remove garbage
Other interesting points		

Indicator	Response	Checklist
4 Laundry		* do own laundry
		* needs help
		* requisites to do laundry
Other interesting points		

Indicator	Response	Checklist
5 Caring for children		* living with patient
		* food preparation
		* laundry
		* assisting with homework
		* money to meet needs
		(source - own, family assist, social grant)
Other interesting points		

3. Who cares for you when you are ill?

Indicator	Response	Checklist
		* partner / spouse
		* children
		* extended family
		* neighbour
		* community health volunteer
		* volunteer
		* nobody
Other interesting points		

4. Do you have money for living expenses?

Indicator	Response	Checklist
1. Food		* quantity
		* quality
		* regularity
		* consistency
		* sustainability
Other interesting points		

Indicator	Response	Checklist
2 Clothing		* regularity
Other interesting points		

Indicator	Response	Checklist
3 Caring for family		* food
		* clothing
		* school fees
		* cooking
Other interesting points		

5. Are you satisfied with support from your family?

Indicator	Response	Checklist
1 Financial		
2 Material		
3 Psychological		
Other interesting points		

6. Are you satisfied with your living conditions?

Indicator	Response	Checklist
6.1 Space		*dwelling size
		* living space
		* number of occupants
		* rental
		* energy supply
Other interesting points		

Indicator	Response	Checklist
6.2 Ventilation		*windows (size, number)
		* temperature control (winter, summer conditions)
Other interesting points		

Indicator	Response	Checklist
6.3 Water		* availability
		* distance from dwelling
		* transport and storage
		* quantity required for family use over 24 hrs
		* cost
Other interesting points		

Indicator	Response	Checklist
6.4 Sanitation		* type (pit privy, chemical, other)
		* construction
		* usage(sharing)
		* old sites
		* other problems
Other interesting points		

Objective 3

To examine the community's organisational ability and future capacity to care for PWA's

Preamble:

I would like to know who is available in the community that can assist you. There are a few questions that I would like to ask you.

1 Where do you go to when in need of health care related to your condition?

Indicator	Response	Checklist
1.1 services and support		hospital
		clinic
		traditional healer
		other
Other interesting points		

2. How do you manage the health problems related to your condition?

Indicator	Response	Checklist
managing health		mouth ulcers
problems		diarrhoea
		pain
		unable to swallow
Other interesting points		

3. Whom do you speak to and get help from when you have a health problem?

Indicator	Response	Checklist
source of assistance		family member
		neighbour
		health professional
		volunteer
Other interesting points		

4. Do you know who your community leader is? If yes, how does he assist you?

Indicator	Response	Checklist
resources		accommodation
		tracing family members
		information on services available
Other interesting points		

5. Do you know who your community health worker is? If yes, how does she assist you?

Indicator	Response	Checklist
5.1 health information		AIDS condition
		treatment compliance
		universal precautions
		hygiene
		nutrition
Other interesting points		

Indicator	Response	Checklist
5.2 referral		health professional
		social services
		councillor
		health facility
Other interesting points		

Indicator	Response	Checklist
5.3 material resources		food
		equipment
		other
Other interesting points		

Indicator	Response	Checklist
5.4 support		assist to health facility
		organise transport
		nutritional
Other interesting points		

6 Do you have a community volunteer visiting you? How does she assist you?

Indicator	Response	Checklist
6.1 health information		AIDS condition
		treatment compliance
		universal precautions
		hygiene
		nutrition
Other interesting points		

Indicator	Response	Checklist
6.2 referral		health professional
		social services
		councillor
		health facility
		other
Other interesting points		

Indicator	Response	Checklist
6.3 material resources		food
		clothing
		equipment
Other interesting points		

7. Whom do you contact when you have a social problem?

Indicator	Response	Checklist
contact person		ward councillor
		community health worker
		volunteer
		social worker
		community leader
		other
Other interesting points		

Objective 4

To examine the ability of the health and social system to provide support and services to people with AIDS

Preamble:

I would like to understand how the health and social welfare departments are able to assist you.
There are a few questions that I need to ask you.

1. Are you able to get to a hospital, clinic easily?

Indicator	Response	Checklist
1.1 physical ability		transport
		health condition
Other interesting points		

Indicator	Response	Checklist
1.2 costs		transport
		admission fee
		other
Other interesting points		

2. Do you get counselling on every visit to the clinic, hospital?

Indicator	Response	Checklist
2.1 disease		understanding the disease
process		
Other interesting points		

Indicator	Response	Checklist
2.2 symptom management		simple remedies
		dehydration-prevention
		diarrhoeal conditions
		anorexia
		pain
Other interesting points		

Indicator	Response	Checklist
2.3 nutrition		food types
		food preparation
Other interesting points		

Indicator	Response	Checklist
2.4 medication		administration
		side effects
		compliance
Other interesting points		

3 Are you given health information about your condition when needed?

Indicator	Response	Checklist
3.1 source		health professional
		other
Other interesting points		

Indicator	Response	Checklist
3.2 quality		addresses all relevant concerns
		addresses some concerns
Other interesting points		

4. Have you applied for a social grant?

Indicator	Response	Checklist
4.1 need		deteriorating condition
		loss of income
		increased expenses
Other interesting points		

Indicator	Response	Checklist
4.2 access		what is available
		application process
Other interesting points		

5. Did you have any problems when applying for this grant?

Indicator	Response	Checklist
5.1 documentation		availability
		hidden costs
Other interesting points		

Indicator	Response	Checklist
5.2 attitude of agency		lack of empathy
Other interesting points		

6. Have you received any support from any person or agency?

Indicator	Response	Checklist
1.source		family
		support group
		church
		other
Other interesting points		

Indicator	Response	Checklist
6.2 quality		fortified
		other
Other interesting points		

Indicator	Response	Checklist
6.3 quantity		meets nutritional requirements
Other interesting points		

Indicator	Response	Checklist
6.4 regularity		how often
		when
Other interesting points		

Indicator	Response	Checklist
6.5 impact on health		feels stronger
status		no difference
Other interesting points		

7. Do your church members visit you?

Indicator	Response	Checklist
7.1 support		physical
		material
		spiritual
		other
Other interesting points		

Indicator	Response	Checklist
7.2 regularity		
Other interesting points		

Appendix 4

Interview Schedule Guide

Household level: Principal family caregiver

Objective 1: To determine the concordance between the prevalence of HIV/ AIDS in the community and the community awareness to of their susceptibility to HIV infection.

Questions

1. How serious is the AIDS problem in Bhambayi?
2. How susceptible are people to getting AIDS?

Objective 2: To determine the perceived needs of individuals, households and the community in order to identify the basic needs those are necessary to care for people living with AIDS.

Questions

1. How do you meet your living expenses now that you are taking care of your sick family member?
2. How has the illness affected your job?
3. Have your expenses changed since taking care of your sick relative?
4. Do you have sufficient nutritious food for the sick person?
5. Are you satisfied with support from your family members?
6. Are you satisfied with your living conditions: space, water, sanitation?
7. Are there any children not attending school?
8. Do you experience any other problems in caring for this person?

Objective 3: To examine the community's organizational ability and future capacity to care for people with AIDS.

Questions

1. Whom do you contact in the community when you need help with your sick family member e.g. food shortage, accessing hospital and clinic, social and health problems and nursing care?
2. Does a community volunteer visit you? If yes, how does she assist you in caring for the AIDS patient?
3. Do you know who your community leader is? If yes, how does he/she assist you with providing care for the AIDS patient?
4. Who is your community health worker? How does she assist you with providing care for the AIDS patient?

Objective 4: To examine the ability of the health and social system to provide support and services to people with AIDS?

Questions

1. What has been your experience when seeking assistance from the hospital, clinic for your family member with AIDS?
2. Has your sick family member applied for a social grant?
3. What assistance do you receive from your church?
4. What assistance do you receive from other organizations?

Note: The questions from the interview schedule are presented above as appendix 4. The actual interview schedule and response sheet used in the study was designed as the one presented in appendix 3.

Appendix 5

Interview Schedule Guide

Community level: Community leaders

Objective 1: To determine the concordance between the prevalence of HIV/ AIDS in the community and the community awareness to of their susceptibility to HIV infection.

Questions

1. How many people do you know who are living with AIDS in Bhambayi?
2. Is AIDS a serious problem?
3. How susceptible are people to getting AIDS?

Objective 2: To determine the perceived needs of individuals, households and the community in order to identify the basic needs those are necessary to care for people living with AIDS.

Questions

1. What are the community's most common concerns in relation to caring for people with AIDS (PWA's) in the home?
2. How are PWA's who are chronically ill people cared for in Bhambayi?
3. Is there an increase in the number of children not attending school due to the AIDS problem?
4. Is there an increase in the number of people who have lost their jobs due to AIDS?
5. Have the income generating activities of people in the community altered in any way due to the AIDS problem?
6. Have families expressed their concern about their present or future ability to care for their relatives living with AIDS?
7. Are family members forced to stop their formal jobs to care for relatives living with AIDS?
8. Are there any other problems in the community related to caring for people with AIDS?

Objective 3: To examine the community's organizational ability and future capacity to care for people with AIDS.

Questions

1. Are there recognised community leaders in Bhambayi?
2. how were these leaders appointed?
3. What capacity building activities have the community leaders engaged in?
4. What are the responsibilities of the community leaders?

Appendix 6

Interview schedule guide: Community volunteers focus group discussion

Objective 1: To determine the concordance between the prevalence of HIV/ AIDS in the community and the community awareness to of their susceptibility to HIV infection.

Questions

1. How serious a problem is AIDS IN Bhambayi?
2. How susceptible are people to getting AIDS?

Objective 2: To determine the perceived needs of individuals, households and the community in order to identify the basic needs those are necessary to care for people living with AIDS.

Questions

1. How are chronically ill people (AIDS, TB, and stroke) cared for in Bhambayi?
2. Do you have sufficient information to provide care for people with AIDS?
3. What are your problems when caring for patients with AIDS and how do you deal with them?
4. Do you have sufficient equipment to provide care?
5. How do you assist your patient with AIDS?

Objective 3: To examine the community's organizational ability and future capacity to care for people with AIDS.

Questions

1. Why did you become a volunteer?
2. Of what benefit has becoming a volunteer been to you?
3. What are your concerns as a volunteer assisting people with AIDS?
4. How does the community feel about your caring for people with AIDS?
5. What would make your work easier?

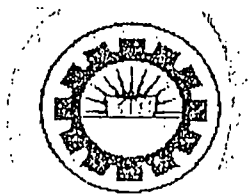
Objective 4: To examine the ability of the health and social system to provide support and services to people with AIDS?

Questions

1. How have you been able to help people with AIDS and their families in Bhambayi?
2. Do you have sufficient information to care for PWA's?
3. What are the most common problems experienced in the field and how do you deal with them?
4. Do you have support in your field of work?

Note: The questions from the interview schedule are presented above as appendix 6. The actual interview schedule and response sheet used in the study was designed as the one presented in appendix 3.

APPENDIX 7



D U R B A N INSTITUTE *of* TECHNOLOGY

LETTER OF CONSENT

The Chairperson
Bhambayi Reconstruction and Development Committee
P O Box 68291
Inanda 4310
Sir

Re: Request for permission to conduct a research study in Bhambayi

I, Matheevathinee Benjamin am a student registered in the Nursing Masters Program., Department of Postgraduate Nursing Studies, at the Durban Institute of Technology (DIT).

I am required to conduct a research study as part of the program.

I hereby request to undertake the proposed study in Bhambayi.

The title of the study is:

An assessment of the Bhambayi community with the view to planning an improved home-based care program for people living with AIDS

This area of study was chosen in response to the health concerns expressed by the BRDC at the initial contact between M L Sultan Technikon (now DIT) and the committee in October 2000.

The study intends to investigate these concerns that were further identified in a Comprehensive Health Survey in 2000. The study will be conducted in a systematic manner using scientific principles. This study would enable us to investigate whether the community is aware of their risk to HIV infection: what the people with AIDS and their family caregivers feel that they need for care in the home and how the community supports home-care for people living with AIDS in Bhambayi. This assessment is needed so that areas of need can be identified and prioritized to facilitate effective planning and implementation of home-based care for people living with AIDS.

The investigation will involve one hour-long interviews with community leaders (5); a group discussion (5 volunteers with the present home-based care programme); family caregivers (10); and people living with AIDS(10).

Each of the above-mentioned groups and individuals will be fully informed of the nature and purpose of the study. They will be presented with an information sheet and a consent form translated into Zulu.

Benefits of the study:

1. Community

Although the study may not benefit you immediately, the information will help to identify the community resources that could assist to develop and sustain home-based care for people living with AIDS.

2. Family Caregivers

This study will enable the researcher to identify the needs in caring for their sick family member in the home environment. We will be able to see more clearly what problems families are faced with and how they may be assisted.

3. Community Volunteers (focus group)

The researcher will be able to identify concerns and what is needed in the caring process. The recommendations could assist in improving the ability to care for people with AIDS with greater confidence.

4. People living with AIDS

The researcher will be able to identify the critical needs and concerns of people living with AIDS, which could help us to understand how much of help the patient may need in caring for himself. It is hoped that with greater knowledge and care provision, that the patient's quality of life can be improved.

A possible concern for the community in participating in a study of a sensitive subject like AIDS is fully appreciated. However, I plan to address this by following a strict recommended code of ethics.

The study will include a written interview and a group discussion will also be be taped with each participants consent. A taped interview allows for more careful listening by the interviewer. Any participant may refuse to be taped.

The record of the interview sheets and tapes will be confidential. I will personally conduct the interview, with no other person present. A coded system using numbers and alphabets will be used so that names of the participants cannot be linked to the investigation in any way. No names will appear on the tapes or the interview response sheets. The list of names will be kept in a safe place in my office at DIT, under lock and key. Apart from myself, no other person shall have access to this list.

The coded interview response sheets and tapes will be kept for the legal period of 3 years, and then be destroyed by shredding.

My supervisor may examine the coded interview sheets and tapes at any time as a requirement.

The findings of the study will first be presented to the participants for discussion before the final report is compiled. The identity of the participants will not be revealed when the study is reported or published. The community will be given a copy of the final report. Funding for the study has been granted by DIT in the form of a student bursary. These funds cover the basic minimum costs only. Documentation of this grant can be produced on request.

The study will be conducted over a three-month period during the process of regular fieldwork. The people selected to participate, do so entirely voluntarily. The participants have the right to withdraw at any time if they care to, without any repercussions or penalty, even in the middle of the interview.

The DIT Research Committee has approved of the study and its procedures.

If you have any questions about the study, please feel free to ask me, Mathee Benjamin. You may call me on 204 2944 (work) or 082 481 3580 (home), or my supervisor, Linda Grainger at 204 2036 (work).

Thank you for your participation.

Yours truly

I, the undersigned, have read and understood the nature of the proposed study. I hereby consent to the study being undertaken in Bhambayi.

02/02/03
Date

Appendix: 8 (a)

INFORMATION SHEET

PARTICIPANT: PERSON LIVING WITH AIDS

I, Matheevathinee Benjamin, am a registered student engaged in the Nursing Masters program, Department of Postgraduate Nursing Studies at the Durban Institute of Technology (now DIT), which involves a research project.

The title of my study is:

An assessment of the Bhambayi community with the view to planning an improved home-based care for people living with AIDS.

This subject was chosen as it could assist health care service providers to address urgent needs of people living with AIDS in their own home and community environment.

Consent to conduct the study in Bhambayi has been given by the BRDC.

Although the study may not benefit you directly, the information that you can provide as a patient in need of home-based care could identify your needs and concerns in caring for yourself. It is hoped that with more knowledge and greater care provision, that your quality of life could be improved.

A possible concern for you as a person with AIDS participating in a study of a sensitive subject like HIV, is fully understood. However, I plan to address this by carefully following all the rules set out by the Technikon Research committee.

You will be required to participate in an interview lasting not more than one hour. Should you become tired, the interview will continue at another time when you are able to. I will personally conduct the interview during a routine home visit. No other person will be present during this interview. You may participate in the study by your own free will. You have the right to withdraw at any time you care to without any problem, even in the middle of the interview. An appointment shall be made to suit you and shall be conducted at a venue of your choice.

The record of the interview sheet will be confidential. A coded system that uses alphabets and numbers will be used so that your name cannot be linked to the study in any way. Your name will not appear on the interview response sheet. The list of names will be kept in a safe place in my office at DIT, under lock and key. Apart from myself, no other person shall have access to this list.

The coded interview response sheet will be kept for the legal period of 3 years, and then be destroyed by shredding.

My supervisor may examine the coded interview sheet at any time, as this is a rule.

The findings of the study will first be presented to you as a participant for discussion before the final report is compiled. Your identity will not be revealed when the study is reported or published.

Funding for the study has been granted in the form of a student bursary. These funds cover the basic minimum costs only.

The DIT Research committee has approved of the study and its procedures.

If you have any questions about the study, please feel free to ask me, Mathee Benjamin. You may call me on 202 2944 (work) or 082 481 3580 (home), or contact my supervisor, Professor Linda Grainger at 204 2036 (work).

Thank you for participation.

ISIQEPHU 8 (b)

IPHEPA LOLWAZI

ONGENELAYO: UMUNTU OPHILA NENGCU LAZI

Mina Matheevathinee Benjamin, umfundi obhalisele iNursing Masters Program, kwiDepartment yePost Graduate Studies e DIT embandakanya locwaningo.

Isihloko Socwanango lwami Sithi

Ucwaningo Ngompkakathi waseBhambayi Mayelana Nokunkekelwa kwabesmakhaya abaphila Lengculazi

Lolucwaningo lwakethwa ngoba lungwazi ukusiza abezimphilo ukuze bakwazi ukunikeza laba abaphila emakhaya lengculazi ngokushesha nomphakathi jikele.

Imvume yokuqhuba lolucwaningo eBhambayi siyinikezwe iBRDC.

Noma lolucwaningo lungeke lakusiza wena qobo, usizo ongalunkeza isiguli esidinga usizo lwasekhaya lungavezwa izidingo zakho nezihloso zakho wena. Kunethemba lokuthi ngolwazi lwakho olukhulu nokunakekla kwakho okukhulu kungenza impilo yako ibe ngcono.

Ukuzihlupha kwako njengomuntu onengculazi nokuzimbandakanye kwakho kulofundo lwesifo esizwelayo njenge HIV, kuzwakala ngokucwele kodwa-ke ngihlela ukuqhuba lokhu ngokuqaphela ngilandele yonke imigomo ebekwe ikomoto lokucningo eTechnikon.

Uzodingeka ukuba ungenele ukuhlolwa okungeke kuthathe ihora, uma ukhathala ukuhlolwa kungaqhubeka ngesunye isikhathi uma usungakwazi. Mina mathupa ngizokuqhuba ukuhlolwa ngesikhathi esihlelwe ekhaya. Akekho omunye umuntu ozoba khona ngesikhathi sokuholowa. Ukuhlangana kwethu kuzoba okugculisa wena futhi kuzokwenzeka endawenieqokwe uweni.

Irekodi lokuhlangana kwethu kuzoba ukwazi kwethu. Indlela esizoyisebenzisa yofeleba nezinamba izosetshenziswa ukuze igama lakho lingahlangani nalolucwaningo ngayoyonke indlela. Igama lakho angeke livele ephepeni lempume yokuhlolwa. Uhla lwamagama lozogcinwa endaweni ehovisi lami eDIT kuzoba kuvaliwe ngansosnke isikhathi. Ngapandhle kwami akekho umuntu ozokwazi ukubhona loluhlu.

Imiphumela yokuhlolwa izogcinwa ngokusemthethweni iminiyaka emithathu bese iyashatshaliswa.

Umphathi wami analihlola ipepha lokuhlwa futhi aliqophe noma ingasiphi isikhathi, njengoma lokhu kungumgomo.

Imiphumela lolucwaningo izoqala yethulwe kuwe njengomuntu ombandakayiwe ngaphambi kokuba imiphumela okugcina ngokugcwele. Imininingwane yakho ngeke izezwe uma lolucwaningo lwethuwa noma luqoshwa.

Ukukhishwakwezimali zocwaningo kuzokishwa njengomfundaze wabafundi lezmali ezokwenza izinto ezibiza kacane kuphela.

Ikomoti lezokucubungula eDIT luyavumelana lolucwaningo nendlela oluqhutshwa ngayo.

Uma unembuzo ngofundo, unganabazi unkungithinta, mina Matheevathinee Benjamin. Uganishayela ucingo kulenombolo ethi (031) 2042944 noma 082 481 3580, noma ushayele wami u Professor Linda Grainger kulenombolo (031) 204 2036.

Ngiyabonga ukuzibandakanya kwakho.

Appendix: 9 (a)

INFORMATION SHEET

PARTICIPANT: PRINCIPAL FAMILY CAREGIVER

I, Matheevathinee Benjamin, am a registered student engaged in the Nursing Masters program, Department of Postgraduate Nursing Studies at the Durban Institute of Technology (DIT), which involves a research project.

The title of my study is:

An assessment of the Bhambayi community with the view to providing an improved home-based care for people living with AIDS.

This topic was chosen in response to health concerns expressed by the BRDC in October 2000, at the initial contact between M L Sultan Technikon (now DIT) and the BRDC.

Consent to conduct the study in Bhambayi has been given by the BRDC.

Although the study may not benefit you directly, the information that you can provide as a family caregiver could enable us to identify your needs and problems in caring for your sick family member. We could be able to see more clearly what problems families are faced with and how they might be assisted.

A possible concern for you as a family caregiver about participating in a study of a sensitive subject like HIV is fully understood. However, I plan to address this by following all the rules set out by the Technikon Research committee.

You will be required to participate in an interview lasting not more than one hour, after the consent form is signed. Your participation is entirely voluntary. You have the right to withdraw at any time you care to without any problem, even in the middle of the interview. An appointment shall be made at your convenience and shall be conducted at a venue of your choice.

The record of the interview sheet will be confidential. I will personally conduct the interview and no other person will be present. A coded system will be used so that your name cannot be linked to the investigation in any way. Your name will not appear on the interview response sheet. The list of names will be kept in a safe place in my office at DIT, under lock and key. Apart from me, no other person shall have access to this list.

The coded interview response sheet will be kept for the legal period of 3 years, and then be destroyed by shredding.

My supervisor may examine the coded interview sheet at any time as a rule.

The findings of the study will first be presented to you as a participant for discussion before the final report is compiled. Your identity will not be revealed when the study is reported or published.

Funding for the study has been granted in the form of a student bursary. These funds cover the basic minimum costs only.

The DIT Research committee has approved of the study and its procedures.

If you have any questions about the study, please feel free to ask me, Mathee Benjamin. You may call me on 202 2944 (work) or 082 481 3580 (home), or contact my supervisor, Professor Linda Grainger at 204 2036 (work).

Thank you for participation.

ISIQEPHU 9 (b)

IPHEPA LOLWAZI

ONGENELAYO: ONAKEKLA UNMDENI

Mina Matheevathinee Benjamin, umfundi obhalisele iNursing Masters Program, kwiDepartment yePost Graduate Studies eDIT, ngicelwa ngiqhube izifundo zocwaningo, njengengxenywe yohlelo, lapha ngicela invume yokuthatha izimfundo zami eBhambayi.

Isihloko Sesifundo Sami Sithi:

Ucwaningo Ngompkakathi waseBhambayi Mayelana Nokunkekelwa kwabesmakhaya Abaphila Negciwane Lengculazi

Leisihloko sakethwa ngenxa yokuthinteka kwezmpilo iBRDC ngoOctober 2000, ekuhlenganeni kwayo kokuqala kwe ML Sultan Technikon (esibizwa ngeDIT) kanye ne BRDC.

Invume yokuqhuba lolucwaningo eBhambayi siyinikezewe iBRDC.

Nanoma ungeke wahlomula lutho kulesisifundo ngqo, ulwazi onalo njengomuntu onakekla umdeni lungasiza ukuthi wazi izidingo kanye nezinkinga ukuze ukwazi ukunakekela ilunga lomdeni eligulayo. Sizokwazi ukuthi sibone ngokusobala izinkinga imindeneni ebhekene nazo nokuthi zingasizakala kanjani.

Ukukhathazeka kwako njengomnakekeli womndeneni mayelana nokubamba iqhaza kulolucwaningo esithinta lesisifo esibulungu kangaka isandulela-ngculazi kuyezwakala okungakhokheli. Unalo ilungelo lokuhoxa noma ingasiphi isikhathi, ngaphandle kwengika, noma ngabe sekuphakathi nokuhlolwa. Ukuhlangua kuyoba sesikhathini esikhethwe uwenasendaweni efiswa uwenasendaweni.

Imininingwane yokuhlolwa wako kuyoba imfihlo. Yimona oqobo lwami oyoqhuba ukuhlolwa akekho omunye umuntu oyoba khona, kuyosetshenziswa umshini wokuqopha ukuze igama lakho lingahlanhaniswa nophenyo. Igama lakho angeke livezwe epepheni lokuhlolwa. Uhla lwagama liyogcinwa endaweni ephepile ehovisi lami eDIT futhi lukhiyelwe. Ngaphandle kwami, akekho omunye umuntu oyokwazi ukufinyelela kuloluhla lwamagama.

Amapheha alokuhlolwa okuqoshiwe ayogcinwa ngokusemthethweni iminyaka emithathu, ngemuva kwalokho ashabalaliswe.

Umphathi wami angalihlola ipepha lokuhlolwa futhi aliqophe noma ingasiphi isikhathi, njengoma lokhu kungumgomo.

Imiphumela lolucwaningo izoqala yethulwe kuwe nengomuntu ombandakanyiwe ngaphambi kokuba imiphumela okugcina igcniwe ngokucwele. Imininingwane yakho ngeke ivezwe uma lolucwaningo lwethulwa noma luqoshwa.

Ukukishwa kwezimali lolucwaningo kuzokishwa njengomfundaze wabafundi lezimali ezokwenza izinto ezibiza kancane kuphela.

Ikomiti lezokucubungula eDIT luyavumelana nocwaningo nendlela oluqhutshwa ngayo.

Uma unemibuzo ngalolucwaningo, ungangabazi ukungithinta, mina Matheevathinee Benjamin. Ungangishayela ucingo kulenombolo (031) 204 2944 noma 282 481 3580, noma ushayela umphathi wami uProfessor Linda Grainger kulenombolo ethi (031) 204 2036.

Ngiyabonga ukuzibandakanye kwako.

Appendix 10 (a)

INFORMATION SHEET

PARTICIPANT: COMMUNITY HEALTH VOLUNTEERS

(Focus group)

I, Matheevathinee Benjamin, am a registered student engaged in the Nursing Masters program, Department of Postgraduate Nursing Studies at the Durban Institute of Technology (now DIT), which involves a research project.

The title of my study is:

An assessment of the Bhambayi community with the view to planning an improved home-based care for people living with AIDS

This topic was chosen to gain a greater understanding of how persons with AIDS were being cared for in the community, who cares for them and what are the main concerns of the caregivers when caring for their ill family members.

Consent to conduct the study in Bhambayi has been given by the BRDC.

Although the study may not benefit you directly, the information that you can provide as community health volunteers could assist in identifying the your concerns and needs in the caring process. The findings of this study could help you to care for people living with AIDS in the home with a better understanding.

A possible concern for you as volunteers about participating in a study of a sensitive subject like HIV is fully understood. However, I plan to address this by carefully following all the rules set out by the Technikon Research Committee.

You will be required to participate in a tape recorded and written interview lasting not more than one hour, after the consent form is explained and signed. A taped interview is necessary so that you may respond with greater freedom and enable the researcher to listen more carefully. You may refuse to be taped. You may participate in the study at your own free will. You have the right to withdraw at any time without any problem, even in the middle of the interview. An appointment shall be made at your convenience and shall be conducted at a venue of your choice.

The record of the interview sheet and tape will be confidential. A coded system using numbers and alphabets will be used so that your name cannot be linked to the investigation in any way. Your name will not appear on the tape or interview response sheet. The list of names will be kept in a safe place in my office at DIT, under lock and key. Apart from myself, no other person shall have access to this list.

The coded interview response sheet and tape will be kept for the legal period of 3 years, and then be destroyed by shredding.

My supervisor may examine the coded interview sheet and tape at any time, as this is a rule.

The findings of the study will first be presented to you as a participant for discussion before the final report is compiled. Your identity will not be revealed when the study is reported or published.

Funding for the study has been granted in the form of a student bursary. These funds cover the basic minimum costs only.

The DIT Research committee has approved of the study and its procedures.

If you have any questions about the study, please feel free to ask me, Mathee Benjamin. You may call me on 202 2944 (work) or 082 481 3580 (home), or contact my supervisor, Professor Linda Grainger at 204 2036 (work).

Thank you for interest and participation.

ISIQEPHU 10 (b)

IPHEPA LOLWAZI

Mina Matheevathinee Benjamin, umfundi obhalisele iNursing Masters Program, kwiDepartment yePost Graduate Studies eDIT, ngicelwa ngiqhube izifundo zocwaningo, njengengxenye yohlelo, lapha ngicela imvume yokuthatha izimfundo zami eBhambayi.

Isihloko Sesifundo Sami Sithi:

Ucwaningo Ngompkakathi waseBhambayi Mayelana Nokunkekelwa kwabesmakhaya Abaphila Negciwane Lengculazi

Lesisihloko sakhetwa ukuze zithole ulwazi mayelana nabantu negciwane le AIDS ngokuthi inulazi. Kudinga sazi ukuthi bapathwe kanjani ngumphakathi abaphila kuwo nobakhathelele. Okubalekile kakulu ukuthola ukuthi abagadi balaba abagula ngalesisifo babanakekela kanjani. Kane namalunga emindeni yabo.

Imvume yokuqhuba lolucwaningo eBhambayi siyinikezewe iBRDC.

Nanoma ungeke wahlomula lutho kulesisifundo nhqo, ulwazi onalo njengemuntu onakekela umndeni lungasiza ukhuthi wazi izidingo kanye nezinkinga ukuze ukwazi ukunakekela ilunga lomndeni eligulayo. Sizokwazi ukutui sibone ngokusobala izinkinga imindeni ebhekene nazo nokuthi zingasizakala kanjani.

Ukukhathazeka kwako njengomnkekli womndeni mayelana nokubamba iqhaza kulolocwaningo esithinta lesisifo esibuhlungu kangaka isanulela ngculazi kuyezwakala. Kowa-ke, ngihlela ukubhekana nolufundo imithetho ebekiwe iKomiti Lokucwaningo e Technikon.

Uzocelwa ukuba ungenele ukuhlolwa okuzothatha isikhathi esigaphansi kwehora elilodwa, emva kukoba incwadi yemvume isisayiniwe ukubamba kwakho iqaza kuzobe kukuzinikela okungakhokeli. Unalo ilungelo lokuhoxa noma ingasiphi isikhathi, sesikhathini esikhthwe uwenasendaweni esifwa uwenasendaweni.

Imininingwane yokuhlolwa wako kuyoba imfiklo. Yimina oqobo lwami oyoqhuba ukuhlolwa akekho umunye umuntu oyoba khona, kuyosetshenziswa umshini wokuqopha ukuze igama lakho lingahlanhaniswa nophenyo. Igama lakho angeke livezwe ephepheni lokuhlolwa. Uhla lwamagama luyogcinwa endaweni ephepile ehovisi lami eDIT futhi lukhiyelwe. Ngaphandle kwami, akekho omunye umuntu oyokwazi ukufinyelela kuloluhla lwamagama.

Amapheha alokuhlolwa okuqoshiwe ayogcinwa ngokusemthethweni iminyaka emithathu, ngemuva kwalokho ashabalaliswe.

Umphathi wami angalihlola ipepha lokuhlolwa futhi aliqophe noma ingasiphi isikhathi, njengoma lokhu kungumgomo.

Imiphumela ya lolucwaningo izoqala yethulwe kuwe nengomuntu ombandakanyiwe ngaphambi kokuba imiphumela okugcina igcniwe ngokucwele. Imininingwane yakho ngeke ivezwe uma lolucwaningo lwethulwa noma liqshwa.

Ukukishwa kwezimali zocwaningo kuzokishwa njengomfundaze wabafundi lezimali ezokwenza izinto ezibiza kancane kuphela.

Ikomiti lezokucubungula eDIT luyavumelana nocwaningo nendlela oluqhutshwa ngayo.

Uma unemibuzo ngalolucwaningo, ungangabazi ukungithinta, mina Matheevathinee Benjamin. Ungangishayela ucingo kulenombolo (031) 204 2944 noma 282 481 3580, noma ushayela umphathi wami uProfessor Linda Grainger kulenombolo ethi (031) 204 2036.

Ngiyabonga ukuzibandakanye kwako.

Appendix 11(a)

INFORMATION SHEET

PARTICIPANT: COMMUNITY LEADERS

I, Matheevathinee Benjamin, am a registered student engaged in the Nursing Masters program, Department of Postgraduate Nursing Studies at the Durban Institute of Technology (DIT), which involves a research project.

The title of my study is:

An assessment of the Bhambayi community with the view to planning an improved home-based care for people living with AIDS.

This topic was chosen in response to health concerns expressed by the BRDC in October 2000, at the initial contact between M L Sultan Technikon (now DIT) and the BRDC.

Consent to conduct the study in Bhambayi has been given by the BRDC.

Although the study may not benefit you directly, the information that you could provide as a community leader could assist in identifying the community resources that could help develop and sustain home-based care for people living with and affected by HIV/AIDS in Bhambayi.

A possible concern for you as a leader about participating in a study of a sensitive subject like HIV is fully appreciated. However, I plan to address this by following all the rules set out and recommended by the Technikon Research Committee.

You will be required to participate in an interview lasting not more than one hour, after the consent form is signed. Your participation is entirely voluntary. You have the right to withdraw at any time you care to without any problems, even in the middle of the interview. An appointment shall be made at your convenience and shall be conducted at a venue of your choice.

The record of the interview response sheet will be confidential. A coded system using numbers and alphabets will be used so that your name cannot be linked to the investigation in any way. Your name will not appear on the interview response sheet. The list of names will be kept in a safe place in my office at DIT, under lock and key. Apart from myself, no other person shall have access to this list.

The coded interview response sheet will be kept for the legal period of 3 years, and then be destroyed by shredding.

My supervisor may examine the coded interview sheet at any time as a requirement.

The findings of the study will first be presented to you as a participant for discussion before the final report is compiled. Your identity will not be revealed when the study is reported or published.

Funding for the study has been granted in the form of a student bursary. These funds cover the basic minimum costs only.

The DIT Research committee has approved of the study and its procedures.

If you have any questions about the study, please feel free to ask me, Mathee Benjamin. You may call me on 202 2944 (work) or 082 481 3580 (home), or contact my supervisor, Professor Linda Grainger at 204 2036 (work).

Thank you for participation.

ISIQEPHU 11 (b)

IPHEPA LOLWAZI

Mina Matheevathinee Benjamin, umfundi obhalisele iNursing Masters Program, kwiDepartment yePost Graduate Studies eDIT, embandakanya nohlelo locwaningo.

Isihloko Sesifundo Sami Sithi:

Ucwaningo Ngompkakathi waseBhambayi Mayelana Nokunkekelwa kwabesmakhaya Abaphila Negciwane Lengculazi.

Lolucwaningo lwakethwa ngoba lungwazi ukusiza abezimphilo ukuze bakwazi ukunikeza laba abaphila emakhaya lengculazi ngokushesha nomphakathi jikele.

Invume yokuqhuba lolucwaningo eBhambayi siyinikezwe iBRDC.

Noma lolucwaningo lungeke lakusiza wena qobo, usizo ongalunkeza isiguli esidinga usizo lwasekhaya lungavezwaa izidingo ezingasiza labo abadinga usizobaphila negciwane kanye nesandulela-ngculazi eBhambayi.

Ukuzinikela nokuzimbanakanya kwako kulolofunda lwesifo esibuhlungu esinjennegeHIV kuyancomeka. Yize noma ukulethula lolufundo kuzofanele ngilandele imithetho kanye nenqubo engibekelwe i Technikon Research Committee.

Kuzofanele kuba ungenele ukohlolwa okungeke kudlule ehoreni elildwa, ngevuma kwemvume isisayiniwe. Ukuzinikela ukuthanda kwakho. Unalo ilungelo lokhoxa noma ingasiphi isikhathi ngaphandle kwemibandela, ngisho phakathi nokuhlolwa. Isikhathi sojulangana kanye nendawo kuyohambisana nesikhathi otholakala ngaso.

Izimpendulo zakho zokuhlolwa ziyoba imfihlo. Uzuke kuqiniseke ukuthi izimpendulo zokho ziyimfihlo kuyosentshenziswa uhlolbo oluphambili lomshini lapho igama lakho ligeke livile uma sekwenziwa uphenyo. Igama lakho ngeke lidalulwe ephepheni oyobe ubahlela kulo izimpendulo zakho. Uhla lwamagama liyogcinwa endaweni ephephile ehovisi lami eDIT. Ngaphandle kwami akekho oyobo nemvume ohleni lwamagama.

Izimpendulo zakho zokuhlolwa ziyocina isikhathi esiingangeminyaka emithathu, zize zidatshulwe ngomshini evuma kwaleminyaka.

Umphathi wami uyhlolla izimpendulo zakho noma ingasiphi isikhathi.

Imiphumela ya lolucwaningo izoqala yethulwe kuwe nengomuntu ombandakanyiwe ngaphambi kokuba imiphumela okugcina igcniwe ngokucwele. Imininingwane yakho ngeke ivezwe uma lolucwaningo lwethulwa noma liqshwa.

Ukukishwa kwezimali zocwaningo kuzokishwa njengomfundaze wabafundi lezimali ezokwenza izinto ezibiza kancane kuphela.

Ikomiti lezokucubungula eDIT luyavumelana nocwaningo nendlela oluqhutshwa ngayo.

Uma unemibuzo ngalolucwaningo, ungangabazi ukungithinta, mina Matheevathinee Benjamin. Ungangishayela ucingo kulenombolo (031) 204 2944 noma 282 481 3580, noma ushayela umphathi wami uProfessor Linda Grainger kulenombolo ethi (031) 204 2036.

Ngiyabonga ukuzibandakanye kwako

Appendix: 12(a)

INFORMED CONSENT FORM

Date: _____

Title of research project:

An assessment of the Bhambayi community with the view to planning an improved home-based care program for people living with AIDS.

Name of supervisor:	Professor Linda Grainger	(031) 204 2036
Name of research student:	Mathee Benjamin	082 481 3580

Please circle the appropriate answer

1. Have you read the information sheet? Yes No
2. Have you had the opportunity to ask questions regarding this study? Yes No
3. Have you received satisfactory answers to your questions? Yes No
4. Have you had an opportunity to discuss this study? Yes No
5. Have you received enough information about this study? Yes No
6. Do you understand the implications of your involvement in this study? Yes No
7. Do you understand that you are free to withdraw from this study? Yes No
At any time;
Without having to give a reason for withdrawing; and
Without affecting your future health care.
8. Do you agree to voluntarily participate in this study? Yes No
9. Who have you spoken to? _____

Please ensure that the researcher completes each section with you.
If you have answered NO to any of the above, please obtain the necessary information before signing.

Please print in block letters:

Participant's Name: _____	Signature _____
Witness Name: _____	Signature _____
Research Student Name: _____	Signature _____

Appendix 13

INFORMED CONSENT FORM
(Focus group)

Date: _____

Title of research project:

An assessment of the Bhambayi community with the view to planning an improved home-based care program for people living with AIDS.

Name of supervisor: _____ Professor Linda Grainger (031) 204 2036

Name of research student: _____ Mathee Benjamin 082 481 3580

Please circle the appropriate answer

- | | | |
|---|-----|----|
| 8. Have you read the information sheet? | Yes | No |
| 9. Have you had the opportunity to ask questions regarding this study? | Yes | No |
| 10. Have you received satisfactory answers to your questions? | Yes | No |
| 11. Have you had an opportunity to discuss this study? | Yes | No |
| 12. Have you received enough information about this study? | Yes | No |
| 13. Do you understand the implications of your involvement in this study? | Yes | No |
| 14. Do you understand that you are free to withdraw from this study? | Yes | No |

At any time;

Without having to give a reason for withdrawing; and

Without affecting your future health care.

- | | | |
|---|-----|----|
| 8. Do you agree to voluntarily participate in this study? | Yes | No |
|---|-----|----|

10. Who have you spoken to? _____

Please ensure that the researcher completes each section with you.
If you have answered NO to any of the above, please obtain the necessary information before signing.

Please print in block letters:

Participant's Name: _____ Signature _____

Witness Name: _____ Signature _____

Research Student Name: _____ Signature _____

Appendix 14 (a)

FOCUS GROUP DISCUSSION WITH COMMUNITY VOLUNTEERS

ENGLISH TRANSLATION

The problem is that a person is sick, maybe he does not have food, and maybe he is an alcoholic such that he cannot continue with his treatment. Some children are up and down in the streets. Maybe they are prostitutes because they don't know what to eat and how they are going to care for their little brothers and sisters as they don't have someone to get them to school and the children don't have something to eat.

The other problem here at Bhambayi, maybe a person is sick; at the same time he does not have an ID (document) or anything. She has children and has no food. These children do not even have birth certificates. Maybe even the husband passed away, she does not have a death certificate, she's got nothing, maybe we try to get her help, (and) maybe she will not even get that help, because she does not have anything.

Yes, volunteers do take a role, but the government must also have a role by sending welfare workers or health workers to teach the community. I can say what makes our community to get this disease so much is that mostly (it is due to) unemployment. The person ends up having 5 partners trying to get money to live with the family such that she can get the HIV disease because of many partners trying to live and there are no jobs

- 2.1. My opinion is that what makes people get this disease here is that people are living together from different places and that these people are from different homes, looking for jobs, and there are no jobs, so they think it is better to fall in love with a man. When they broke up she falls in love with another man that makes this disease to travel faster, and the way people live. People are from different cultures. Having different cultures within the community leads to lots of different things. That is why this disease is so high.
- 2.2. Yes, here within the community, if there is someone with AIDS they just give their hope to me as a volunteer such that I've got some knowledge on like if bath the patient, I need to put gloves on. If a patient has diarrhoea, I just make glucose for him those who are looking after him at home must love him, because others even say take to the village of his birth. Whereas he has to stay here and they (the family) need to love him and take care of him.
- 2.3. Sometimes the main problem is that as the people are sick in the community, they've got TB or HIV, the family members do not love that person any longer. So, we, as volunteers have to take care of that patient, bath her, because you find that the patient is on his own in the house. There is no one who can comfort her or do anything for her. Maybe this person has passed urine the night before, so we, the volunteers have to help change her and clean everything. Sometimes you find that the food served was not eaten maybe the family have not seen whether she has eaten or not and the food now has houseflies and cockroaches. All those things need the volunteers help.

- 3.1 Mostly the people living with the patient usually run away from him, leaving him all alone in the house.
- 3.2 You see these people who are very sick, are just here in the community. Maybe the person stays with a partner. The partner just leaves her like that very sick in bed. OK you arrive as a volunteer and help. You would take your team to assist you bathing this person and feeding her with food, if you have soup, you cook it for her. If she does not have paraffin, we have to buy her paraffin, another thing that hurts is that other people here in the community, came here (Bhambayi) when they were young and they do not know where their homes (place of birth), and she is sick, ad does not where her parents are. As a volunteer you know that this person needs to be taken home, because when this person dies, the police will ask the volunteer who had taken care of the patient the whereabouts of the family. She may have arrived here (Bhambayi) at the age of 13 and now she is 34 years old, that's our main problem.
- 3.3 The big problem is that the patient does not have food but needs to take treatment after meals. Others do not continue with the treatment because they cannot take their treatment without food. That's the main problem and not having the facilities to help her. Others do not have a place to stay as they may have been chased away.
- 4.1. The main problem person with AIDS is that they do not have food. Some of them are staying on the streets as they do not have a place to live, because where they used to live, the owner has chased her away when she became sick and now she does not have money to pay the rent and there she now sleeps anywhere. We sometimes do not have the facilities to work or to take good care of them. Sometimes you find that she does not have clothes, not to mention something to eat. You find that she has not eaten in 3-4 days, not until we soup from Sister Benjamin. They don't even have paraffin and it is so difficult, we end up bringing (stuff) from home that was for our families. Because it is not nice to eat whereas you know that there is someone who is sick and does not have food. We take from our families and try to cook for them and that makes it better.
- 4.2. I can say something that hurts about AIDS patients is that, as we are divided into sections you find that there are few volunteers to care for many AIDS patients. When I get to a home and find a patient who needs care all on her own, she may not want me to help her, but may want some other volunteer. And that is so painful because we work as a team, we have to help each other but the patient can chase you away from her house. It becomes difficult to help such patients. This illness comes up with different illnesses, sometimes a person is mentally disturbed and they are so traumatised including the community members around them. The patient will run away from you and you will have to run after her. If the sick person cannot wake up, as a volunteer you do not always have money o hire a car to take her to the clinic if the need be. She may not be able to walk. You end up asking some people to help you take her. Even if they agree, you do not have a stretcher, you cannot manage to carry her you at least think of a wheelbarrow, and it will hurt her also. You know we cannot work like this and we have lots of problems.
- 4.3. Firstly, I know the night before if I have to take a patient to the hospital and check when is her appointment and if she has taken a bath, if not I have to bath her quickly and then take her to the doctor. And I make sure she's got her treatment in

the right way and she takes it and I take her back home. Sometimes a patient may ask you to stay wither, but you cannot stay long and chat, because you have to check other patients. Sometimes her child may also be sick and the mother needs your help to get the child to hospital. By the time you come back, you are in a hurry to go home and do your own things. Then the patient may ask you to stay awhile and now she wants to tell you everything because she needs to talk and cannot trust anyone else. She feels that the family talks about her illness. She feels that you are the only one who understands her.

- 5.1 As we all know our job is home visits and this is how we find people who have AIDS. I am so lucky that other people just come out telling me that they have AIDS, and how long they have been living with the disease. I simply sit down and talk and sympathise, giving the person hope that she can still live. But to those who are very sick, who cannot even swallow tablets; we try to get them to the clinic. The clinic may only give a drip, and then the patient is discharged. It is so difficult. We have to use a wheelbarrow to get the patient home. Sometimes the clinic refers the patient to the hospital (Mahatma Ghandi) and you have to go with her. The hospital may not admit the patient and you have to take the patient back home. You are using your money for both of you. It is so difficult; it's not easy, very difficult.
- 5.2 When I visit a certain home as a volunteer I go door to door. When I find a sick person I try to find out what sickness she has. I have to sit if I am welcome because usually they do welcome us and give us permission to sit and chat. The patient may tell you that they do not know what sickness they have and that they have been sick for a long time. Then I would ask if they have been to the clinic. Some say yes, while others say, no. Some do not go to the clinic at all. I would beg her to go to the clinic, even if she were visiting and trust in other places (traditional healer), because sometimes she cannot get much help at the traditional healer. I advise that the clinic can help and can find out exactly what illness she may have. Sometimes the patient understands, because the next time she will tell you she has visited the clinic and that she has TB. We follow-up all patients with TB and teach them about how to take care of themselves. If the patient does not get any better on treatment and is still losing more weight and power, I would encourage her to have her blood tested for the virus. Some people are so scared to go to the local clinic because the nurses know them. Then we suggest that they can go to any other clinic. They like going to other clinics and tell their families and you that they have tested positive. OK the way you have counselled the patient may have assisted her in getting help. Others do not tell you the truth, and we do not just leave her alone, but have to think of her life and can we help her. We look at her treatment from the clinic and then tell our sister in charge that there is a sick person in a certain house and give sister the report. The sister makes a home visit and the patient may tell the sister her problem. Others trust us and tell us, others are scared thinking whom are they going to leave their children with. They are also afraid of what their families would say if they found out. If someone in the community knows about the illness, nobody would visit that person anymore. But we are so happy that most of them just come out saying that they are HIV positive.
- 5.3 The first thing we have to know as volunteers is that when we get this training we need to have knowledge, so that we know what we are going to say to that sick person. If she is telling me about her problem, how am I going to handle it? In fact we need to be taught how to nurse a person. They need to get us food and a working

set like gloves and aprons, the whole set (of equipment) to help that person at the particular time we are with her.

- 6.1. Ok what hurts me most is that we do not have a working set (of equipment) for the community. I can be happy if someone can think about it that it is too far for us to get to the community and take the patient to the clinic. If they can maybe provide us with wheelchairs, because it is difficult to take a very sick person and put her in the wheelbarrow. There is no money to hire a car. It costs R100 to hire a car to the clinic. That's not good for us, (the wheelbarrow), but we end up doing it. Its like you are killing that person if you put her in the wheelbarrow, but we do it because we have no choice.
- 6.2. What worries the AIDS is that they do not like you to talk about this disease, because some people just take it as a joke. When partners have a fight, he will shout at her about the AIDS problem. If a patient has not been well counselled or did not get the right counsellor, when people chat the patient may think that they are talking about her, even if they laugh, she may feel that they are laughing at her.
- 6.3. OK. Some of them have the problem of whom to leave their children with when they die. Others just think that as they are already infected with HIV, that it is easier to drink (excessively) and sleep, to forget about the illness. They feel that death is near and worry about who will bury them and how they will be buried because the ill patient does not have money to care for themselves nor their families. OK. Most people with AIDS usually mention what my colleagues have mentioned, the concern for the children, and that they are not yet ready to die. They did not know that they would find themselves in his position, they have not been working, do not have nay money, and in their entire lives, were unable to maintain their children, so when they die, they worry about who would look after these children, how would the children live, will the children also die and the fear of the children being abused by anyone.
- 7.1 I became a volunteer because I thought to myself that I will be a nurse, but I was unsuccessful to pass my Matric because of the death of my parents. But here in the community I have availed myself because I want to help our community by helping those patients in their homes in every way.
- 7.2 I became a volunteer to help the very sick people in my community. Many sick people do not have anyone to help them. It has become a good way to go out and see how the community is doing, what do they need. I like helping people. If I do not go to the field, I feel sick, because I am used to this now.
- 7.3 What made me to be a volunteer is that one day I was doing my washing in my yard. My house is nearby the road and that is where people are going up and down. I saw a very sick person walking on her own, sometimes sitting down to rest and then moving slowly again. That hurt me a lot such that I found myself asking her where she was going. She was on her way to the clinic. I just thought when I took my washing out; God wanted me to see that life to other people was not the some. Someone needed my hand. From that day I had that feeling to ask my family that I need to volunteer. You sometimes hear from the neighbours that there may be a dead person in a certain cottage. The person could be dead for as long as a week

before being found. I thought that this is a challenge that I have to be a volunteer and help those people dying all-alone.

- 8.1. People have different ways; some people do love us such that they wish we could get something (incentive) others even think of buying you a present when they get paid. Those whom we have helped speak well of us, appreciating our work. And there are those who have not needed our help as they do have sick people needing care, say that they do not know the use of volunteers. But the majority of people like the work being done by the volunteers, as they are hard-working.
- 8.2. Some people are very happy to have volunteers assisting in the community, as it is so nice and it was not there before. The volunteers going house to house has helped a lot, and the committees in other places (townships and informal settlements) are calling us nurses, because previously people used to go to the clinic not having bathed, and now the patient is bathed and cleaned with the volunteers' help before going to the clinic. Most people are very happy with our work, and if they do not see us they become very sad even if it is for a few days. The community is very happy, they appreciate everything and also that we do it out of love for our people.
- 8.3. Here in the community, people appreciate a lot the way we treat them, such that they even ask if we do get something (incentive) for our work. We have told them that we do not get paid for our work. The community has said that God must help us to get something because what used to happen previously does not happen anymore. Sick people had no one assisting them. The volunteers have made a difference in the Bhambayi area because the community believes that as people living in Bhambayi, their lives are in the hands of the volunteers, as the volunteers first see them when they get sick. They are visited by the volunteers in their homes and are taught to clean their homes, open their windows in the morning, what foods to prepare (for good health), and the importance of clinic visits.
- 9.1 I have learnt a lot. Especially that I have to be kind to every person, whether sick or not. Sometimes if a person is sick, people do not love them. As a volunteer I need to have love, I've also learnt that other people can disclose their sickness (AIDS), while some people hide it until death.
- 9.2 I have learnt a lot, especially which I have to love a person and accept her the way she is, even with AIDS. I have learnt that you do not take decisions for the patient. Now I know that I have to ask her what she needs and then do as she wishes. I do not have to force the patient to go to the clinic, whereas she does not want to do that. I do have to force the patient to visit the traditional healer, whereas she does not like that. I have learnt that I have to hear from her, and ask her what she thinks, get her view and assist from there.
- 9.3 I have learnt a lot by being a volunteer, because even in my own house I used to cook anyhow, saying as long as I have something. Now I know how to cook nutritious food and that is what I tell people out there, what they should eat. I used to be scared of a very sick person but now I can go to any sick person in the community who may have died. I could not even close her eyes. I was a coward, but now I know that when a person dies, that is nothing, it's just like a chicken. That is also learning. I have learnt a lot.

Appendix 14 (b)

FOCUS GROUP DISCUSSION WITH HOME CARE COMMUNITY VOLUNTEERS

ZULU TRANSCRIPTION

1.1. Into eyinkinga kuyaye kube umuntu uyagula, mhlaumbe akahakho ukudla futhi uyaphuza utshwala, ahluleke ukuqhubeka netreatment yakhe. Ezinye izingane zihamba ziwuvanzi la emgwageni mhlaumbe zidayise nangomzimba ngoba zisuke zingazi ukuthi zizodlani futhi zizozinikani nezingane zakwabo, zigcine zingasafundi. Njenboba zikhona la ziyehla ziyenyuka akekho nomuntu ozozifundisa , nentoyokudla azinayo.

1.2. Enye into eyaye ibe yinkinga la e Bhamabyi ukuthi umuntu ethi egula enjalo uthole ukuthi akanyo i I D akana itho, unezingane, zingi, akanakho ukudla. Lezingane azinazo izitifiketi nayeakonayo i I D, mhlawumbe nomkhwenyana wakhe seweshona, akanyo nedeath certificate yokuthi sewashona, akanalutho nje. Nhlawumbe singa mxhumanisa nosizo ukuthi athole, nosizo agcine engalutholanga ngoba akonalutho. Ukuthi abanye abasebenzi futhi abafundisekile ngalesisfo ukuthikufanele bazivikile kanjani, abazi ukuthikufanele basivikele kanjani lesesifo.

1.3. Ya amavolontiya nawo ayalibamba iqhaza, kodwa naye uhulumeni kufanele alibambe iqhaza ukuthi athvumele abezenhlalakahle abakwahealth ukuthi bazofundisa umphakathi ukuthi ma ngbheka mina okwenza ukuthi abantu bakithi bathole lesisifo kangaka. Okukhulu kakhulu kuyikhona lokungasebenzi umuntu ogcina esnophathini abangu-5 , ngoba cza ma ukuthi athole imali aphile ne family yakhe. Okunga lulake laapho ukuthiasithole isifo sengculazi mangabe esenophathiniabaningi kangaka ngoa naye usuke szizamela ukuthi akwazi ukuziphilisa nomsebenzi awukho-ke.

2.1. ngokubuka kwami ukuthi kube lula ukuthi abanengi bathole lesisifo la ukuthi abantu abahleli ndawwonye abaqamuka ezindaweni ezahlukahlukene nanokuthi labantu baphuma emakhaya bethi bazofuna umsebenzi imisebenzi abayitholi bayabona ukuthi kungcono ukuthi muntu athande lona. Uma kungukuthi sebahlukene aphinde athande omunye. Khkho kuyasenza ukuthi isifo siqubeleke kakhulu nangendlela-ke okuhleliwe ngayo abantu abayizinhlobo zezinhlangana eziningi ukubakhona kwezinhlange eziningi endaweni kuyye kube khona izinto ezinigi ezohlukahlukene. Yingakho-ke lesisifo sidlangile.

2.2. ya khona la emphakathini mangabe benayamuntu one AIDS bayaye bathembeke kimina njengevolontiya ngokuthi mina nginolwazi lokuthi mangabe egeza fakani amagloves. Bona benza noma kanjani mangabe mina ngingabanikanga lololwazi. Mhlawumbe ukhishwa isisu baze batshelwe yimina ukuthi menzeleni i glucose. Bona yabe abamgadayo ekhaya abamthande lowomuntu ngoba abnye baze bathi akayohlala emfamu. Kanti umuntu kufanele abe khona la bamuphe uthando bamnakekele.

2.3. Kusho ukuthi okuje kube inkiga kakhulu ukuthi njengoba abantu begula le emphakathini bephethwe yiTB yiyona i HIV lena. Umndeni kakhulu awube usa mthanda lowomuntu. Kuyaphogeka-ke ukuthi amavolontiya okuyiwonw okufanele okuhi onu ekelele kwesinye isikhathi omgeze ngoba siye sithi ma sihambele khonza la emphakathini uthole ukuthi uvallelwe endlini uhleli yedwa. Akanamuntu omduduzayonomenza lutho nje. Nhlawumbe uthole ukuthi lomuntu selokhu ekake ngayozolo kudinga ukuthi manje siqwazi thina njengamavolontiya ukuthi silekelelane siqwazi ukuthi simshintshe sense yonke into kwesinye isikhathi uthole ukuthi uyafika nokudla akade ephakelwe khona ngayozolo akakudlanga, mhlawumbe -ke abazange bambheke noma udlile sekunezimpukane na makokoroshe. Yonke leyonto sekudinga ukuthi amavolontiya alekelele. Imvamisa nje abalekeleli lababantu abahlala nomuntu ogulayo bayambalekele, okungale kwalokho bamshiya yedwa endlini.

3.1 Khona uyabo lababantu abagula kakhulu kushuthi bakhona la emphakathini. Uye uthole ukuthi umuntu mhlape uhleli nophathini wakhe, uphathini wakhe usemshiye kanjalo elele yedwa embhedeni. OK ufuke-ke wena njengevolontiya ozomuza umsize ma umsize uthathe iteam ozakweni ekutheni bahambe bakulekelele ukuthi lomuntu nikwazi ukuthi nimhlanze nimenze yonke into, nimfide nangokudla mhlawumbe nisizwe yitho ukuthi kukhona nalelosobho elikhona nithole ukuthi nimphekele lona. Ma enganwo uparaffin yithi mhlawumbe seihlanganisayo ukuthi athenge uparaffin. Okuye kube buhlungu kakhulu ukuthi abantu abakhona la emphakathini baye bafike lapha bezingane bengasakwazi emakhaya uthole ukuthi uyagula manje akabazi ukuthi abazali bakhe bakuphi. Wena njengevolontiya kufanele ukuthi lomuntu azothathwa eseshonile, uweni athwala inkinga emaphoyiseni ebuza ukuthi njengoba lomuntu ubukodwa umbhekile akaziasho ukuhi nhlawumbe wafika eno-13 years manje useno 34 years; yi yona nkinga futhi kakhulu leyo.

3.2 Inkinga enkulu ukudla usulele engenakho ukudla ngoba kufanele ephuze letreatment ekade edlile manje omunye uye aze oyiyeke itreatment ngoba ethi mina ngeke ngikwazi ukudla amaphilisi ngingadlile inkinga enkulu-ke leyo. Noku ngabi bikho-ke kwezinto zokumsiza, mhlambe omunye angabi nalo ikhaya, uthole ukuthi nala zkade ehlala khona sebeyemkhi pha-ke.

3.3. Inkinga kakhulu kubantu be-AIDS yikhona ukudla, abanatho ngempela ukudla abanye babo bahlala ezigangeni kumanje abanazoizindawo zokuhlala ngoba nala umuntu asuke bedede egashe khona, uma esegula engasenmali, yoku renta bamkhiphela emnyango ahlale nje esingangeni. Mina-ke izito zokusebenza zibuye zingabi khona kahle kahle zokubanakekela ukuthi mhlampeukuthi uzomshintsha ngani ngoba futhi siye sifike nasezindlini la ehlela khona umuntu akasenayo ngosho into yokugqokoke manje eyokudlake angisayi phathi ngaba ufika umuntu ena 3-4 days engenayo into azoyidla. Kuze kufike lona isobho leli esilunikwa uSister Benjamin nalo futhi likhona kutho akunalutho kuye kubenzima size sigcins sesi caphu na Kokwekamly yethu senzela ukuthi akumnandi ukuthi ngithi ngidla mina mgiba ngazi ukuthi omunye umntwana wabantu uyagula futhi akanakho ukudla. Sicaphuna khona ukudla komndeni sizome ukuba phekelake-ke bese beyadla mhlampe kube ngcono-ke.

4.1. Mina intoeye ingiphathe kabuhlungu kakhulu kubantu abasuke begula ngale sisifo ukuthinjengoba sihlukaniswe ngama section uye uthole ukuthi thina abesivolontiyile sibancane kwenye unkathi kunalabantu. Kuthole ukuthi bafanele ngchanibe ngiye

kukoyamuzingiyosiza lomuntu olele phansi, engizomfica ehleli yedwa umfice esekulesismo sokhuthi???? Akasatuni lutho lapaha endlini. Umuntu ozongena mhlampe onjani njani mhlampe uzokhetha lolumuntu amdinga ngalesoskhathi athi mhlampe ngidinga usbanibani lapho kusuke sekubuhlungu kimina kuye kungiphathe kabuhlungu ngoba njegoba sisebenza siyiteamyikufanele silekelelane ngalesiskhathi uthole ukuthi yena usedumbe umuntu oyedwa amdingayo kuleyondlu yakhe. Manje bese kuba nzima-ke ukuthi usezosizwa ndlelnai ngoba manje useyakhetha usekulesesimo esinjengaliso nanaklo-ke ukuthi nalesisifo ngendlela esighamuka ngayo siqomika ngezinto eziningi kumuntu uthole ukuthi umuntu usesangane kulokho kusangana kwekhe senihlukumezekile ngisho nani enihleli naye nomphakathi usuhlukumezekile ngoba uzoke aphume endlini abaleke kufanele ajahdwe. Uma kungukuthi umuntu ogulayo uselele phansi inkinga esiye sibhekani nayo ebuhlungu kakhulu ukuthi awukwazi wena njengomuntu oyivolontiya ukuthi uhlale unemali yokuthi mhlampe unga gasha imoto umyise eclinic makuwukhuthi uyambona ukuthi isimo sake kufanele aye eclinic manje amandla okuthi azihambele awekho. Uze uncenge abantu bokuthi bamyise eclinic ngokuthi bakulekelele kwakhona lokho ukuthi bakulekelele akukho stretcher akukho lutho angeke ukwazi ukumbeletha ngoba uzokuphula umhlane uyoze ucabanga ibhala, nalo lizombulala futhi. Manje uyabona nje akusebenzeki ngendlela okufanele kusebenzeka ngayongoba manje sinezinkinga ziningi kakhulu.

4.2. Okokuqala nje ngiye ngilele ngazi ukuthi ngizomyisa esibhedlela mangabe kuyidate ugezile yini ngizomgeza ngimsheshise ebese-ke ngimhambisa lapho codokotela. Maseke ngibona kahle ukuthi itreatment yakhe uyithole ngendlela yini kufanele ayiphuze ngendlela yini, ngimbuyise futhi kokunye ke mhlampe izofunaukuthi ucele ukuthi uhlale naye manje awkwezi ukuthi uhlale naye uxoxe kakhulu naye manje awukwazi ukuthi uhlale kakhulu naye ngoba kuzofanele ukuthi ubhekeni ndabanye abanye abantu. Okunye-ke nje mhlampe nezingane, ingane jakhe iyagula nayo-ke mhlampe kusaso nyavuka uhambisa nayo esibhedlela uyeludinga usizo lwakho, uzothi ubuya lapho mhlampe usujahe ukuyokwenza umsebenzi jakho mhlampe athi benicela eke sihlale koncane nje nawe ngobamanje uthanda ukukhipa yonke into nawe, akasthemba Bantu. Ngoba nona bexoxa abaeskaya kube ngathi sebekhuluma ngaye. Kanti kube ngathi uwena volontiya kuphela omunderstandayo.

4.3. Okushuthi-ke ngiye ngifike mhlampe kwenye inkathi vele umsebenzi wehuukweza ama home visits bese siyathola ukuthi kulelikhaya kunomuntu ogula kanye ngujabe-ke nenhlanhla yokuthi mhlampe umuntu angitshele yena ukuthi usephila nalesifo kanje kanje . mhlampe sesimphele isikhathi esingaka wathola ukuthi simphethe ke engiye ngifike ngikwenze mhlampe ngiye ngifike ngihlale mhlampe sixoxe naye mhlampe ngimduduze ukuthi angalahli ithemba usazophila njengoba ephila. Kodwa abanye abasuke sebegula kakhulu umuntu ku ngasavumi nokuthi gwinyeamaphilisi nokuthi enze njani sizame ukuthi sinuse eclinic. Mhlampe eclinic afike afakwe idrip nje kuphela. Bese kuthiwa godukaa naaye. Kuba nzima kakhulu-ke lapho ngoba ugcina unga sizi ukuthi uzumenzenjani mhlampe umfake ebaleni. Noma kwnye inkathi bamdlulisele esibhedlela eMaGandhi lapho uyaphogeka-ke ukuthi hamba naye lomuntu. Niyafika laphaya angalaliswa esibhedlela kungumthwalo wakho futhi ma senibuya. Usuke usebensizwe imali yakho nigibele nalomuntu simbuya ukhokhela yena nawe. Khona kunzima impela nje. Akuve kunzima , akulula.kunzima kakhulu kabi.

5.1. Uma-ke ngifica ekhaya komunye umuzi kukhona ngivakashile yenbona ngijivolontiya ngihambe ngingena door-to-door ma nafika kukhona ogulayo ngisuke

ngingokazi ngalesosikhathi uphethwe yini okusho ukuthi ngihlale phansi uma ngimukelekile ngoba isikhathi esiningi bayasemukela bayaye basinike imvume ukuthi lihayi-ke ngena nje, ngomoya omuhle ebeseke sixoxa bese engitshela ukuthi homu nene ngiyagula lana kodwa angazi ukuthi ngiphathiwe yini. Eyi senginesikhathi esingaka ngagula. Howu kodwa uke uye eClinic na? Omunye athi yebo ngiye ngiye. Omunye athi cha, iClinic nje anguyisebenzisi angikaze ngiye e Clinic. OK njengomuntu oyivolontiya-ke ngiye ngibe senginigquzela ukuthi akahambe aye eClinic noma ngabe uthembele kwezinye izindawo ngoba angasizakala lapho kodwa mhlampe abanye abantu bengakwazi ukumsiza ngempela. iClinic ezomsiza agcine azi ukuthi impilo yakhe incibe kuphi. So okusho ukuthi-ke baye ba-understande-ke ngoba uye uthi uma uqhamuka usuphinda uzobavakashela uthole umuntu esekutshela ukuthi hawu ngciyile eClinic, bathe ngoba mhlampe bengikhwehlela nje bathe ngine TB. Mhlampe bese ulandela-ke ngoba uhlale ulandela bese ethi-ke ngoba akupheli ngyankipha ng injani njani sekuvela lokhu nalokhu, ngibe sengicabanga ukuthi yenbona wawukade ungibonosile ukuthi sekukhona lezisifo ezikhona enihambe nifundisa ngazo emphakathini kungenzeka.mhlampe nami ngibonile kungenzeke ngoba iTB ithatha isikhathi esingaka kodwa ayipheli kungenzeka mhlampe nginaleligcinwane. Ebese ehamba umuntu ephindela eClinic. Ebese eyekokwenza itest. Kuye kusabekē-ke kwabanye ukuthi baye kuleclinic eseduze naye ngoba onesi bakhona bayabazi. Sase sithi-ke okungenani uma bethi bayasaba ukuya kuleclinic eseduze nabo sase sithi-ke hlayi awuke uye kule eghelile kunawe. Bayathandake ukuthi baye la okughelile khona-ke ebese ebuya -ke muntu. Omunye angawutsheli umndeneni wakhe. Ebese ehlebele wena njengevolontiya ukuthi ngihambile amareults ami kuthiwa ngingeciwane. OK ngendlela wena osuke umcounselishe ngayo, omunye uyakuthola ukusizakala, omunye akathole ongathandi ukunitshela lonke iqciniso ukuthi yena ufike wathola ini lowl-ke asimyeke, kuphela sigada mpilo yakhe ukuthi yini esizomisa ngayo, ekhna aschambile mhlampe wayithola eClinic sibe sesikhulumake sesilshela usister osiphetheyo ukuthi laphayana uhayi, kuyagulwa janje kanje masesiphethe amareport. Kukagulwa laphaya ubani khanje kanje . uboke umvakashele nawe, mhlamphe ebese eyahamba-ke usister ayomvakashela. Mhlampe abese etshels usister-ke inkinga yakhe ukuthi lapha kwabamba kanje. Abanye bafike basisthele ngokusethemba abanye, babe nalokho ukuthi izingane bazozishiya nobani. Uma sekwazi udadewethu layikhaya, uzonggithuka ngayo lento le. Ma sekwazi ubani ngoba ngihleli naye la emphakathini, mhlampbe usezoba nalokho ukuthi mhlampe angabe esangivahashela. Kodwa siye sikuthokozele kakhulu, abaningi impela nje umuntu usevele athi nje ngoba angibona ngiphila nao. Uthokozele lokho ngoba abaveli isikhathi esiningi abanale igciwane.

5.2. Ningathi nje into yokuqalq okufanele siyazi thina mavolontiya, ukuthi na sithola amtraining ulwazi kuqala okufanele sibe nalo ukuze sazi ukuthi ma ngiya kuloyamuntu nje ngiyothini. Mangabe engi xoxela anenkinga yakhe kufanele ukuthi ngiyibeke kanjani. Nami ngimbekele kanjani ukuze azi into o, iyixoxoyo, ngibe nokwazikuqal. Ngoba ng iyazi vele isikhathi esiningi ukudla ukuthi ukudla kuhlele kungekho nje. Kodwa ulwezi mina okufanele ngibe nalo. In fact yikona ukuthi mhlampe sithole ukufundiseka sazi ukuthi umuntu uhlangwa kanjani. Bese besetholela ukuthi abe zokudla nokuthi basitholele nezinto zokusebenza njengawo amaglove, abrons yonke nje iset ukuthi umuntu simsize nhalososikhathi seincnane ngalelosikhathi esisuke sikuyena.

5.3.OK Mina okufike kungishaye kakhulu ngempela ukuthola ist yokusebenza emphakathini, nakho ngingajabula kakhulu uma singase sicabangelke njengoba kukude ukuhi ufike la emphakathini ukuhambisa isiguli eClinic. Kodwa nje ma singase sicabangele ukuthi makungase kube khona abangasinika khona njengewheelchair ngoba akuve khublungu ukuthi ethi umuntu egula elele phansi ubona ukuthi ugula

ngempela umfake ebhaleni. Ngokuthi imali ayikho yokuqasha imoto. Imotoiya eClinic u R100 kokho ikhona okufie kusishaye kakhulu, kodwa sigcina sikwenzile. Ngoba nathi ungathi sinaso isandla lapho ukubulala umuntu simfake ebhaleni asikuthandi kodwa siyakwenza ngoba siphokwa isimo.

6.1. Into ebaworrishayo ukuthi omunye mhlampe ma uxoxa lento uyaye angathandi ukuthi ayiveze ngoba omunye usuke abathathe njengejoke noma ma bexabebe uzobe esnmthuka ngayo lento yujona nkinga enkulu kulabobantu, kodwa naye ukuthi ma ungafundisikile noma engenalo ulwazi naye engatholanga ecounsellor e right uyaye athi mhlwmbe noma kuxoxani bese ethi kuxoxwa ngaye noma abantu bezihlekela acabange ukuthi kuhlekwa yena.

6.2. OK kuskuthi abanye babo baye babe nalenkinga yokuthi njengoba benezigane egula abe ncnkinga yokuthi kombe izofa lezingane uzozishiya nobani. Okungangokuthi abanye babo umuntu uye othi evele epethiwe iHIV avedane aphuze, aphuzele ukuthi khona ezolala akhohlwe yilento emphethe. Abanengi ba worishwa yilezingane abanazo ukuthi ma eta zizoba yini lezizingane zizogcinwa ngubani. Nalokho nje umuntu esehlale elindele ukuthi anytime ngizofa. Okubawonisha kakhulu abanye baboyiloko nje ukuthi ngoba uma ngifa izingane zanu ngizozengenjani nobani, uma ngifa ngizo ngcwatshwa ngai ngoba akanayo name mali yokuthi aziphilise yena nomndeni wakhe.

6.3. OK Abaye bakubalule nje ngempela yiko lokho ozakwethu asebekushilo ukuthi izigane abazi ukuthi bazozishiya nobani nanokuthi abazilungisele. Bebengazi ukuthi bazoficwa yilelithuba, bebengasebenzi kabuhlungu kakhulu ukuthi njengoba mina ngikade ngiphila, ngihlulekile ukondla lezizingane ngabe ma sengifile zizokondliwa ngubani, zizofunda kanjani, ngabe khona ke zonke –ke zizophila yini noma nazo zizolandela mina noma ngizothi ma ngizishiya la kube yinto yabantu nje abazenzele noma ngabe yini abayithandayo. Babae bakuphathe impela ubone njeukuthima bayiphatha uma bekhuluma ngalezi zinto izino ezibashaya kakhulu. Nanakho ukuthi-ke mzuwane umphefumilo uphuma, ngiyoshona kanjani, umuntu ake axoxe ngalokho athi angazi, kodwa khona ngiyabona ukuthi esngizofa noba namfica sebengilandile sebela eduze kwamiabangilandileyo kodwa ngiyakusaba ukufa.

7.1. Mina ngaba yivolontiya ngoba empeleni nje ngikhula ngangizithela ukuthi ngizoba unesi, kodwa angizange ngiphumemlele utuphasa umatric. Ngenxa yokushona kwabazali, kodwa manje la em phakathinin undlela engizinikele ngayo. Kuahamba khona lapha othandeweni lami ukuthi ngiyafisa ukuthi abantu bakiti abagulela emakhaya ngibasize noma ngabe ingayiphi indlela, ngothando lonke enginalo.

7.2. Ngaba yivolontiya lokusizaumphakathi ngoba beginbona ukuthi umphakathi wakithi ukuhi uyagula mhlampe umuntu nama ngabe egula, angazi ukuthi uzisizwa ngubani.susuke kwaba isport esimnandi nje egazini lami ukuhi ngiphume ngibabheke ambantu ukuthi banjani, baphila kanjani, badinga ini. Sekuze kwaba yinto nje, ma ngingeyanga nje ukuyosebenza efildini, sengigcina sengigula enzimbeni ngoba sengizijwayeze ukuthi ngibabheke abaantu bakithi. Abagulayo, banjani, bangcono; badingani. Yilokho okwengenza ngivoloyite.

7.3. Into eyangenza ukuthi ngibe ivolontiya kwathi ngelinye ilanga ngenza iwashing egcekeni, kuseduze komgwago-ke kwami futhi yila abantubedlule khona behla benyuka, ngabona umuntu owayegula ehamba yedwa, ehamba egoba, abuye ahlale

aphansi, asukume ahambe ega phelezelwa umunt. Kwangishaya lokho kangagoba ngaze ngazithola sengila eduze kwakhe ngambuza ukuthi uyaphi, wathi uya eClinic. Ngathi uhamba nobani, wathi uhamba yedwa. Ngabone- ke ukuthi uNkulunkulu ngalesosikhathi ukuhipha kwami iwashing ubengitshengisa ukuthi impilo kwabanya abantu ayinjengoba mina ngiphila. Isandla sami siyadingakala. Kushu thi kwasukela ngalelolang nganalokho ukuthi angicele emndenini wami ukuthingicela ukuvolontiya ingiyojoyina ivolontiya. Nanakho ukuthi uyezwa kewamakhelwane njengoba nje la kugasshiwekethina siyi zakhamizi uzoyhola emqashweni la okuyikotishi khona. Eskukhona muntu oshonile, ubevale isicabha, esenesonto eshonile ngaphakathi endlini uyabo. Ngebona kuyichallenge konke lokho ukuthi kufanelekile ukuthi ngihamba ngiyovolontiya kwenzele ukuthi ngisize labobantu abefa bengaziwe umuntu.

8.1. Indlela zabantuzihlukene-ke, abanye abantu basithanda ngalendlela yokuthi base bafise ukuthi ngabe kukhona esikutholayo. Omunye uze afise ukuthi ngabe ukuthengela into ethize ma ehola yena. Labo Bantu osuke wangena ezindlini zabo ibona abakhuluma kahle ngathi, ababongayo umsebenzi wethu. Bese kuba nalabo-ke abangakaze bagulelwa okuyibona abathi umsebenzi wevolontiya abawazi. Kodwa abaningi abantu umsebenzi wamavolontiya bayawathanda, indlela akuthele ngayo.

8.2. Abye bejabula impela iningi labo ngoba ukuvela nje cwamavolontiya seiza umphakathi bekukade kuyinto engekho before. Kusho ukuthi uuqula ukba khona kwamavolontiya engena imizi ngemizikusiza kakhulu, futhi amakomiti asenzindaweni asibiza ngonesi, kuthiwa singonesi ngoba umuntu kukuqala ubekwazi ukusuka eClinic engagezile enclolile, kodwa manje sebeyazi ukuthi umuntu ayasuka endlini ukhona wena volontiya uzongeza ucleane athi ehamba eya lapha eClinic usuke eseclean, eclean we ithina mavolontiya. Esisiza wona umphakathi. Abye bejabula abaningi babo nje ngomsebenzi wethu. Kanga ngokuba ma bengasiboni baphatheka kabi ngoba noma ngabe ufise ukugoduka uvakashele ekhaya, uthi ubuya mhlampe kungu msombhluko beti kodwa ubunggekho ngani ngoba nje besibona ukuthi awukho. Abye besijabulela , abaye besincoma, kuyikhona-ke ukuthi sikwenza ngothando kona loku.

8.3. Lapha emphakathini-ke bayabonga abantu ngendlela esibaphehe ngayo ngoba bayebeze besho bethi. Eyi baye basibuze bethi ngendlela enisebenza ngoya ngabe kukhona yini esenikuthola sibatshele siti cha asiholi lutho. Bethi uNkulunkulu ngomiso aze anisize nithole ngoba akusenezeki lokhu okukade kwenzeka ekuqaleni ukuthi abantu bagulele endlini kungekho muntu omusizayo. Ngani myilungisile indawo okusho kuchasa ukuthi thina ngoba sihleli lapha izimpilo zethu ziphethwe mina esinbona kuqala ukuthi sesiyagula nisivakashele emakhaya nisitshele ukuthi kufane siclean ezindlini, sivule amawindi ekuseni, asipheke ukudla okunjani kufanele ukuthi uye eClinic. Khona lokho si gquguzelwa mina. Bayabonga kakhulu.

9.1. Langfunda okuningi ngoba kungifundisa ukuthi mina kufanele umuntu ngimthande noma ngabe uyagula noma ngabe akaguli. Ngoba phela kukhona ukuthi umuntu mase eseguli besebanye bengamyhandi. Mina njengevolontiya kufanele ukuthi ngibe nothando, ngifunda okuningi nokuthi omunye u muntu uyakwazi ukuthi asiveze isifo sake, omunye futhi uyasifihla othule naso aze ashona.

9.2. Ngifunde nje okuningi, ukuthi ngikwazi nokuthanda umuntu nginmukele ngaleyo ndlela asuke egula, nayo nanokuthi ngafunda ukuthi esikhathini before bengi ngazi ukuthi umuntu akathathelwa izimgumo. Sengiyazi manje ukuthi umuntu kufanele nibuze kuyena ukuthi yini ayidigayo bese ngiyamenzela yona. Ngingavele nje ngithi

hamba eClinic kanti umuntu akathandi ukuya eClinic. Futhi ngingasho hamba uye enyangeni kanti umuntu akathandi. Kufane ngiwe ngaye, ngibuza kuyena ukuthi wena ubona ukuthi asenzenjani. Ngizwe umbono wkhe bese ngcyambekelela ke lapho.

9.3. Ngifunde okuningi ngokuthi ngibe ivolontiya ngoba kwakhon nje mina ekhaya lami. Bekhuti ma ngipheka nje ngiziphekele isinoma ikanjani. Ngithi nje ma ngdile kuyamanje ngiyazi ukuthi ukudla okunempilo kufanele ngikupheke kanjani, lokhu okufanele engikutshela abantu. Ukuthi kufanele badle khona. Nanokuthi nje empilweni yami bengikade ngimsaba umuntu olele phansi ogulayo kakhlu. Kodwa manje ngoba sengikwzi ukuhamba emphakathini, kusekshona loku enikwazi nokumcinimezisa ngiyi gwala, ngangikade ngcyigvala, kuyamanje sengiyamanje ukuthi ukushona komuntu kuwubala, sengizokuthatha nje ngithi uhayi yinkuku njengenkukhu ukufunda nakho lokho engikufundile kuningi.