Community participation in health: Home/community-based care as an alternative strategy to institutional care–a case study of Dunoon home-based caregivers

by

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DECLARATION

I, Abraham Warren, the undersigned, hereby declare that this mini-thesis entitled *Community participation in health: Home/community-based care as an alternative strategy to institutional care–a case study of Dunoon home-based caregivers* is my own work, that it has not been submitted for any degree or examination in any other university, and that all the sources I have used or quoted have been indicated and acknowledged by means of complete references.

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ABSTRACT

In South Africa, since 2000, an increase of awareness in community involvement has become apparent, owing to the response from people to the need to be more engaged in decisions pertaining to their community. This positive move echoes an increasing acknowledgement by those in authority that community participation is essential to the main demands of renewing democracy, expanding service provision and constructing robust communities. The development of innovative patterns of participation development means that local communities should be empowered to participate in decision making, whilst government establishments need to have the determination and ability to respond to various community needs.

The Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS) pandemic has placed an enormous responsibility on public health services, such as South African hospitals, which are already functioning with limited resources. This has shifted the load of nursing to family members and communities as public health services are often stretched beyond their limits. Several community or home-based care programmes and facilities have materialised in reply to this necessity. In the context of participation of communities, the duty of community involvement in health plays a vital role in the future of public health in South Africa. Accordingly, this research was conducted to explore the nature and extent of community participation within the HIV/AIDS context in the Dunoon suburb in the Western Cape.

An empirical research design, which consisted of qualitative methods, was used in this exploratory study to investigate the nature and extent of home-based care as an alternative strategy to institutional care. The research population was comprised of community members at the Dunoon informal settlement, the home-based workers employed at Heavenly Promise NGO, as well as staff and management of the Caltex/Chevron Refinery, members of Project Management 4 Africa (PM4A) and representatives of the Department of Social Development (DSD), which together constitute the partnership that is dedicated to combating the spread of HIV/AIDS in Dunoon.

In general, the research findings demonstrate that home-based caregivers displayed strong levels of participation right from the outset of the project. The findings also established that participation among the community members was a combination of passive, weak and non-participatory, whereas home-based carers displayed a level of active participation. Furthermore, home-based care staff played a key role in decision making, while carers essentially undertook the work in the community. Hence, home-based care and communities participating in health matters are considered to be substantial as home care focuses primarily on palliative care of the patient at home, with the support of the family and the immediate community. Consequently, it is hoped that this research will prove significant and will enhance the existing knowledge of the potential benefits of home-based care as an alternative strategy to institutional care.

KEYWORDS

Community participation, development, home-based care, Heavenly Promise NGO, Dunoon, Caltex/Chevron, primary healthcare, decision-making process, health services, institutional care.

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Solio Deo Gloria

ACRONYMS

ABC	Abstinence, Be Faithful, Condomise
ANC	African National Congress
CCAP	Chevron Community Advisory Panel
CDW	Community Development Worker
DOH	Department of Health
DSD	Department of Social Development
HBC	Home-based care
HIV/AIDS	Human Immunodeficiency Virus/ Acquired Immune Deficiency Syndrome
IAP2	International Association for Public Participation
NGO	Non- Governmental Organisation
PM4A	Project Management 4 Africa
PLWA	People living with AIDS
PAHO	Pan American Health Organization
UNICEF	United Nations Children's Fund
RDP	Reconstruction and Development Programme
SANCO	South African National Civic Organisation
TB	Tuberculosis
WHO	World Health Organisation

CHAPTER ONE: INTRODUCTION

Since 1994, South Africa has faced the challenge of complete transformation of the national health delivery structure. The government has initiated a process of developing a national health plan and health-services delivery system based on the principles of the primary healthcare strategy adopted from the Alma-Ata Declaration of 1978.

At the time of writing, hospitals in South Africa are over-burdened and face extreme overcrowding as a result of the AIDS pandemic. Van Dyk (2005:259) maintained that the magnitude of the HIV/AIDS crisis inevitably means that families and the community of people living with AIDS (PLWA) will have to become far more involved in care programmes. This awareness of community participation and the role of home/community-based service evolved as the result of the rapid spread of the HIV/AIDS pandemic in South Africa. Home-based care (HBC) can be described as a service that "offers basic support services to sick people who need assistance with the activities of daily living at home" (Peu, 2008:4). Similarly, HBC is regarded as a strategy to promote healthy living.

According to Russel and Schneider (2000), a great number of HIV/AIDS patients spend the main part of their illness in their home environment. Uys (2003) reported that a study conducted on home-based and communal care determined that there has been an escalation in the number of AIDS patients being attended to in their homes, as government hospitals dismissed those infected, to be nursed by community and relatives, in accordance with government regulations.

Undoubtedly, there is an immense demand for assistance and encouragement offered by a home-based care (HBC) programme to individuals infected with and affected by HIV/AIDS. In sub-Saharan Africa, where the HIV/AIDS pandemic is of main concern, the nature of the affliction, poor public health infrastructure, escalating health costs and shortage of resources have made community-based care indispensable for people living with the condition. An effective HBC programme for people living with HIV/AIDS can produce major health and communal advantages for the patients and their relatives, and accordingly, the entire community. Peu (2008:4) proposed that this can be accomplished by means of persistent,

organised dedication amongst societies, government departments, institutes and development organisations/donors.

1. Rationale for the research

The reduced capacity of many government healthcare departments creates the expectations of a plan for caring for people with HIV/AIDS through a comprehensive home-based care progamme all the more appealing to governments. Fox, Fawcett, Kelly and Ntlabati (2002: 56), in their study entitled *Integrated community based care in South Africa*, noted that South African hospitals reported that a patient's average stay decreased from 14 days to 3.5 days when it was possible to refer her or him to a home-based care organisation. They further indicated that a possible advantage of home-based care is that ill patients are constantly surrounded by individuals they love and are acquainted with and thereby experience further assistance and sustainable treatment (Fox, Fawcett, Kelly & Ntlabati, 2002).

Beechley (2004) pointed out that individuals with terminal illness generally spend their final moments at home, as this also obviates the cost and inconvenience of travelling to and from the hospital when they are most vulnerable and keeps them stable, which enhances the effectiveness of their nursing care. In addition, people living with AIDS (PLWA) will be less exposed to hospital-based transmittable infections such as tuberculosis and cholera.

Peu (2008) reported that South African health authorities have recognised the necessity and significance of caring for PLWA in their homes. Peu further posited that in South Africa, HBC programmes has been acknowledged by authorities in 2001 as being an adequate service measurement and requested the formation of home-based care programmes by 2005. The rationale behind this exploratory research is to investigate the nature and extent of home-based care as an alternative strategy to institutional care. Specifically, the viability of community participation within the HIV/AIDS discourse in the Dunoon informal settlement, situated in the Western Cape, was examined during the study.

1.1 Delineation of case study

The selected case study area, Dunoon, is located east of Table View and north of Killarney Gardens, a few kilometres away from the Chevron Refinery. Dunoon is situated along the N7, about 18km from the centre of Cape Town.

It falls under the jurisdiction of the Blaauwberg Municipality, within the Cape Town magisterial district, and is clustered together with the "township" Joe Slovo, which lies a few kilometres away from Dunoon. This informal settlement is a Reconstruction and Development Programme (RDP) housing establishment for the poor, and the majority of people in this community are poverty-stricken and illiterate.

The high incidence of unemployment and widespread poverty in Dunoon has an adverse effect on the development of the community and the Cape Town economy. Furthermore, appalling housing conditions in Dunoon, including absence of important amenities, combined with impoverishment, are the primary causes of health problems in the community.

1.2 Research problem

In 2006, of the 39.5 million people living with HIV worldwide, more than 63% were estimated to be in sub-Saharan Africa (Department of Health, 2007:7). At least 5.4 million people were estimated to be living with HIV in South Africa (Department of Health, 2007:8). The epidemic has resulted in hospital overcrowding, staff shortages, lack of resources for treatment and the purchase of drugs, a shortage of hospital resources and a high cost for service provision. According to Peu (2008: 140), doctors in a least two hospitals in Durban noted that "between 55% and 65% of medical inpatients are HIV positive, the vast majority with AIDS-related illnesses." The Department of Health report (DOH, 2001) stated that if the situation continues, the number of beds will be exceeded by the number of patients needing to be hospitalised (Fox, Fawcett, Kelly & Ntlabati, 2002:4).

In South Africa, the awareness of the role of home/community-based care services and the need for such services resulted from the rapid escalation of HIV/AIDS infection The high prevalence of this condition has placed a burden on community clinics and hospitals, and HBC is considered to be part of the solution to the healthcare-service provision crisis created by HIV/AIDS.

In this regard, community participation is regarded as an empowerment method through which local groups are able to take accountability for identifying and networking to resolve their personal health and development challenges. Furthermore, community involvement in

health can create understanding amongst local individuals of the benefits of participation in such expansion programmes.

It is against this background that this research will be focused on investigating the nature and extent of HBC as an alternative strategy to institutional care at grassroots level in the Western Cape in order to ascertain its value and contribution to the overall development goals of primary healthcare.

1.3 Aims of the study

The specific aims of this study are to

- provide a theoretical framework for the research and literature concerning participation of bodies, such as the World Health Organisation, the Department of Health (DOH), and the Republic of South Africa's public participation policy, in order to determine their effectiveness in HBC programmes;
- document the extent and nature of home-based care in the case study area, focusing on how communities participate in the current structures that facilitate participation;
- assess the level of understanding, perceptions of community development and engagement in terms of carers and clients in existing home-based care processes;
- explore obstacles to home-based care in existing public participation processes; and
- provide summary findings and recommendations to policymakers and other stakeholders.

1.4 Research design

This research drew on qualitative methodology tools, as these were deemed most appropriate for gathering information in order to answer the research question. According to Neuman (2000) and Mouton (2001), this method helps the researcher to understand different kinds of human interaction, within natural settings, from the perspective of the participants. It also provides the advantage of giving personal insight in order to undertake detailed descriptions and understand certain phenomena within the community. Qualitative research is more

flexible and allows modifying the methods, time structure and additional features of the investigation to fit the purpose of the research.

1.4.1 Research methods and procedures

In order to gather more in-depth dynamic data, this study made use of semi-structured/informal interviews, participant observation and direct observation of the dynamics of and phenomena in the case study area. Qualitative tools such as participant observation and semi-structured interviews are used to understand human behaviour from the perspective of the insider, that is, the people involved in home-based care (Babbie & Mouton 2001). This technique helped in selecting individuals who would be suitable participants in the study.

1.4.2 Semi- structured interviews

Semi-structured interviews were used in this study to gather information about the existing structures, the respective roles of the different stakeholders, and the nature and extent of community participation in Dunoon.

Random sampling methods were utilised to target community members in the case study area. A total of 44 semi-structured interviews were conducted in this study. In particular, 30 semi-structured interviews were held with community members in Dunoon. Ten semi-structured interviews were held with the volunteers who serve as home-based caregivers in the Heavenly Promise NGO. One interview was held with the supervisor of the HBC programme, who acts as the liaison between the HBC and Department of Social Development and other role players in the partnership.

Another interview was held with the director of Heavenly Promise responsible for the maintenance of the HBC projects within the community. An interview was also conducted with the social worker from the Department of Social Development, the project manager of PM4 Africa responsible for capacity training for the HBC, and a representative of the Caltex Refinery partnering the HBC project, which is one of the main donors of the HBC programmes. The purpose of these interviews was to obtain an internal perspective on the viability of community participation within the Dunoon community.

1.4.3 Participant observation

Babbie and Mouton (2001:293) stated that participant observation is a type of observation where the researcher is simultaneously a member of the group she or he is studying and a researcher doing the study. Penderis (1996:15) described participant observation as allowing the researcher to "experience the reality of the social world of the participants" and to "observe social interactions in particular contexts through participating in a wide variety of actual day-to-day life activities".

Direct observation was used in order to ascertain the overall successes or failures of the project as well as to observe the actual involvement of different role players and their interactions with each other. Observation was participatory in nature, meaning that the researcher worked alongside the HBC as they were conducting their home visits in Dunoon. This facilitated interaction with various role players, who provided pertinent information about the HBC project. Information was recorded in diary and photographic format.

Dunoon HBC meetings were also attended in order to determine the extent to which community members are involved in decision-making processes, to assess the level of participation of community members, and to determine the different roles that HBC members play in meetings. Furthermore, the structure of the meetings was observed in order to evaluate whether the meeting setting and/or power structures encourage or inhibit participation.

1.4.4 Secondary analysis

Secondary data was acquired from existing material such as official documents, research reports, in-house brochures, correspondence, and the minutes of meetings in order to inform the study and gather information about the HBC process and community participation.

1.5 Research procedure

The research case study area was visited prior to conducting the research to assess the work of the home-based caregivers, the facilities and the community, and to select which community sites would be most appropriate for the research. The aims and procedures of the proposed research were carefully explained to the HBC workers, the supervisor and the voluntary community members working at the Heavenly Promise offices.

When requesting participation in the study, it was emphasised that it would be completely voluntary (see Appendix A) and potential participants were assured that the information obtained would be treated in the strictest confidence and in accordance with the accepted research ethics. Following this, all the respondents, as well as the members of the partnership, were given a formal letter by the University of the Western Cape as validation of the research (see Appendix J).

The data was collected in the months of June, July and August 2010. The voluntarily home-based carers, the supervisor, and community volunteers were requested to participate in a one-on-one interview process, which lasted approximately 30-35 minutes per interview. The interviews were conducted at the premises of Heavenly Promise, as well as in the office of the Dunoon Masincedisane Advice Centre. Although the research study area was situated in a predominately isiXhosa-speaking community, a translator was not required as the participants were able to speak fairly fluent English. However, in one or two instances, when the need for a translator arose or the home-based caregivers requested assistance, a fellow-participant was asked to oblige.

The research procedure was comprised of the following five stages:

Stage 1: Literature Review and secondary analysis

Stage 2: Construction of a semi-structured interview

Stage 3: Conducting of semi-structured interviews

Stage 4: Continuous observation throughout the data-gathering phase, with all interviews recorded on a tape recorder to ensure the correctness of the data gathered

Stage 5: Processing, arrangement and interpretation of data:

a) dictation and placement of interview data in various categories,
b) presentation of data in the form of textual explanations, categories and tables, and direct quotations.

1.6 Research agenda

This mini thesis is divided into six chapters:

Chapter 1 (entitled **Introduction)** contextualises and provides the rationale for the research and presents the background to the study, the research problem, the aims of the study and the research design and methods used.

Chapter 2 (entitled **Theoretical Framework)** sketches the basic theoretical background to the research and presents the conceptual foundation of the study. In this chapter, the key concepts with reference to community participation and home-based care are defined and the various models that exist in home-based care programmes discussed.

Chapter 3 (entitled **Literature Review)** provides a review of the relevant research literature and a legislative framework regarding community participation in order to define, inform and assist in explaining the research questions of this study.

Chapter 4 (entitled **Overview of the Dunoon community, the Heavenly Promise NGO and Partnerships)** provides a synopsis of the case study area, and the role of the Dunoon Community, Heavenly Promise organisation, the Department of Social Development, Caltex/Chevron, and Project Management 4 Africa in the case study area is discussed.

Chapter 5 (entitled **Discussion of Research Results)** gives details the data collection techniques used, and the results of the research are discussed. The characteristics of community participation in the Dunoon community and the role and responsibilities of caregivers, staff and partners within the organisation are outlined. Finally, the nature of training of caregivers and future expectations with regards to the partnership are discussed.

Chapter 6 (entitled **Recommendations and Conclusion**) presents the general findings and theoretical considerations of the research, reflections on participation, recommendations to stakeholders, and the final conclusion.

CHAPTER TWO: THEORETICAL FRAMEWORK

2. Introduction

This chapter provides the theoretical framework for the topic under investigation. The study was undertaken from a developmental perspective; hence, the chapter begins with a discussion of development theory. In the first section, the term *development* is conceptualised, followed by a discussion of classical development theories, namely modernisation and dependency theory.

Focus then shifts to a discussion of the alternative development paradigm and a people-centred development approach, which includes an examination of the concept of participation, understanding of the different levels of participation and the dynamics of participatory processes. Some of the benefits of participation in projects will be examined, such as capacity building, empowerment and ownership. Thereafter, attention will be placed on the concept of *home-based care* and the advantages of following a home-based care (HBC) approach. The chapter will conclude with an evaluation of hospital-based care as opposed to using a HBC approach in treating people living with HIV/AIDS.

2.1 Conceptualising development

Development is a multifaceted term and several authors have provided a wide range of definitions (Allen & Thomas 2000; Chambers 1992; Coetzee, Graaff, Hendricks & Wood 2001; Todaro 1992) to increase understanding of the concept. Despite the complex nature of the term, there is agreement among development academics and practitioners that development carries a constructive connotation synonymous with progress and an improved quality of life.

In general, development is perceived as encompassing values such as participation, capacity building, empowerment, conscientisation, and sustainability (Chambers, 2003; Davids, Theron & Maphunye (2005:15; Freire, 1972; Rahman, 1993; Swanepoel, 1992), transparency, accountability, equity and equality; (Narayan, 2002; Todaro, 1987). Other scholars have noted that the concept relates to enhanced opportunities and continuous improvements, socially, economically, politically, environmentally and materially (Allen & Thomas, 2000; Coetzee, Graaff, Hendricks & Wood, 2001; Todaro, 1987).

The *Oxford dictionary of current English* (cited in Lewis & Gardner, 1996:3) defines *development* as a 'stage of growth or advancement'. Lewis and Gardner (1996:3) maintained that in virtually all its usages, development implies positive change or progress. For Coetzee et al. (2001:120), development infers a form of social change that will lead to progress, the process of enlarging people's choices, acquiring knowledge and having access to resources for a decent standard of living and a condition of moving from worse to better.

2.1.1 Classical development theories

The 1950s marked the beginning of a paradigm shift in the development debate as a result of vigorous debates on what constitutes development and how to stimulate progress in developing nations. As a result, between the early 1950s and 1970, the classical development theories of *modernisation* and *dependency* emerged. These macro theories of development are included in this discussion in order to trace the evolution of development theories and sketch the background for the emergence of alternative theories of development.

Modernisation theory was promoted by the United States of America (USA) throughout the 1950s to the 1970s. The main theme of modernisation theory, at the time, was that in order for the so-called Third World to develop, it would have to follow the path of its First World counterparts. This view was interpreted as seeing the former moving away from its backward traditional state to the advanced, modern state of the First World. This entailed political, economic and social change to move away from the "shackles of tradition" (Graaff, 2003:15). Modernisation theory called for economic, political and social change which entailed moving towards a capitalist economy based on industrialisation, high levels of consumption, urbanisation and the commercialisation of agriculture, a democratic government, free press and adopting individual and rational values (Graaff, 2003:7; Lewis & Gardner, 1996:7).

De Beer and Swanepoel (1998:6) postulated a link between modernisation theory and community development, stating that early versions of community development originated within the modernisation school of thought. Such a top-down approach implies that the elite, with power over communities, initiate and control the development process. These elite, rather than the poor, are the key beneficiaries of the development process; communities are not included in decision making or planning, and thus their needs are not the focus of development (De Beer & Swanepoel, 1998). Sustainability of projects, therefore, decreases as

the beneficiaries have no control over the different stages of project planning and implementation.

Dependency theory was initiated in Latin America during the 1960s as a consequence of the failure of modernisation theory to explain the underdevelopment of developing countries. It was a political response from the so-called Third World academics and activists (Cardoso, 1965; Frank, 1969), who criticised the impact of the modernisation approach in their own countries (Davids, Theron & Maphunye, 2005:12; Graaff, 2003:35-36). According to Korten (1990:76), the underdevelopment of specific countries is fashioned and sustained by global capitalist economic structures which drain crucial supplies from the poor (marginalised) countries and transfer these resources to the rich (core) countries. This process of exploitation of the surplus results in poor countries becoming further underdeveloped. Long (2001:5) argued that "the theory's advocacy of socialism in less developed countries has been criticised by those who believe that the transition from a capitalist system to a socialist system would create more social problems than it would solve."

2.1.2 The alternative development paradigm

Kotze, 1997:36), together with Allen and Thomas (2000:32), explained that due to the failure of 'macro theories' (such as modernisation and dependency) to address development issues, development theorists and practitioners realised that development cannot be studied or brought about by merely concentrating on broad theories and macro-strategies, but must rather focus on local beneficiaries who must be positioned at the centre of their own development. This new human positioning of development in the late 1980s ensured a shift from the macro theories of development (modernisation and dependency) to a micro approach that focused on people and the community (Allen & Thomas, 2000:32; Kotze, 1997:36).

2.1.3. Evolution of the alternative development paradigm

The failure of the impact of classical theories resulted in a search for alternative approaches which address development needs of developing countries. Thus, alternative theories of development have their origins in the critiques of classical theories. Whilst the macro development approaches were largely capital-centred, as opposed to people-centred, current micro approaches focus on participatory development, empowerment, community

development, self-reliant development (Burkey, 1993; Oakley, 1991; Rahman, 1993) and the notion that meaningful development emanates from the capacity of the ordinary people to manage their own development.

During the mid-1980s, an understanding of development as the expansion of capabilities emerged, following Amartya Sen's work on capacities and entitlements. Sen (1999:53) stressed that "the ends and means of development call for placing the perspective of freedom and development at the centre of the stage". In order for people to live more freely, certain fundamentals must be in place. Sen (1999) further elaborated that these fundamentals include political freedom, social opportunities, transparency guarantees and protective security.

The concept of participatory development and community participation gathered renewed strength in the 1990s. Slocum, Wichhart, Rocheleau and Thomas-Slayter (1995) claimed that the key essence of participatory development theory is the dynamic participation of individuals in making choices regarding the execution of procedures, programmes and developments which directly influence them at local level. During this period, the United Nations Children's Fund (UNICEF) undertook a formal examination of the usefulness of the participatory approach to its work (Oakley, 1991), and in 1994, the World Bank took the decision to build a participatory approach into its loan operations (World Bank, 1994). Such challenges required a significant alteration both in approaches and in policy to terminate decades of top-down, non-participatory practices. Slocum et al. (1995) maintained that the solution to the challenge of effective development in underdeveloped countries is not obtained in bureaucratism and centrally authorised development programmes, but preferably in the community itself.

However, in the 1990s, the growing democratisation in Latin America, the retreat of the state and the philosophy of participation and empowerment, which were in the past reserved for the social movement development discourse (Gaventa, 2002). Simultaneously, the term *empowerment* was zealously embraced by international development agencies, which were influenced by the views of Sen (1999) and the endorsement of his "capabilities approach". The concept *empowerment* can also be related to that of Paulo Freire's notion of "conscientization" that advocates for self-reflected awareness of people and enabling people to exert power, to assert their voice and to stimulate their self-driven collective action to

transform their reality (Freire, 1972). Freire, Brazilian academic and radical activist in the 1970s, was amongst the leading advocators of participatory development.

However, several schools of thought (Chambers, 2003; Pieterse, 2009) are increasingly correlating participation with neo-liberal policies and the World Bank's mainstream development agenda (Pieterse, 2009), where development is controlled by the more powerful, who have access to resources. Chambers (2003) emphasised that such conditions result in beneficiaries being disempowered as a result of the implementation of top-down, pre-designed development programmes submitted to community beneficiaries in order to obtain their approval without any form of meaningful engagement and participation in the process.

2.1.3 Participatory development

Other scholars, such as Chambers (1983:45), who have contributed to the discourse on participation in development, argued that "putting the last first" was the only way to achieve rural development. The participatory perspective acknowledges that people have a wide knowledge base that is derived from their vast experiences and this entails the possession of a sufficient combination of mental and material resources which should be used to inform local development initiatives.

According to Paul (1987), participatory development allows people to directly control the process of action that they initiate. Conyers and Hills (1990:56) posited that the underlying principle behind the advent of participatory development methodology is that "participation and involvement of beneficiary groups cultivate and reinforce the capabilities of beneficiary groups in development initiatives"; therefore, this shifts power to communities. This paves the way to self-renovation and independence, thus safeguarding sustainability (Rahman, 1997).

2.1.3.1 Levels of Participation

A number of scholars have presented significant insights into the different intensity levels of partcipation. Paul (1987:4) differentiated between four ascending levels of community participation in development initiatives: information sharing, consultation, decision making and iniating action. Similarly, the International Assiociation for Public Participation (2007)

incorporated a continuum of increased levels ranging from informing and consulting to involving and empowering.

Likewise, Arnstein (1969) formulated a typology of eight levels of participation, which indicates the extent and power citizens have over development processes and iniatives. Figure 1 illustrates the categorisation of these levels of participation, which range from non partcipation to tokenism to citizen power. The lowest levels of the ladder illustrate the degree of non-participation, where authorities "educate" or "cure" the participants. The middle level indicates advancement to tokenism that enables the marginalised to be partially informed and to have a minimal voice.

Figure1 shows that only levels 6, 7 and 8 represent partnership, delegated power and citizen power, which characterise true participation, whereby citizens have the power to negotiate and participate fully in the decision-making process (Arnstein, 1969). Much of the literature on participatory development suggests that meaningful participation occurs very rarely and, in most cases, participation falls within the category of non-participation, as decisions are taken by authorities and citizens are merely informed.

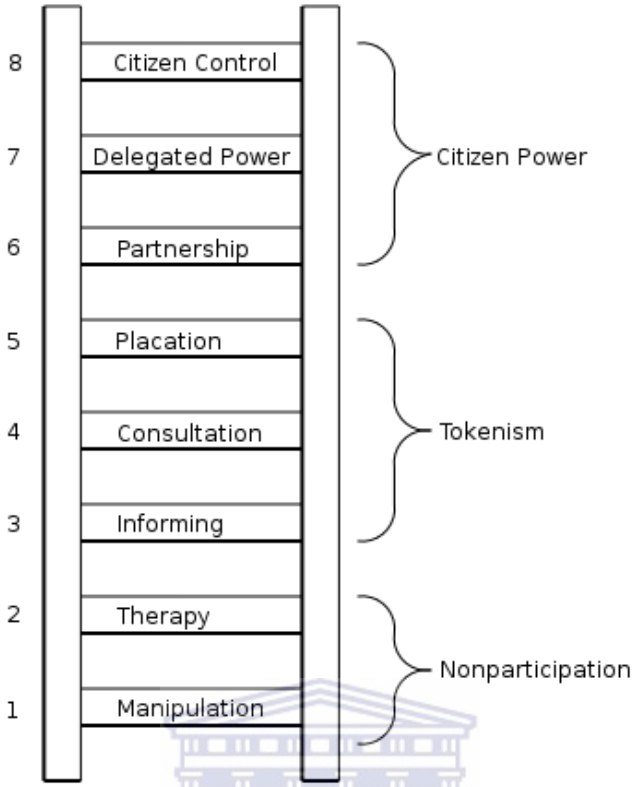

Figure 1. A ladder of participation

Source: (Arnstein, 1969)

2.1.3.2 Spaces for participation

The spaces in which individuals are enabled to participate are of essential importance in development and democratisation. One aspect that needs to be explored when examining the spaces for particpation is to ask how they were shaped, in whose interest and with what terms of engagement. Brock, Cornwall and Gaventa (2001) suggested three continuum of spaces, namely *closed*, *invited* and *claimed spaces*, which will be discussed below:

Closed spaces. Cornwall and Pratt (2003) claimed that decisions are made by actors behind closed doors, without pretence of broadening the boundaries for inclusion. Closed spaces are selectively restricted to bureaucratic power-holders, and all others are excluded. Various civil society attempts concentrate on opening up closed spaces by means of greater community participation, transparency and accountability.

Efforts to widen participation involve the creation of new ***invited spaces***, that is. those in which people, as citizens and beneficiaries, are invited to participate by state authorities. Brock et al. (2001) suggested that these authorities possess a large amount of power and stage the agenda around which individual participation can occur. They also generally dominate the spaces in which discussion takes place and decisions are made. Williams (2004:12) posited that in the abundance of "new governance spaces" around the world, communities are requested to enter these spaces and participate in the authorities' discussions.

Finaly there are the the ***claimed*** or *created spaces**,*** which are claimed by less powerful actors from or against the power-holders, or created more autonomously by them. Cornwall and Pratt (2003:13) referred to these spaces as "organic spaces" which emerge "out of sets of common concerns or identifications and may come into being as a result of popular mobilisation or may consist of spaces in which like minded people join together in common pursuit."

These created spaces for participation are usually instituted by citizens who have been excluded from formal decision-making processes and, as a result of their powerlessness, initiate these spaces in an attempt to make themselves heard (Lefebvre, 1991). Futhermore, these spaces vary from ones shaped by social movements and community affiliations, where citizens come together to debate, discuss and be in opposition, to institutionalised policy domains.

2.1.3.3 Participation as power

Evaluation of participatory approaches to development and governance sometimes seeks to involve people without examining the underlying power dynamics. Power analysis can help to deal with this. Power is often multifaceted: however, it is best understood using a variety of frameworks. These vary from the more evident and noticeable to those that function mainly overlooked behind the scenes. An evaluation of the different dimensions of power is described in the following section.

Visible power: Brock et al. (2001) are of the view that in this approach, access to these decision-making domains by moderately powerless groups is reasonably open. Moreover, individuals with grievances are able to communicate them in the formal decision-making

processes and contribute fully in the decision-making process. Gaventa (2002) suggested that visible power presumes that decision-making arenas are unbiased playing fields, in which any actors who have concerns to raise may contribute without restraint. This approach also assumes that actors are conscious and aware of their grievances and have the resources, organisation and agency to make their voices heard.

However, there are numerous ways in which specific participants are restrained from the decision-making agenda and certain matters are kept "off the table". These are referred to as *hidden* and *invisible* power.

Hidden power: VeneKlasen and Millers (2002) claimed that these secret forms of power are employed by vested interests to safeguard their power over exclusive rights by creating barriers to participation, by preventing essential issues from being aired in the community arena, or by controlling politics behind the scenes. Cornwall and Pratt (2003) asserted that this hidden power may occur not only inside political processes, but in management and other group contexts such as the working force, NGOs or community based establishments. Scholars such as Brock et al. (2000), Gaventa (2002), and VeneKlasen and Millers (2002) have identified this form of power as the mobilisation of partiality, where some issues are structured into politics whilst others are structured out.

Invisible power: VeneKlasen and Millers (2002) observed that possibly the most harmful of the three proportions of power is invisible power. Important issues and events are not only held back from the decision-making table but also from the minds and consciousness of the different players involved, even those directly affected by the crisis. Time and again, government authority prevents ordinary citizens from questioning or envisioning possibilities for changing these relationships or addressing injustices. In other words, processes of socialisation, traditions, and principles, which are determined by authorities, bring about segregation and discrimination by dictating to local citizens what is standard, satisfactory and secure (Brock et al., 2001).

Lastly, for marginalised communities, being denied information can reinforce impressions of powerlessness, ignorance, and self-blame. Nevertheless, it also has the potential to incite individuals to action. To address the dimensions of power discussed in this chapter, NGOs and community groups should collaborate with academic institutes and government

authorities to uncover the nature and scope of the various challenges that confront communities.

2.1.3.4 Benefits of community participation

Participation implies a greater probability that resources available to development will be used more efficiently. Oakley (1991) claimed that participation helps minimise misinterpretation or potential differences; therefore, the time and energy often consumed by specialised personnel interpreting or persuading individuals of development's advantages can be reduced. Midgley, Hall, Hardiman and Narine (1986) asserted that participation is also cost-effective since if local people take responsibility for their own projects, fewer costly outside resources will be required.

Rahman (1987) noted that participation intensifies the effectiveness of projects designed as instruments of community development. He further explained that if participation allows people to have a voice in determining objectives, supporting project administration and applying their local knowledge, with the concomitant extra skills and resources thus more available, it will result in additional effective projects. Chambers (1984) held that several projects have been ineffective or failed because local people were not included in the development initiative.

Oakley (1991:17) saw participation as a means to "break the mind-set of dependence" which characterises a large amount of development work. Rahman (1993) further explained that participation is concerned with human development, as it increases people's sense of control over issues which affect their lives by assisting them in acquiring experience, organizing activities and executing plans. On a broader front, it grooms them for participation at provincial or even national level. Some of the many benefits of participation in projects include capacity building, empowerment and ownership. These will be discussed briefly below:

Brynard and De Coning (2006:199) explained that ***capacity building*** is understood to include availability and admission to "distinctive tangible resources (human, financial, material, technological and logistical)" as well as intangible requirements such as authority, inspiration, dedication, readiness, courage, durability and other qualities required to change

theories into deeds. They added that capacity building refers to support which is given to organisations, communities, or even countries which have a need to acquire particular skills or competencies or to upgrade their ability to perform their mission (Brynard & De Coning, 2006).

Empowerment is about the handing over of power to the marginalised groups in the local community. Rappaport (1987:45) supported this concept and claimed that empowerment is the ability of people to "gain control socially, politically, economically, and psychologically through access to information, knowledge and skills, decision-making, individual self-efficacy, community participation and control". According to the benchmarks of empowerment, individuals participate since it is their democratic privilege to do so. Participation is therefore a natural result of empowerment and requires more than just having the authority to make decisions.

According to Flynn (1995), ***ownership*** entails that individuals are required to have a sense of accountability for and proficiency in running programmes endorsing transformation so that they will continue sustaining them after the initial launching effort. Dennill, King and Swanepoel (1999) maintained that community development projects do not belong to the initiating NGOs, which only help to facilitate the running of the programmes by the people themselves so that ownership is vested in the community. Communities therefore need to be inspired to take charge of their own projects.

2.1.3.5 Barriers to effective community participation

The authors of literature on participation have identified numerous barriers facing participatory practices. For the purpose of this study, a selection of obstacles to participation will be discussed.

Pretentious approach to the notion of participation: De Kadt (1982:174) observed that the concept of community participation has popularity without clarity and is subject to "growing faddishness and a lot of lip service". Midgley (1987) confirmed this and referred to the emotionally appealing case for participation, but stated that it is important to disentangle ethical issues from theoretical and practical considerations. Furthermore, community involvement does not often guarantee success, and there is no distinct methodology of

community participation. Lastly, Uphoff, (1986:85) was of the view that community participation indicates a condition of "pseudo participation and argues that in many projects the participatory element is more illusory than real".

Inadequate understanding of the community: Midgley (1987) argued that the proponents of community participation have neglected to deal adequately with the problems of interpersonal relationships that arise in communities. Similarly, studies of urban squatter settlements (Baum, 2008) indicate that poor communities are extremely varied, being comprised of individuals with different earnings and levels of possessions. As Coetzee (2001) observed, even those who may be considered relatively "elite" amongst these disadvantaged groups in many poor communities are themselves comparatively poor and exploited. Theron, (2005) maintained that rather than acknowledging these elements, the activists of community participation induce an inaccurate representation of the "elite" that is isolated from the actual community.

Mentality of dependency: Probably the most frequent and powerful social obstacle to the participation in the health of communities in development projects is a mentality of dependence which is deeply and historically ingrained in their lives. Oakley (1991) remarked that in many so-called Third World countries, local people have for generations been dominated by and become dependent on the elite groups. In practice, this means that the local poor have become accustomed to leaving decisions and initiatives to their leaders. Moodley (2006:24) added that this mentality of dependence is further reinforced by the fact that mere existence is for most locals their ultimate challenge and exhausts much of their energies, leaving them with barely an opportunity to contribute to community matters.

For the purposes of dealing with community projects in a particular community, these obstacles and challenges must be taken into account, as they will have an impact on the sustainability of the projects implemented in a community. Role players must be made aware of the possible obstacles and find proactive ways to deal with challenges and dynamics in order to minimise their impact.

The original broad goal of home/community-based care was to look after the sick and needy in their homes and communities. In the following section, an operational definition of the term *home-based care* will be presented and the history of home-based care will be examined.

Moreover, the benefits, objectives and various models that exist in the field of home-based care will also be explained.

2.2 Home-based care

Home healthcare is not a new concept. Tshabalala (cited in Peu, 2008:3) pointed out that it can be traced back to the 1600s, when religious and charitable groups devoted themselves to caring for the sick. According to Clemen-Stone, McGuire and Eigsti (2002), the St Francis de Sales Association arranged for wealthy women who were willing to assist to visit and care for the sick in their homes. Allender and Spradley (2005:27) observed that this kind of nursing of the sick experienced a setback during the Industrial Revolution, which brought a radical shift in the balance of rural and urban populations.

The Industrial Revolution gave birth to the idea of the construction of large hospitals. As a result of the increased number of physicians and medications, the practice of care for the sick in their homes declined. However, both the Catholic and Anglican religious nursing orders continued their work of caring for the sick in their homes during and after this period (Allender & Spradley, 2005). Today in South Africa, groups of home-based carers drawn from churches visit patients in their communities, provide them with palliative and spiritual care, and educate the patients' families on how to care for PLWA.

2.2.1 Conceptualising home-based care

Haug (1985) stated that the overall goal of home/community-based care is to provide high quality, appropriate and cost-effective care to individuals that will enable them to maintain their independence and have the best quality of life. Van Rensburg (2004) defined HBC as the care provided to an individual in his/her own environment (home) by his/her family and assisted by experienced welfare officers and communities to meet not only the physical needs, but also the spiritual, material, and psychosocial needs of the patient and his/her family members. The World Health Organisation (WHO, 1985:87) explained that HBC is "*the provision of health services by formal and informal caregivers in the home in order to promote, restore and maintain a person's maximum level of comfort, function and health including care towards a dignified death.*"

2.2.1.1 Palliative home-based care

According to Akintola (2004), palliative care refers to the moderating of pain or sorrow by making it easier to bear. This is given to patients as early as possible in the course of any chronic, ultimately fatal illness. Furthermore, palliative care includes symptomatic and pain control, nutritional support and meeting the patient's holistic needs through counselling.

The World Health Report (2008) defined the full scope of palliative care as a method which enhances the value of patients and their families confronting severe illness through the prevention and relief of distress, by means of early detection and impeccable assessment and treatment of pain and other problems, whether physical or spiritual. The World Health Report (2000) advised that palliative care should commence at the time of analysis of a terminal sickness and can be interrelated with treatments for nursing opportunistic illnesses. Van Dyk (2005) asserted that the intention of terminal nursing is to develop the value of day-to-day living, and at the end of life, by alleviating symptoms (particularly pain) and allowing patients to die in peace, with self-respect and in keeping with their wishes.

Peu (2008:31) recommended that palliative care services need to be incorporated with and well-adjusted to other care services to address the necessities of patients and their families Care should incorporate clinical management, direct patient care, education, counselling and social support. Pearson, Vaughan and Fitzgerald (1996:15) stressed that the notion of palliative care underlines individual choice, assisting patients to make the maximum of every day and preserving a sense of confidence.

2.2.1.2 Objectives of home-based care

The ultimate goal of HBC is to provide outstanding and suitable care to assist sick patients and their relatives to maintain their independence and achieve the best quality of life in the comfort and familiarity of their own homes (Uys, 2003). Furthermore caregivers are trained to counsel patients and their families, help to monitor their medication needs, teach the primary caregivers about symptomatic treatment, and monitor the needs of the children in these homes (Peu, 2008).

One of the most lasting benefits of HBC is the way in which it reduces the stigma surrounding HIV/AIDS, as the community sees the way these caregivers touch and care for

those who are infected with HIV. The caregivers' affection towards their patients enables the community to address its misconceptions and prejudices about HIV/AIDS, making the community less afraid and less inclined to reject those infected with the virus (WHO 2000).

2.2.1.3 Advantages of home-based care

Frölich (1999), Peu (2008), Van Dyk (2005) and Uys (2003) maintained that patients who are ill or dying would rather remain at home so that they can spend their last days in a familiar environment. This is also the case when they are aware that hospitals do not offer any cure. Ill patients are supported by being in their private homes and neighbourhoods, with relatives and loved ones near them. Marston (2003:79) pointed out that, as a result of HBC, the pressure on hospitals is "systematically reduced" and health professionals can use their time more effectively to care for other critically ill patients in hospitals. Uys (2003) agreed and stated that HBC programmes reduce the enormous pressure on provincial and national health budgets, which are already strained to breaking point.

Table 1
Comparisons between hospital-based care and home-based care

Hospital Care	Home-based care
High costs to set up and run	Low cost in comparison to hospitals
Focus of care is on the disease	Focus is the whole person
Quality of medical care is good	Quality of medical care is good
Non-medical care is not available	Non-medical care is available
Relationships exists with medical staff only	The patient is part of a web of relationships including medical staff, volunteers, community and other HIV-positive people
Awareness and prevention are regarded as separate activities	Awareness and prevention are integrated
Patients are referred to outside organisations to access long-term holistic care	Patients are helped to access hospital treatment when needing care

Source: Beechey 2004:76.

Table 1 reveals that there are many positive indicators why HBC is an attractive alternative to hospitalisation. Rather than just visiting a hospital for treatment, HIV-positive persons become part of a network of caring relationships. Beechey (2004:78) showed that these networks support them medically, as well as provide socio-emotional support, whilst simultaneously encouraging the patients and their families to remain healthy. Fawcett (1989:12) added that HBC facilities develop links between the HIV-positive patients and their families and other people living with HIV/AIDS who understand what it means to be HIV-positive.

Care and support is holistic and inclusive because the patients are cared for physically, emotionally, spiritually and socially by trained caregivers with the aim of healing their bodies and souls. Beechley (2004) argued that a holistic approach is particularly important in dealing

with a condition that may last for many years and which has wide-ranging social ramifications. Perhaps the most important difference between hospitalisation and HBC is the support groups that arise out of this care, both for the patients and the caregivers.

Marston (2003:115) highlighted a critical point in that HBC is sympathetic to the culture and the value systems of the local community, an understanding that is often absent in clinical hospital settings. He suggested that HBC workers are in an ideal position to identify the needs of children who are affected by the illness of their siblings (Marston, 2003). The HBC givers can then also assess issues pertaining to children such as, for example schooling, child psychological support, and the question of who will look after the child after the death of the parent or guardian.

2.2.1.4 Potential problems associated with home-based care

According to Van Dyk (2005), numerous people in the community are not ready for HBC because of ignorance and superstition and often the fear of stigmatisation by other members of the community. The United States Agency for International Development (USAID) (2004) (cited in Peu 2008:141) noted that many PLWA fear that, if the HBC-givers enter their homes, it will be known that they are HIV-positive and they will suffer social isolation. This results in clients seeking medical assistance at a very late stage, when they already have complications. Marston (2003:123) observed that an absence of information about the syndrome, medication, trauma conditions and community resources often hinders HBC, and that many family caregivers are frightened they themselves possibly will become infected with HIV.

Van Dyk (2005:261) pointed out that "non-compliance with treatment" often occurs because the patients or primary caregivers do not know how or when to administer medication because they are educationally disadvantaged. She also noted that often the medication is unaffordable, and that they do not know where to go for financial aid. Uys (2003:5) argued that one of the greatest setbacks of HBC is that the caregivers might give up because of "exhaustion and burnout" resulting from the extreme demands of caring for a terminally ill patient. It is therefore vital for caregivers to have support systems and to take care of themselves to prevent burnout.

2.2.2 Models of home-based care

Pearson, Vaughan and Fitzgerald (1996:19) observed that, over the past years, different models have appeared which reveal the origin of the care organisations, their goals and intentions and the needs of the recipients of care. Various communities have offered some form of home/community-based care for ill clients. Owing to the differences in culture, socio-economic conditions and clients, the models for providing HBC differ considerably in structure and complexity (Peu, 2008).

Allender and Spradley (2005) reiterated that the common thread, however, in the development of HBC models is the need to provide care to people who would otherwise not be cared for adequately. Practice models of home-based care recommend the usage of a multidisciplinary team to work with families and communities in the provision of care. Table 2 illustrates three home-based care models, namely, *integrated home-based care*, *single service home-based care* and *informal home-based care.*

Table 2

Models for home-based care.

Integrated home-based care	**Single service home-based care**	**Informal home-based care**
Work by linking all the service providers with patients and their families in a continuum of care.	One service component (a hospital, clinic, a N.G.O, or a church) organises care by recruiting volunteers, and linking them with patients and their families at home.	Families care for their members at home, with the informal assistance of their own social network.
The patients and family are supported by a network of services, such as community caregivers, clinics, hospitals, private sectors, support groups, NGOs as well as larger community.	A member or members of the community convert their homes into a care-giving setting which is then utilised for caring for the sick.	Patients are supported only through family, and those who assist are usually other relatives, the church or voluntary members of the community.
Caregivers receive comprehensive training on supportive counselling, cleaning and dressing of wounds and hygiene, administration of medicine and all basic care needed by the patients.	Caregivers are being trained by one service component (a hospital, clinic, an NGO, or a church). Services are offered on either a long-term or short–term basis, depending on the availability of resources and the identified needs of the clients.	Nobody has any specific training or external support, and there is no organisation or supervision of the care. Primary caregivers lack the necessary knowledge, skills and emotional support needed to care for patients.

Source: Uys and Cameron (2003:5).

Integrated home-based care model: Table 2 indicates that this integrated home-based care model links all the service providers with the patients and their families in a continuum of care. Pearson et al. (1996) indicated that this continuum of care includes primary prevention (health promotion and disease prevention), secondary prevention (curative care and support) and tertiary prevention (correction and prevention of deterioration) as illustrated in Figure1.

Uys (2003) observed that this integrated model allows for referrals between all partners as trust is built, and it ensures that community caregivers are trained, supported and supervised. Louden (1999) stated that the goal of this model is to implement home community care which is affordable, accessible and equitable and which provides assistance to clients, families and communities through the use of professional health education, so that they can cope with the more dependent clients in their families and communities. Figure 1 also illustrates a comprehensive HBC programme that has been expanded to incorporate orphan care, social support, and income-generation activities.

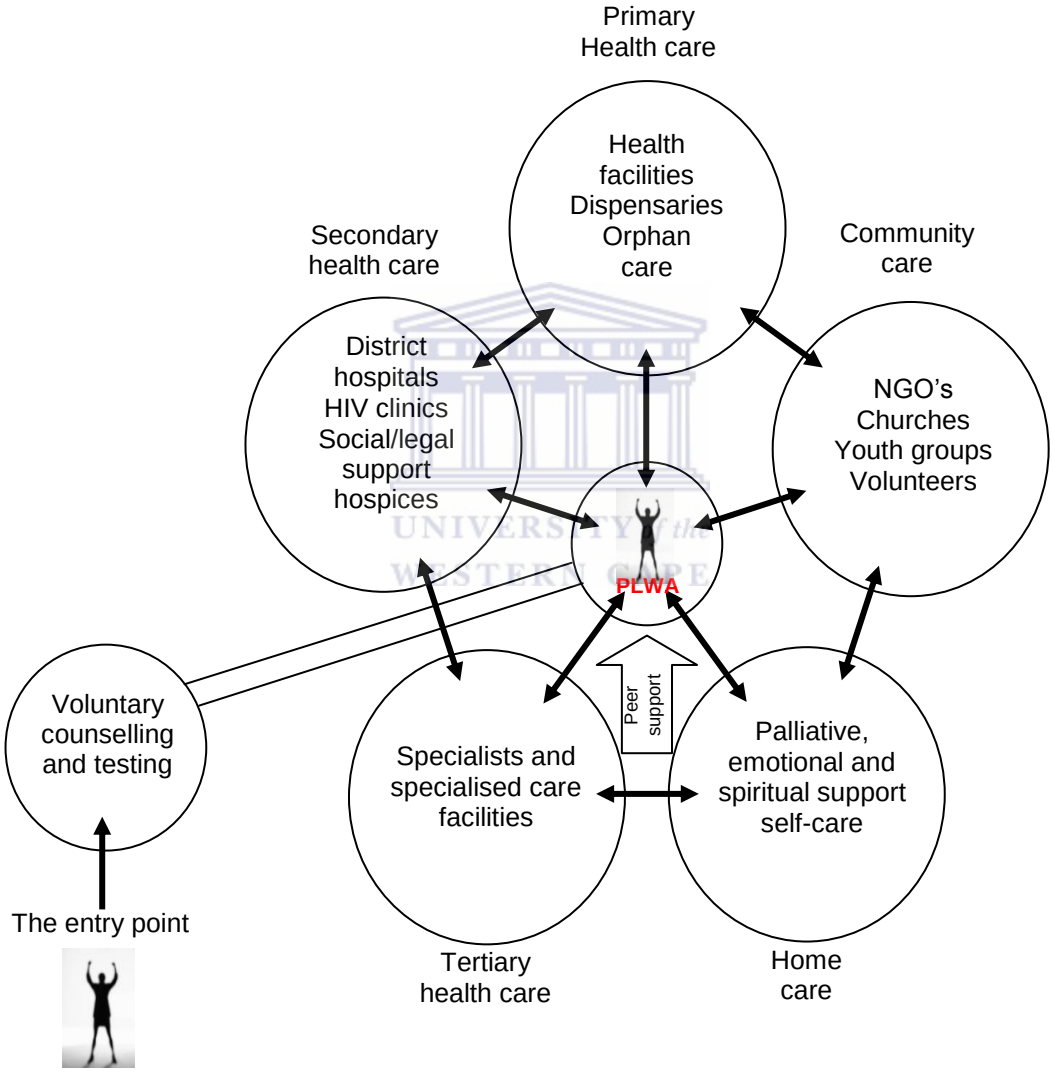

Figure 2. An integrated home-based care model

Source: UNAIDS (2002) cited in Van Dyk (2005:263)

Single-service home-based care model: Table 2 shows that in the single-service home-based care model, the services are offered in a residential setting other than the client's home. Spier and Edwards (1990) noted that this model makes provision for one service provider—usually a clinic, hospital, or church—that organises the HBC by recruiting and training volunteers and bringing them into contact with patients and families at home.

Services, according to Peu (2008), are offered on either a long- or short-term basis, depending on the availability of resources and the identified needs of the clients. Fawcett (1989:172) noted that a disadvantage of the model is that there is little supervision of the quality of care given to such clients, and that this often results in sub-standard levels of care, which further compromises the clients' condition. Many home-care programmes start this way and develop further to offer integrated care as they recruit other partners.

Informal home-based care model: Table 2 illustrates the informal home-based care model, whereby families care for their sick members at home, with the assistance of their extended family and the community network. Those who assist are usually relatives, members of the church, or voluntary members of the community. Van Dyk (2005) indicated that the limitation of the informal home-based care model is that there is nobody with formal training, and if there is, the person may not be directly involved with caring, but rather act as an advisor.

Allender and Spradley (2005) reported that, in most cases, especially in the care of terminally ill HIV/AIDS patients, the caregivers are either elderly people, who have to take care of their sick children, or young children, who have to take care of their sick parents. Hence, as Table 2 indicates, in the informal home-based care model, a lack of knowledge and skills may exist. Spier and Edwards (1990) pointed out those children whose parents are ill have to leave school and assume the role of the parent to the other siblings.

Madumo (cited in Peu, 2008:80) noted that caregivers may not be available to address the needs of the patients adequately, and also the caregivers could burn out from stress due to a lack of support, which may prevent continued care. The informal home-based care model often proves very strenuous because these caregivers have to deal with the burden of a lack of necessary skills, training, knowledge and emotional tenacity to care and support their patients.

There are several variations of the HBC model, but what is important is that in each case, the model has to be agreed upon by both the caregivers, who include the family members, and the clients. Fawcett (1989:3) argued that these models provide a distinctive frame of reference for their adherents, indicate to them what to look for, and determine how the community is viewed and what aspects of the community are to be taken into consideration, thus providing a "systematic structure and rationale" for activities.

The ideal would be if all home-based care programmes could be delivered via the integrated model as illustrated in Figure 2. This integrated model is particular significant to this research as it represents the focal point of this study and ensures that both patient and family members receive all the care and support they need from the point of diagnosis through to terminal care. Support is made available to the families when the patient dies. Moreover, this integrated model ensures that the quality of care is optimal, since there is regular supervision and support from the caregivers and the 'employing' non-governmental organisations (NGOs), which strive to improve care. As this model relies on high levels of recruitment and involvement, the single-service HBC model is used more frequently and this will continue until more partners can be recruited and formal structures are put in place.

At the time of writing, thousands of PLWA, and their families, are still not being cared for by a dedicated HBC team. Where such programmes have been implemented and evaluated, PWLA hope that their caregivers, as well as health service providers, will all be convinced of their intrinsic value. Within the home-based environment, there are many skilled and dedicated people who should be recognised and incorporated in both professional and community healthcare work.

2.3 Conclusion

Social development, fundamentally, is about social transformation and an enhancement in peoples' standards of living. There are several theories of development, of which the classical theories of modernisation and dependency, popular in the 1960s and 1970s respectively, no longer hold relevancy for development practitioners. This research has drawn on people-centred and participatory development to frame the theoretical context through which to view the research question.

The theoretical framework indicated that community participation is achieved and ensured through adopting a people-centred, participatory approach to development. A working explanation of the term *home-based care* was also presented in the chapter and the objectives, advantages and potential obstacles of home- based care examined. Finally, a comparison was made between hospital-based care and HBC in nursing people living with HIV/AIDS, and the personalised nature and cost-effectiveness that only home-based care can offer were stressed.

CHAPTER THREE: LITERATURE REVIEW

3. Introduction

The focus of this chapter is firstly to provide an overview of community participation in health. Thereafter, the South African legislative and policy framework will be outlined. The necessity of home-based care programmes in South Africa is supported by reference to literature reviewed on this topic. Furthermore, the HIV/AIDS and STI Strategic Plan for 2007-2011, which represents the country's multi-sectoral response to the challenge of HIV infection and the comprehensive impact of HIV/AIDS in South Africa, is discussed. Lastly, the literature review is used to examine the healthcare funding of the South African government, which forms the backbone of HIV/AIDS programmes.

3.1 Community participation in health

Some 30 years ago, the WHO (1978) stressed the essential principles of community involvement in health. Governments have accountability to the people, which can be fulfilled only by the provision of adequate healthcare and social measures. The WHO further maintained that primary care and other services of healthcare should meet up with the needs of all individuals, irrespective of their gender, age, status and socio-economic class. Communities, therefore, have the right and obligation to participate individually and vigorously in the preparation and execution of their own healthcare progammes (WHO, 1978).

Allender and Spradley (2005) believed that community involvement in health is a process by which "partnership is established between the government and local communities in the planning, implementation and utilisation of health activities in order to benefit from increased local self-reliance and social control over the infrastructure and technology of primary healthcare." Rifkin (1996) summarised the benefits which community participation can be expected to bring to primary health programmes. Firstly, people would make better use of existing health services and would ensure the sustainability of new services by being involved in decisions about their own development.

Secondly, people would be able to contribute resources such as money, labour and materials to support the scarce resources allocated to healthcare (Rifkin, 1996). Lastly, Lankester

(1994) suggested that people would change their poor health habits and behaviour if they were included in exploring the consequences. Community involvement in health thus implies co-operation among people in the community, community organisations, NGOs and health specialists, by which all role-players participate in the discussion of health matters, and, together, approve methods of how to tackle them. For Dennill et al. (1999), community involvement provides other important benefits such as constructing self-esteem and inspiring a sense of responsibility. Other scholars have stressed that as many health services in developing countries are contingent on restricted resources, local information and resources can be used to complement those provided by the formal health services (Marquis & Huston, 2000).

Wallerstein (1993) maintained that participatory development in health is a deliberate strategy which systematically endorses community participation and reinforces and supports societies in order to deliver better health care for the bulk of the people. The notion of greater involvement in the health sector was emphasised in the Declaration of Alma-Alta of 1978, and at the International Conference on Primary Healthcare in Russia in the same year, the need was expressed for serious action by all countries, all health and development employees and the world community to safeguard and ensure the health of people throughout the world (WHO, 1978).

According to the World Health Organisation (WHO, 1978:2).), the Declaration of Alma-Alta convincingly reaffirms that

> *health, which is a state of complete physical, mental and social well-being is a fundamental human right and that the attainment of the highest possible level of health is a most important social goal whose realisation requires the action of many other social and economic sectors in addition to the health sector … [and that] … the people have the right and the duty to participate individually and collectively in the planning and implementation of their healthcare.*

This declaration clearly emphasises that all governments must collaborate in determination, co-operation and assistance to guarantee primary healthcare for all individuals, since the achievement of health by individuals in any nation inevitability affects other governments. Oakdale and Kahssay (1999) pointed out that the Alma-Ata Declaration requires and

promotes maximum community and individual self-reliance and participation in the planning, organisation, operation and control of primary healthcare, making full use of local, national and other available resources and, to this end, develops, through appropriate education, the ability of communities to participate.

The Declaration contains a series of 22 recommendations to implement the participatory healthcare (PHC) approach. One recommendation the WHO (1978) makes is that governments should encourage and ensure full community participation through the effective propagation of relevant information, increased literacy, and the development of the necessary institutional arrangements through which individuals, families, and communities can assume responsibility for their health and well-being.

3.2 Community participation in South Africa: Legislative and policy framework

The birth of the new South Africa has accelerated the search for appropriate strategies to increase the participation of the public in all spheres of government. Community participation is essential in post-apartheid South Africa in terms of achieving government's aim of participatory democracy and bringing about transformation. The South African government is clearly committed to genuinely empowering citizens, through active participation and not token consultation. These forms of participation involves a variety of activities including democratic representative structures such as ward committees which are institutionalised mechanisms to engage with local citizens and gain their input in terms of development needs at community level. Public participation has been referred to by Masango (2002:52) as the "heart-beat of democracy" as it enables fostering awareness to communities' demands and assists the processes of policy implementation and community development. The following section will provide an outline of the legislative and policy framework which informs South Africa's vision for a participatory democracy and inclusion of the voice of its people in development initiatives.

3.2.1 Public participation

The constitution of the South African government provides a sound framework for taking legislative policies closer to the people. The participation of citizens in policy making and implementation is important to strengthen and deepen democratic governance. The significant documents reviewed for the purpose of this study include the Constitution (Act

108, 1996); the White Paper on Local Government (Act 117 of 1998) and the Municipal Systems Act (Act 32 of 2000), which will be discussed below.

The significance of public participation is captured in Section 195 (1) (e) of the Constitution, which states that people's needs must be responded to, and the public must be urged to participate in policymaking (RSA, 1996). Sections 59, 72 and 118 of the Constitution further mandate both the national and provincial levels of government to facilitate public participation. It is emphasised in the Constitution that active public participation will promote evidence-based policy making and responsive service delivery. The notion of public participation is articulated in Section 59 (1) (a) of the Constitution, which states that the national assembly must enable public involvement in the legislature and other developments of the assembly and its committee (RSA, 1996).

The White Paper on Local Government of 1998 does not only deal with a sectoral policy, but focuses on the entire sphere of local government. Local government is the sphere of government that is closest to communities and is responsible for the delivery of services and infrastructure that is necessary to people's well-being. Local government is assigned with assuring the growth and development of communities within its jurisdiction in a manner that encourages community participation and improves accountability.

Section B of the White Paper on Local Government Act 117 of 1998 (RSA, 1998) emphasises that municipalities should cultivate mechanisms to ensure citizen participation in policy initiation and construction, as well as the monitoring and evaluation of development initiatives. The Act further affirms that municipalities need to be mindful of divisions between organised civil society and local communities and seek to endorse the participation of marginalised and excluded groups in community processes (RSA, 1998).

This implies that municipalities must adopt comprehensive approaches to fostering community participation, including strategies aimed at removing obstacles to, and actively encouraging the participation of, marginalised groups in the local community (RSA, 1998). The White Paper on Local Government of 1998 particularly advocates support for the organisational development of associations, particularly in poor marginalised areas where the skills and resources for participation may be less developed than in more affluent areas (RSA, 1998).

Community involvement and inter-sectoral co-operation are both identified in local government legislation as the foundation of integrated development planning. This implies that local government is assigned to interact directly with its communities; this includes interacting on issues such as the delivery of housing and public healthcare. The Municipal Systems Act of 2000 emphasises the significance of community participation and inter-sectoral collaboration in local government affairs.

The promulgation of the Municipal Systems Act (Act 32 of 2000) further focuses attention of municipalities on the need to encourage the involvement of communities in the matters of the municipality (RSA, 2000). In Chapter 4 of the Act (Act 32 of 2000), it is stated that municipalities must develop a culture of municipal governance that will complement formal representative governance, together with a system of participatory governance. Furthermore, the municipality must purposefully encourage and create conditions for the local community to participate in the affairs of the municipality (RSA, 2000).

3.2.2 Health and participation

Health authority structures are one of the vehicles through which community participation can be achieved. According to Mantzaris and Ngcobo (2007) the basic philosophy of healthcare was the development of a comprehensive health strategy that not only provided health services but also addressed the underlying social economic and political causes of poor health.

The Department of Health (DOH) (2001) adopted a participatory approach in the healthcare sector and committed itself to providing services that will encourage, restore and uphold an individual's maximum level of well-being, function and health services. The purpose of including community healthcare in its strategy is to encourage community groups, families, neighbours or volunteers to assist with continuing home needs, thus encouraging participation in communities (DOH 2001). Currently, the Health Department (DOH, 2008) has endorsed the idea of community involvement and participation in its official policy document.

The Constitution of the Republic of South Africa (Act 108 of 1996) provides a number of important guidelines on health issues, and Sections 10 and 27 are of particular relevance to this study. In Section 27 of the Act, it is stated that everyone has the right to have access to

appropriate healthcare services, sufficient food and water, and social security, even when they are not able to support themselves and their families (RSA, 1996).

Furthermore, Section 27 of the Act indicates that the government is obliged to create legislative measures to recognise the rights of every citizen and ensure that there are adequate resources available. These resources should include access to medical treatment, transportation to health service points, support, food and shelter, including various other resources that may be of help to the disadvantaged and people living with HIV/AIDS, as well as to their families who are affected by the pandemic (RSA, 1996).

Section 10 of the Constitution focuses on the role of HIV/AIDS and home-based caregivers. The act stipulates that people living with AIDS (PLWA), their families and home-based caregivers are entitled to be handled with reverence and respect (RSA, 1996:2). Furthermore, the Constitution makes it clear that, as citizens of the Republic of South Africa, people living with HIV/AIDS have the right to be protected from any form of discrimination (RSA, 1996:3).

The essence of the National Health Act No 61 of 2003 is to regulate national health and to provide uniformity with regards to health services across the nation by constituting a national health structure. These structures include public and private providers of health services, setting out the rights and duties of healthcare providers, health workers, health establishments and users.

Section 7 of the National Health Act No 61 of 2003 indicates that health providers have to obtain the patient's consent before treatment and care can begin. This is important because not all AIDS patients want to make their status known at the start of the process. Another factor HBCs should consider is to ask the permission of the patient's relatives before the commencement of the homecare programme. PLWA also need to agree to and understand the role of the HBC that nurses and cares for them (DOH, 2003).

Section 49 of the National Health Act (Republic of South Africa) recommends that the district health councils implement programmes for the appropriate distribution of healthcare providers and health workers (DOH, 2003: 112). The Health Act further supports the creation

and implementation of healthcare programmes, thereby creating the provision of healthcare services to all (DOH, 2003:113).

With regard to Section 21 of the National Health Act, it is the responsibility of the Director General to facilitate engagement with the community to ensure effective planning, provision and evaluation of the health services. This will result in the community gaining an understanding of how the sick should be cared for in their communities (DOH, 2003:72).

3.3 Home-based care in South Africa

In South Africa, the awareness of the role of home-based care services and the need for these came about as a result of the rapid rate of growth of the HIV/Aids epidemic (Lankester, 1994). The high prevalence of HIV/Aids in South Africa has laid a burden on both the community clinics and the hospitals. The epidemic has resulted in overcrowding in hospitals, staff shortages, and a lack of resources for treatment and the purchase of drugs. The concept of home-based care is now closely associated with the HIV/Aids epidemic.

According to Van Rensburg (2004:90), early in the 1990s, the South African government demonstrated a commitment towards developing healthcare, namely accessibility, effectiveness, equity and acceptability. Similarly, Russell and Schneider (2000) noted that the provision of home-based care has grown rapidly since 1900, with guidelines having been developed and training provided for carers. The South African HBC Programme was launched at the Odi Stadium, Mabopane on 25 February 2004. At the time, the Minister of Health, Manto Tshabalala-Msimang (Tshabalala-Msimang, 2004:1) stated that the HBC programme's main objectives were to improve health service and promote health, but that the HBC programme could only be made possible if there were effective support and referral structures.

Scholars have observed that in most African countries, there are well-developed HBC programmes and systems, although access to these programmes is still not universal (Allender & Spradley, 2005; Fox, Fawcett, Kelly & Ntlabati, 2002; Uys, 2003). Russell and Schneider (2000:17) noted that HBC was identified by the National Convention of South Africa (NACOSA) as a vital strategy in addressing the social and personal impact of HIV/AIDS.

The specification of healthcare powers and procedures is derived from the Constitution. Nevertheless, the Constitution allows for the assignment or delegation of such powers and functions. This may permit the provision of primary healthcare at the local sphere of government, more accessible to the community, if the provincial government so intends.

The following section will address the HIV/AIDS and STI Strategic Plan for 2007-2011. This Strategic Plan 2007-2011 is a consequence of the National Strategic Plan 2000-2005. It represents the country's multi-sectoral response to the challenge of HIV infection and the comprehensive impact of HIV/AIDS in South Africa. Subsequently, the healthcare funding of the South African government, which forms the anchor of HIV/AIDS programmes will also be emphasised.

3.3.1 HIV/AIDS and STI Strategic Plan

In response to the escalating rate of HIV infections in South Africa, the government devised a strategic plan to fight the pandemic. In 2006, the South African National HIV/AIDS Council (SANAC), under the executive leadership of the then Chairperson, the Deputy President of South Africa Phumzile Mlambo-Ngcuka, mandated the DOH to guide the process of establishing the HIV/AIDS and STI Strategic Plan for 2007-2011 (DOH, 2007).

The HIV/AIDS and STI Strategic Plan 2007-2011 is a comprehensive national strategy to steer the country's reaction to the HIV/AIDS pandemic. This strategic plan clearly summaries that, at all levels, government structures are accountable for addressing the HIV/AIDS pandemic (DOH, 2007). It is also the role of each government department to have a focal team responsible for engaging in this process to ensure that there is an effective planning, budgeting and implementation process (DOH, 2007).

The primary aims of the plan are to decrease the impact of HIV/AIDS on individuals, families and communities. This also includes improving the care and treatment of AIDS patients in order to promote access to a better quality of life and limited hospital care, and to reduce the number of HIV infections by 50% (DOH, 2007).

3.3.2 Healthcare funding by government

Van Rensburg (2004:380) reported that a large proportion of healthcare funding comes from the South African government. He further stated that the government has allotted resources for healthcare with the purpose of providing for every home (Van Rensburg: 2004:382). The budget for healthcare continues to intensify as a consequence of the growing number of people affected by the pandemic. In order to ensure the sustainability of HBC in different communities, it is essential that efficient monetary backing be obtainable.

According to Hennessy and Spurgeon (2004), the lifeblood of healthcare organisations and structures of care is monetary feasibility. The future of HBC will be contingent on careful consideration of how finance is made available, and that health projects are planned on a long-term instead of a short-term basis. Therefore, it is vital that financial support for HIV/AIDS programmes is provided, because it is the backbone of such programmes.

3. 4 Conclusion

In this chapter, a synopsis of community participation in health has been presented and community participation within the constitutional framework of South Africa explained. Incorporating these policies into meaningful community projects and programmes will strengthen and enhance community participation in health. The significance of home-based care programmes in South Africa has also been emphasised, supported by relevant research reviews.

In addition, the HIV/AIDS and STI Strategic Plan for 2007-2011, which represents the country's multi-sectoral response to the challenge of HIV infection and the comprehensive impact of HIV/AIDS in South Africa was discussed in the literature review. Lastly the healthcare funding of the South African government, which forms the backbone of HIV/AIDS programmes, was emphasised. Therefore, using the literature review as a structural base, the function of the Dunoon community and the relevant stakeholders in the case study area will be discussed in the next chapter.

CHAPTER FOUR: OVERVIEW OF THE DUNOON COMMUNITY, THE HEAVENLY PROMISE NGO AND PARTNERSHIPS

4. Introduction

In this chapter, the socio-economic circumstances of the informal settlement of Dunoon, in the Western Cape, are highlighted. Chapter 4 will provide an overview of the Dunoon community, the Heavenly Promise HBC organisation, and the other HBC partnerships in the case study—the Project Management 4 Africa (PM4 Africa), Caltex/Chevron Refinery and the Department of Social Development (DSD). Furthermore, it proceeds with a description of Heavenly Promise HBC's structure, mission, policy and objectives. The chapter concludes with a discussion of the roles that PM4 Africa, Caltex/Chevron and the Department of Social Development play within their partnership with Heavenly Promise.

4.1 The Dunoon community

Dunoon is an informal settlement located to the east of Table View and north of Killarney Gardens, a few kilometers away from the Chevron Refinery. It falls under the jurisdiction of the Cape Town Magisterial District and is clustered together with the nearby "township" of Joe Slovo (see Appendix K).

For the past 30 years, there has been an influx of black Africans into Cape Town. The majority of these are predominantly isiXhosa-speaking new arrivals who have have migrated from the so-called previously independent homelands of the Eastern Cape (Transkei and Ciskei). According to Weaver (2004), an estimated 48,000 migrants move into the city every year, which Dreyer (2004) argued, contributes to the large number of informal settlements around the city of Cape Town.

4.1. History of Dunoon Township

Information provided by the Department of Provincial and Local Government (2007) shows that the majority of Dunoon residents come from Marconi Beam, a small shack settlement to the north of Cape Town. People had been squatting on the privately owned land on which Dunoon was built since the 1960s, and the number of shacks and residents mushroomed during the early 1990s. Milnerton Municipality, the local authority, temporarily succeeded in

having 20 to 30 dwellers evicted before the informal settlers won a court order preventing them from being evicted. Political tensions and sensitive negotiations during the 1990s made conditions unsuitable for the authorities to pursue any further action against the informal settlers; consequently, the settlement's rapid growth was allowed to continue unchecked (Saff, 1996).

In 1994, South Africa launched the Reconstruction and Development Programme (RDP) to address the needs of previously disadvantaged citizens, followed by a R1.5 billion housing development project for Dunoon the following year. A Marconi Beam trust was set up and people were re-housed in Dunoon despite objections from the white communities, and in particular from businessmen, who feared an increase in the number of burglaries.

Figure 3: High population density in the area

4.1.1 Socio-economic profile of the Dunoon residents

Lasserve (2006:1) stated that in "most cities, according to the United Nations Human Settlements Program (UN-Habitat), the worsening state of access to shelter and security of tenure results in severe overcrowding, homelessness, and environmental health problems." Consequently, the informal dwellers had no alternative but to depend on illegally occupying informal property as a safe haven, as has happened in Dunoon.

4.1.1.1 Economic activities

Like most of the informal settlements in South Africa, Dunoon is familiar with active and creative entrepreneurship projects by its local people. There are daily activities on the street corners such as the selling of raw meat (trotters and heads, which are specialties), live chickens, braai sausages, cigarettes, vegetables and fruit. Taverns, spaza shops, hairdressing salons, innovative car wash and taxi businesses are popular in Dunoon. Local businesses are engaged in the selling of building material such as bricks, windows and frames, timber and second-hand clothes. A number of shack dwellers are involved in forms of entrepreneurship such as cell phone, motor vehicle, punctured car-tyre and footwear repairs.

4.1.1.2 Employment

The various types of employment within and around Dunoon play a decisive part in the standard of living of its residents, most of whom are believed to be unemployed. It is, however, difficult to determine the level of unemployment in Dunoon, as indeed in most informal settlements, because of the continuous influx of people into the area.

According to Tex Dludla, project co-ordinator of the Masincedisane Advice Centre in Dunoon (personal communication with the author, 28 July 2010), the estimated unemployment figure in Dunoon is around 80%. The majority of the residents who are engaged in the public sector are either unqualified or have inadequate skills. The men in the community are employed as labourers in the surrounding industrial area, while the women are usually employed as domestic workers within the surrounding Blaauwberg and Table View areas. In most cases, the women are the primary breadwinners, often working long hours and spending a larger proportion of their income on their family in comparison to men.

The high incidence of unemployment and widespread poverty in Dunoon has an adverse effect on the development of the community and the Cape Town economy. The youth in Dunoon are particularly vulnerable, because lack of experience makes it even more difficult for them to find employment, with a result that they often resort to prostitution and other forms of crime in order to survive.

4.1.1.3 Housing

The research study area encompasses a considerable number of shacks and a limited number of brick houses. The shacks are a depiction of a creative and skilful method of building a home using reprocessed material, for example newspaper, plastic, second-hand timber, cardboard and metal sheets that are obtainable from rubbish-dump sites or purchased from informal traders. The shacks vary in size and quality; some are small, slanted shacks, ill-equipped to withstand the rainy, wet weather of the Western Cape, others are larger, and a few double-storied structures with a satellite dish (See Figure 3) generally belong to tavern owners and drug merchants in the community.

On the one hand, the lack of irrigation and suitable sewage aggravates the present health dangers in the community, leading to an increase in the mortality rate; on the other hand, the lack of electricity in the settlement enables burglary and other forms of criminality.

4.1.1.4 Health

Dunoon is serviced by a small municipal health clinic which only began functioning in 2005. The clinic is built on an old building-construction site and offers services such as childcare, family planning, TB treatment, cervical smears, diagnosing and medication of sexually transmitted infections, and HIV testing. Of the patients 75% are female and 25% are male.

On a daily basis, prior to the consultations, the health personnel provide health training on the prevention of HIV/AIDS to alleviate the frustration and suffering caused by the condition. The most common diseases are tuberculosis and the opportunistic diseases associated with HIV infection among adults (interview with a community health worker on 28 July 2010). Owing to the limited health services on offer, local residents have to travel long distances to receive other medical treatment in Table View or Milnerton, or at the nearest day hospital in Brooklyn, approximately 15 km away. Public transport is expensive and Dunoon residents use taxis to visit a hospital, which usually takes them the whole day. In addition to treating the diseases previously mentioned, the local clinic also has to deal with the challenge of teenage pregnancies.

Inadequate housing conditions in Dunoon include overcrowding and high-density living, which are stressful because they limit personal autonomy and expression and break down

communication patterns. The appalling housing conditions in Dunoon, including absence of important amenities combined with impoverishment, are the primary causes of health problems in the community. As shacks tend to have damp walls and floors, particularly in winter, the shack dwellers are frequently more vulnerable to infections than the affluent. The World Health Organization (2001) noted that deficient housing environments may deliver weak resistance against infections, injury and death, and may even increase susceptibility to them.

In addition, poor insulation in Dunoon permits dirt, rain, bugs and rodents to infiltrate the shacks; and poor ventilation in overcrowded conditions increases the risk of inhaling the airborne droplets which spread TB and other infectious diseases. These conditions are closely linked to inadequate housing and congestion in the community. Baum (2008) stated that unemployed people suffer worse health than those in employment, and that the poverty and stress afflicting the unemployed cause them to lose social status, social contact and their reason for living.

Uys (2003) suggested that lack of food or an unbalanced diet is a major problem associated with poverty, as low income significantly affects food choices and nutrition, stunts growth and development, and leads to various diseases. Baum (2008) argued that a high-level proportion of HIV/AIDS and TB is detected amongst toddlers varying from 0-4 years. Perhaps still more startling than the figured for TB is the escalation of HIV-positive individuals in Dunoon.

4.1.1.5 Education

The majority of people in Dunoon are poorly educated and have a lack of the expertise required in the present commercial workplace. As unskilled workers supply the majority of the workforce for the Metropolitan area, they are frequently exploited by companies due to a minimal level of literacy.

Dunoon has three schools: one secondary school and two primary schools. Crèches and play-schools, as in most communities, are associated with primary schools and function similarly to kindergartens, but other informal crèches have flourished in Dunoon due to mothers having to seek employment.

Although there are two primary schools and a new high school, there is a lack of educational facilities such as libraries, after-school care, swimming-pools and other appropriate educational community facilities. The illiteracy rate is very high due to school dropouts and child-headed households.

4.2 The Heavenly Promise home-based care organisation

Heavenly Promise HBC is a non-profit, non-partisan, non-governmental organisation, which operates in the Dunoon community. It was established purely to address the HIV/AIDS crisis in the community and has been involved in various community activities and programmes in the Dunoon area for a number of years. The majority of these programmes focus on issues such as healthcare, education, and poverty-relief in the community. Furthermore, as a result of the close contact that one of directors of Heavenly Promise had with the local community, it was soon realised that the HIV infection rate and the number of people living with AIDS had reached pandemic proportions, and that the resources available to deal with the effects of the condition were limited, often non-existent and poorly co-ordinated.

Consequently, around 2007, and in response to the HIV/AIDS pandemic, local women joined forces together with representatives of various organisations from the Parklands area, including local health workers, government departments and others, in the hope of initiating a holistic assault on the HIV/AIDS pandemic, while recognising the limited resources available in the area.

One of the directors of the Heavenly Promise Organisation, Enid Sithole affirmed that, in order to fast-track this project of trying to alleviate poverty and the suffering of the community and its people, key role players were referred to the organisation, given that they had experience working with the community and its people (Sithole, 2010). The Heavenly Promise Organisation was therefore formally conceptualised in 2007, and was managed under the auspices of the Department of Social Development in the Western Province of South Africa.

4.2.1 Vision and mission of Heavenly Promise

Sithole (personal communication with the author, 28 July 2010) states that the vision of Heavenly Promise HBC is to

> *endorse and preserve the individuality and well-being of people and families in Dunoon by producing to the community a synchronized and inclusive selection of healthcare and basic services that fulfill their needs.*

Community-based outreach programmes, providing home-based care and education in the home and in the community, using volunteers, are also included in this. The Heavenly Promise programme has adopted a community-driven approach to HBC. According to the DOH (2002), the community-driven model is essentially based on the premise of integrated service provision through community and locally driven initiatives. Furthermore, unlike other models, where there is a central structure or co-ordinating organisation, this model does not necessarily need to be attached to a community structure or organisation (DOH, 2002).

According to Sithole (personal communication with the author, 28 July 2010), the mission of Heavenly Promise is

> *to seek a safe, caring community of hope by offering a variety of HIV services for PLWA, safeguard the weak, encourage resilient and empower community, and promote personal and family strength.*

As an organisation, Heavenly Promise offers HBC services, hope and support to PLWA. Heavenly Promise does its work by making it possible for its members to become responsible role models in responding to the pandemic in Dunoon, the Western Cape and South Africa.

4.2.2 Roles and responsibility of Heavenly Promise

The structure of the organisation is hierarchical, with power and control of the organisation vested in the hands of the board of Heavenly Promise, who are responsible for making all decisions in the organisation. The board is comprised of a group of elected individuals whose primary responsibility is to act in the organisation's interest and decide on policy and strategy that are delegated to the directors of the organisation. Their role is to support and oversee the projects of the NGO and to serve as guardians of the Heavenly Promise programme. The board also determines the outcome of projects and provides direction on how the projects should operate within the HIV/AIDS programme. Overall, the board needs to be effective in ensuring an accessible and responsive means of service accountability to the local community of Dunoon.

The directors are the founders of the NGO and are responsible for the maintenance of the HIV/AIDS projects within the community and the routine operation of the organisation. It is the duty of the directors to promote and champion the projects and to provide advice to the supervisor and caregivers. Similarly, the directors are responsible for the election of tasks and collection of all operating developments that are seen as suitable methods in achieving the goal of the organisation. They report formally to the board of directors on a monthly or quarterly basis.

The directors of Heavenly Promise receive their authority from the board to run the organisation. They need to be informed of everything that is happening in the organisation, which includes budgets, organisational assets and all other resources, and how to effectively utilise these assets in order to raise the organisation's effectiveness and profile. In addition, the directors also guarantee that their caregivers are properly remunerated and that their annual leave is respected.

It is the role of the directors to motivate and encourage the caregivers in order to create a sense of appreciation. The directors ensure that an atmosphere of high morale and self-confidence exists within the organisation so that the supervisor and caregivers at every level are aware that their work is recognised and important. Consequently, their duties entail ensuring that the caregivers have comprehensive community assessment knowledge so that they become well acquainted with the community they will be working with.

The supervisor of the organisation serves as the key informant for the project programme in Dunoon. Her role as supervisor involves acting as the liaison between the caregivers and the partnership as a whole. Her further responsibilities are to create a supportive environment for the caregivers to work in by ensuring that a good network system exists. Other information provided by the respondent indicates that she consciously tries to make every effort to keep the stress of the staff within reasonable limits and therefore has an important function in being responsible for the caregivers' welfare. Consequently, the caregivers know where to go for help and when to refer a client to the supervisor.

The caregivers of Heavenly Promise are primarily responsible for comprehensive social services through community care-giving in the homes in the Dunoon community in order to promote among PLWA a maximum level of comfort, including care towards a dignified

death. The home visits, which are an essential ingredient of the integrated home-based care model, promote the health of individuals and families.

Caregivers are tasked with the duty of delivering soup to the patients five days a week and providing some basic care, such as washing the patients and helping to clean their beds and sometimes feeding them. The caregivers' role is to empower the community, to support people living with HIV/AIDS and their relatives, and to effectively manage the physical, physiological and spiritual needs of PLWA in Dunoon.

Furthermore, the caregivers' function is to support PLWA families in their care-giving role and to lessen the individual and social effect the pandemic has on the community. Lastly, they are expected to prevent diseases such as tuberculosis, cholera and other acute intestinal infections in the home through the education of clients and the PLWA family and by means of referrals to the clinic for immunisation where necessary.

The kitchen cooks are responsible for the daily cooking of meals at the soup kitchen centre. Caregivers are then tasked with the duty of delivering the soup to the homebound AIDS patients, five days a week. The kitchen cooks' function in the HIV/Programme is crucial as they provide daily nutritional meals to between 100 and 150 people in Dunoon.

4.3 Partnerships within the Dunoon community

Community participation in health is a procedure in which partnerships are constituted between authority and local community organisations in the preparation, execution and operation of health services. Fonaroff (1983) observed that the benefits of such partnerships include improved local self-dependence and social control over the infrastructure and technology of principal healthcare. In many instances, HBC programmes usually come about through partnership and joint sponsorship of programmes. Government and NGOs frequently develop partnerships to fund and assist HBC organisations. In addition, community-based organisations and the private sector also join forces in supporting HBC. Members of HBC teams are generally actively involved in establishing and maintaining these partnerships. Peu (2008) maintained that HBC members frequently require technical support to assist in compiling proposals and negotiating contracts, as well as in building capacity in terms of the

accounting and administration skills required for the planning and implementation of projects.

4.3.1 The Chevron community advisory panel

It is necessary firstly to briefly explore the wider network in which Heavenly Promise and Chevron operate. Although Heavenly Promise and Chevron Refinery are partners in the fight against HIV/AIDS in Dunoon, they are also a collective partnership that forms part of the broader community within the jurisdiction of the Blaauwberg Municipality, known as the Chevron Community Advisory Panel (CCAP). The function of the CCAP is to facilitate communication between the Chevron Refinery and neighbouring communities. It serves to identify and participate in resolving issues of mutual concern. This partnership was formed in February 2008 to build trust between the community and Chevron Refinery, and no political parties or political or religious organisations may be represented on the CCAP.

The advisory panel acts as a liaison between the Refinery and the communities, sharing information in an open, transparent manner. It focuses on issues of mutual interest (for example, the environment, crime, unemployment, safety, risk) and works on resolving these matters. Another key objective is building a healthy relationship between the Refinery and the neighbouring communities. The advisory panel also provides feedback to the Refinery on ways to improve communication with the community, as well as providing valid information to the community on how to respond in an emergency situation. Membership is open to bona fide, constitutionalised community or business organisations from the following communities: Milnerton, Parklands, Joe Slovo Park, Doornbach, Dunoon, Edgemead, Richwood, and Bothasig.

4.3.2 Caltex/Chevron Refinery

Chevron is one of the leading refiners and marketers of oil products in South Africa, and operates a refinery in Milnerton, Cape Town, which manufactures petrol, diesel, paraffin, fuel oil and other products. The Chevron philosophy focuses on investing in people, partnerships and performance. The company's social investment programme in South Africa promotes sustained economic growth, and focuses on education and training, HIV/ AIDS awareness, and community development.

In 2009, Chevron approved the construction of a kitchen on a primary school property to prepare nutritious meals for bed-ridden HIV/AIDS patients. The intention is for 10 home-based caregivers to cook meals in the kitchen and do daily home visits to provide meals to approximately 200-300 patients as well as assist with basic household chores. Chevron plans to expand the current 10 HBC-givers to 50, reaching approximately 1500 patients per week. The kitchen facility aims to serve as a training venue at night for AIDS/HIV-related community training/peer groups.

Figure 4: The soup kitchen

Figure 5: A look inside the new soup kitchen

4.3.3 Project Management 4 Africa

The project manager of Project Management for Africa (PM4 Africa) is the person responsible for achieving Heavenly Promise's project objectives. Chevron, the project sponsor and principal stakeholder, assigned PM4 Africa to this project in 2007. The project manager has 20 years' experience in project management and has specialised in information technology. PM4 Africa, as part of its social responsibility initiative, has taken on the project of working for previously disadvantaged persons in informal settlements.

According to the project manager Mr R Brown (personal interview on 23 July 2010), the PM4 Africa mission is to significantly increase the awareness of the importance of project management as a life skill by means of transferring skills to the project participants of community-based projects in previously disadvantaged areas such as Dunoon. This will ensure that the individuals and communities are more likely to take control of their own future rather than depending on government to sustain them. The project manager believes that empowerment of the previously disadvantaged in Dunoon can lead to the alleviation of poverty in Africa. Project management as a life skill is an effective method of enabling empowerment. Mr Brown argued that project-based learning is the best method to teach project management as a life skill and simultaneously PM4 Africa engages with corporate clients through their corporate social investment business units. In addition, PM4 Africa acts

as the implementer of its community engagement programme and offers project management as a life skill to all project participants.

4.3.4 Department of Social Development

In 2009, the Western Cape Department of Social Development (DSD) collaborated with Heavenly Promise to combat the increasing number of HIV/AIDS instances in the Dunoon community. The HIV/AIDS programme is significant to the DSD and, in partnership with Heavenly Promise, helps in developing social amenities for people affected by HIV/AIDS. The department's intention is to join families to a variety of applicable incorporated facilities throughout DSD programmes and other departments within their community, such as housing, healthcare, community safety and education (Department of Social Development, 2009).

The DSD provides the caregivers with two days of training on minimum norms and standards, which includes the code of conduct for HBC and networking the HBC team to other role players within the community. The department also facilitates and co-ordinates family consolidation programmes for relatives infected with and affected by HIV/AIDS and ensures that caregivers obtain recognised capability building programmes are subsidised correctly and provide excellent services (Department of Social Development, 2009). Caregivers are unemployed volunteers who receive a small stipend of R720 per month from the DSD.

4.4 Conclusion

This chapter provided an overview of the socio-economic profile of the Dunoon community, Heavenly Promise, Caltex Chevron, PM4 Africa and the DSD. The project and context in which the project was established has been described, including the organisational structure. The Heavenly Promise HBC group is part of a CCAP programme. Hence, an overview of the CCAP mission, objectives, and the roles and responsibilities of the programme and project approach were provided. The latter descriptions serve to provide an insight into the empirical fieldwork and research findings presented in the following chapter.

CHAPTER FIVE: DISCUSSIONS OF RESEARCH RESULTS

5. Introduction

Theron (2005) views participation as a structured endeavour wherein a group of persons stand in an affiliation with the government in order to gain access to resources and development programmes and projects. The origin of community development initiatives for programmes must be based on the beneficiaries' own thinking and deliberations. Therefore, beneficiaries take control of the development process, and the needs of a particular group of people, called a *community*, lie at the heart of the programme. De Beer and Swanepoel (2006:8) argued that participation is a process of initiating community-based development though projects with local members and is aimed at empowering communities, ensuring sustainability, building self-reliance and thereby releasing them from the poverty trap.

With this in mind, the research findings of the study regarding the extent and nature of community participation in Dunoon and the role and function of Heavenly Promise, the organisation that provides caregivers to the wider community, will be presented in this chapter. The analysis will firstly focus on the participatory role of community members in the case study area. Attention will then shift to the Heavenly Promise organisation in order to examine the function and responsibilities of the different categories of staff to the community.

Finally, the participation and contribution of partner organisations in Dunoon will be explored. The research findings will be based on the analysis of data collected through observation and the use of semi-structured interviews. The chapter is divided into three sections in accordance with the different categories of respondents that were targeted by the research, namely the role of the community, the role of the Heavenly Promise home-based care organisation, and the partner organisations discussed in Chapter 4.

5.1 The role of community residents

This section provides empirical information gleaned from the data collected during the research study with regard to the nature and extent of participation of community residents, which, it is hoped, will offer insight into the community's knowledge and understanding of the concept and process of participation.

This first category of respondents includes 30 community members from the Dunoon case study area. The semi-structured interviews focused on the members' participation within the local community and their level of involvement in decision-making processes regarding their health in the community. Other information gathered from respondents focused on the community's active involvement in HIV/AIDS campaigns, as well as their level of knowledge of HIV/AIDS and the methods used to combat its prevalence in the community (see Appendix B).

5.1.1 Community organisations and participatory structures in Dunoon

A number of community organisations operate in Dunoon. In addition to the Heavenly Promise NGO, which is the focus of this research, two other home-based care organisations operate in Dunoon, namely St John's and Zusakhe. Both of these organisations operate in a similar manner to Heavenly Promise in providing voluntary and health education, in the home and in the community.

In Dunoon, eight community development workers (CDWs) operate from the Masincedisane Advice Office. These CDWs are community-based individuals who work together with other district members to assist local community members to acquire information material, such as background and statistical information from service suppliers with the intention of educating them about how to interpret their needs, understand their ambitions and sustain their welfare. Furthermore, the CDWs' role is to inform and create awareness among the communities regarding available resources and services, and to attend to problems raised by community members (Mr. Tex Dludla. Personal communication with the author, 28 July 2010).

The South African National Civic Organization (SANCO) plays a vital role in Dunoon and was established initially to attempt to address the backlog in the housing sector. SANCO is a decentralised, local grassroots civic structure and works at different levels within communities. SANCO's executive committee is composed of residents who are elected by and accountable to the local community and whose main function is to address local issues and conditions. Furthermore, SANCO functions outside of governmental organisations and political parties and exists as an alternative to statutory structures.

The Dunoon Masincedisane Advice Centre is an information hub, which acts as a participatory structure where community members can express their views and concerns through community meetings. The role of the advice centre is to create an opportunity for local residents to improve their lives through access to information. The advice centre acts as a link between the government, various organisations and the community in order to offer assistance with social problems, acting as a proponent for community participation. Local government therefore utilises the advice centre in dealing with the community. Other non-governmental organisations such as the Black Slash and St John's home-based care also use the centre for training and awareness programmes.

The project co-ordinator of the advice centre, Tex Mboniseni Dludla, who was interviewed during the study, is convinced that access to information helps to educate the community. Therefore, the centre also makes its facilities available for community projects, which encourages community participation. One voluntary female respondent who participated in the research study reported having established a senior citizen's club at the centre, which runs two skills development workshops each week to train elderly women to create handbags and pillow-cases out of recycled material.

5.1.2 Community participation in Dunoon

The local municipality in Dunoon runs campaigns to ensure that people living with HIV/AIDS have access to anti-retroviral medication and treatment, and to prevent new infections. In addition, it also runs a literacy programme to educate people living with or at risk of contracting HIV/AIDS, their family and friends about the prevention and treatment of the disease. This is in line with the aims of the World Health Organisation (1978:2) as stated by the authors of the report:

> *Physical wellness, which is a specification of comprehensive physical, psychological and social well-being is a primary human right and that the accomplishment of the maximum possible level of health is a most essential social objective whose comprehension necessitates the achievement of several other social and economic sectors in addition to the health sector and that the communities have the right and the responsibility to partake*

discretely and co-operatively in the development and execution of their health-care.

Semi-structured interviews were conducted to collect data from the community members relating to the nature and extent of participation in the case study area. The interviews contained closed- and open-ended questions. A total of 30 interviews were held with community members of the Dunoon community.

When asked if they attended any HIV/AIDS campaigns in the community, 66.3% of the respondents said they never attended any, while 43.7% said they did. One respondent noted that "*the community doesn't bother any more as they say it is just another HIV/AIDS awareness campaign*". Another respondent claimed that the municipal clinic does not collaborate with the people at grassroots level: "*If the clinic comes with their HIV/AIDS campaigns to the community, they approach us with their strategies and plan of action, and never consider our thoughts and proposals*."

These findings fit in well with Cornwall and Pratt's (2003) research which reveals that in many cases decisions are made by actors behind closed doors, without pretence of broadening the boundaries for inclusion. These "closed" spaces are selectively restricted to bureaucratic power-holders, whereas others are excluded, and this does not lead to the empowerment of people in the community or to the sustainability of projects. Oakley (1991) reiterated this view, in his book *Projects with people*, that in many supposed Third World countries, indigenous people have for decades been subjugated by aristocratic groups.

However, one respondent appreciated the clinic's awareness campaigns, stating: "*I now understand the importance of how the ARV treatment works, as my sister is HIV-positive*." In this regard, De Beer and Swanepoel (2006:8) explained that, when community involvement is promoted, co-operation is fostered and positive change can be observed.

With regard to understanding the concept of participation, a total of 28% of respondents understood that community participation is the active involvement of the community in decision-making processes in collaboration with health authorities. One HIV-positive respondent explained: "*Now that I'm HIV-positive, it is my duty to stay informed and to work alongside the municipality to effectively combat HIV/AIDS*." Another respondent, who had

lost a family member to HIV/AIDS, emphasised that members of the community need to "*stand up and join hands with the local clinic if we want to conquer this disease*".

Whilst 8% of the respondents had no idea what community participation meant, 64% of respondents regarded it as unnecessary. The majority considered community participation as unnecessary as they viewed Dunoon as a place of mere survival. An unemployed single-parent respondent remarked, "*My concern is that my children remain in school, therefore I focus all my attention on raising them, and not community matters*." These findings are disconcerting as they corroborate Brenner's (1993:56) warning that unemployment and the lack of access to sustainable livelihoods are often accompanied by increases in certain types of dysfunctional conduct, such as depression, suicide, delinquency, and participating in hazardous sexual behaviour that leads to HIV infections.

The interview results indicated that all nine employed respondents actively participated in the community and this group clearly had a far greater sense of hope and optimism towards the community than the 21 unemployed respondents. One respondent, who is a computer technician, enthusiastically described his involvement with the arts, dancing and hip hop music in Dunoon. Another female respondent, who is employed at Woolworths, stated that she is involved with a group of physically challenged persons in the area. "*Once a week I visit the disabled group and assist the staff in bathing the disabled*", she added.

A number of employed respondents belong to football clubs and a few run programmes to recruit and teach young boys in the community football skills. One male respondent, who works as an operator at a nearby factory, mentioned his active involvement in coaching boys' football: "*These boys need role models in the community and often I make financial contributions to see that the football club in Dunoon excels*."

The other 21 unemployed respondents were not so positive in terms of community participation. The unemployment status in Dunoon clearly determines the individual's opportunities for participation in their community. One respondent said, "*I need employment and food in my house, therefore I don't care what goes on in the community*." Chambers (1984:109) elucidated what he identified as the deficiency trap. He expounded how many effects of poverty have lead to a ferocious cycle whereby the poor are ensnared in a situation of poverty from which it is extremely difficult to escape. He argued that the poverty situation

in informal settlements has many consequences, what he called "clusters of disadvantages". These groups interrelate with one another and this interaction is what leads to the deprivation trap. Chambers identified five intertwined clusters of disadvantages that characterise the lives of the poor in informal settlements: poverty, physical weakness, isolation, vulnerability, and powerlessness. These disadvantages cause the poor and unemployed to hardly ever participate in community programmes.

5.1.3 Community sense of belonging and community pride

The data reveals that community members who participate actively in community initiatives have a stronger sense of belonging than those who do not. Figure 6 shows the sense of belonging within Dumont, as perceived by the community.

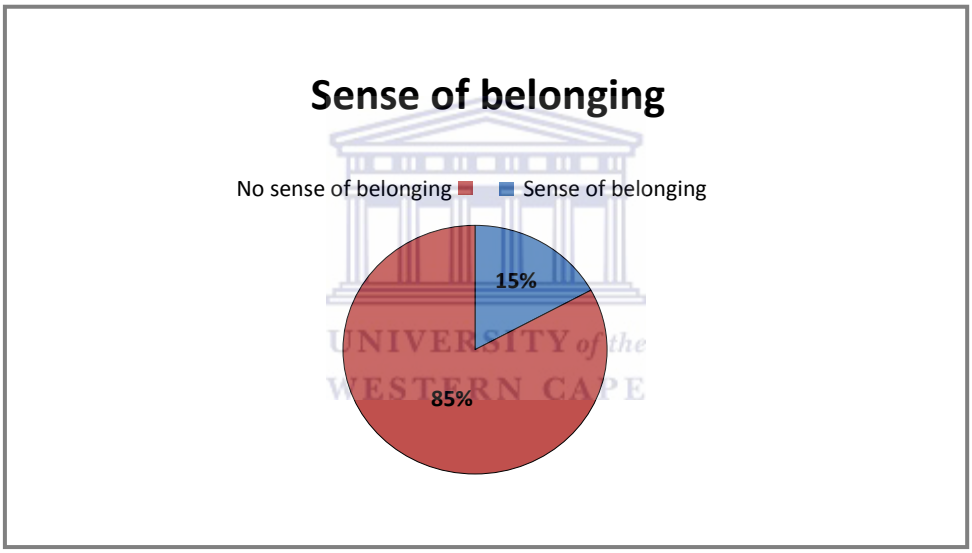

Figure 6: Respondents' sense of belonging

A total of 85% of respondents indicated that they did not have a sense of belonging to their community. One of the reasons given was the dangerously high levels of crime in the area. A few respondents described how they had been robbed, stabbed and threatened. One respondent, who earns his livelihood selling sweets and fruit, explained how he had been robbed and humiliated by a mob of youngsters. Other reasons cited were rampant unemployment and lack of housing. "*I feel dehumanised living in this matchbox (informal house)*", replied one respondent. "*We cannot afford to hang out our washing overnight and dare not leave our houses unattended*", another respondent remarked.

An elderly woman, when asked if she had a sense of belonging in the area, stated "*Dunoon, hayikhona* ["Dunoon, never"], *we as elderly people feel unsafe*." She stated that the young have no respect for the senior citizens, who fear the youth. An unemployed interviewee stated: "*Maybe I should move to Khayelitsha or Gugulethu; I hate this place*". The reason why the majority of interviewees had no sense of belonging, and did not participate in community matters, can be attributed to the fact that the majority of Dunoon residents are unemployed, have little, if any money, and are struggling to survive.

Figure 7 represents the sense of community pride of the Dunoon respondents. A total of 83% of the respondents stated that they were not proud of the community, and only 17% indicated that they were proud of the community despite facing immense challenges in Dunoon. One of the reasons for this lack of pride relates to the visibly polluted community environment. During the observation phase, it was noted that residents dump their rubbish, for example, cans, carrier bags and household refuse, in the streets throughout the community.

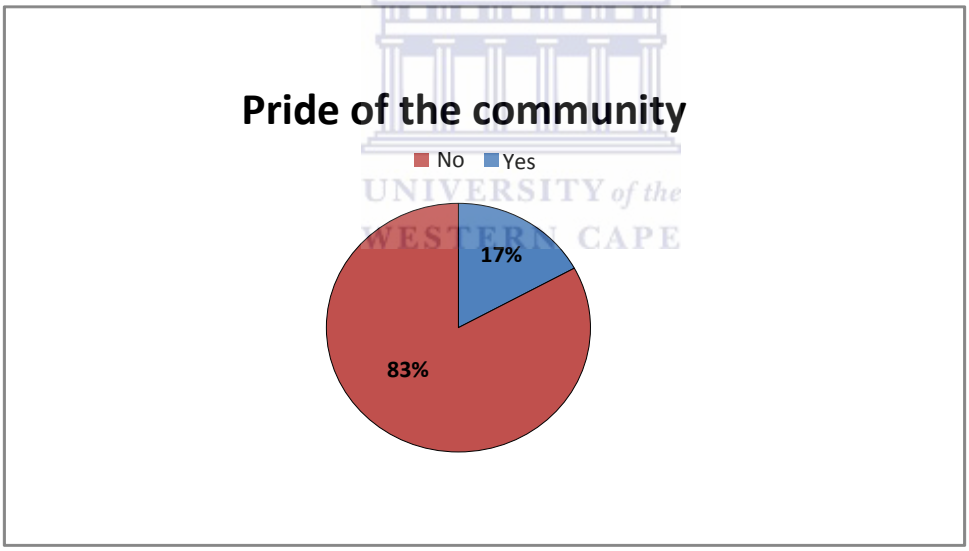

Figure 7: Dunoon respondents' sense of community pride

Interviews revealed that community pride in Dunoon was strongly linked to the poor conditions experienced by residents in the community. Respondents were clearly very dissatisfied with service delivery processes in the community. One respondent felt that Dunoon is not fit for habitation as it is an industrial area with a high population, and remarked: "*I want to move to Delft. It is better there.*" Another respondent commented, "*This is just a place of survival*", and said she could see herself leaving the area within the next two

years. Oakley (1991: 13) claimed that this mind-set is further reinforced by the fact that mere "existence is for most residents their ultimate challenge and exhausts much of their energies, leaving them barely opportunity to participate in health matters".

However, two respondents mentioned that they have better access to facilities such as health and education in Dunoon than in the Eastern Cape. One respondent, who was born in Dunoon, reasoned that "*looking back from where the area comes from, it is only fair to acknowledge that a good task has been accomplished in the area. All the basic needs of our people have been provided for in a small space of time*".

5.1.4 Community perception with regards to HIV/AIDS

A variety of suggestions were offered on how to reduce the number of people living with HIV/AIDS in the community. One respondent said that if the community adhered to the government's "Abstinence, Be Faithful, Condomise" (ABC) approach, it would reduce the incidence of the pandemic in the area. Another respondent reiterated that "*condoms should be placed at strategic points such as public toilets and shebeens,* (unlicensed drinking establishments) *to ensure our community practices safer sex*". Yet another respondent stated that the message of the Love Life Campaign is not distinct enough and noted that: "*Young people are not urged to abstain from sex until marriage; sex is God-given but should be practiced only in the framework of a spousal relationship (marriage), and remaining faithful to your spouse is therefore the solution for the AIDS pandemic*".

Other respondents indicated that young people flock to the shebeens and when they become inebriated, all morals seem to desert them. Alcohol encourages sexual risk-taking, together with encouraging sexual craving. One male respondent stated that "*in that respect there are some women in the community who do not sexually conduct themselves appropriately due to alcohol. As soon as they are under the influence, they are unable to think rationally, and turn into victims of exploitation, ending up HIV positive, not knowing who they had sex with*".

Another respondent claimed that unemployment seemed to be a great concern as "*coming to taverns is connected with sexual trade as a merchandise of financial difficulty, several teenage girls visit our taverns for fund-raising because of their social circumstances, in order to acquire alcohol and money in exchange for sex*". Menda (2006:23) considered that

women's vulnerability stems from an inferior power, unlike men whose vulnerability to HIV transmission is caused by their masculine power, predominantly explained by the dominant role of male sexuality, which is often characterised as natural, spontaneous and initiatory, and expected to be more energetic and dominant. Furthermore, Menda (2006) contended that females' financial dependence on males strengthens their susceptibility to HIV/STI infection by increasing the likelihood that they will exchange sex for money or favours and by decreasing the likelihood of them succeeding in negotiating protection against highly risky sexual practices.

5.2 The role of the Heavenly Promise home-based care organisation

The second category of respondents included the different levels of staff of the Heavenly Promise home-based care (HBC) organisation. The role of the home-based care workers, the function and responsibilities of the supervisor of the organisation and, finally, the role of the directors of Heavenly Promise will be examined in this section.

5.2.1 Home-based care workers

Ten home-based care workers, employed by the Heavenly Promise HBC organisation, were targeted in order to examine their role and function in the organisation and the community. Focused in-depth interviews were conducted with each worker in order to provide background information about the home-based care project. The sample population group was exclusively African. Although all the participants' mother tongue was isiXhosa, they were able to converse in English.

The interview schedule also included open-ended questions in order to gather in-depth data about the types of emotional and psychological support being provided by and for the caregivers at the Heavenly Promise HIV/AIDS Programme, the degree and extent of their training, as well as the type of issues that they have to deal with on a daily basis (see Appendix C).

5.2.1.1 Motivation for the participation of home-based caregivers

Of the 10 caregivers interviewed, 80% stated that the reason for their participation in the community health service was the personal loss of a family member in their household due to HIV/AIDS. Their participation in the community has been on-going throughout both the

project and operations management phases, and this is one of the key factors which sustain the programme. Paul (1987:36) associated sustainability with "continuity" and saw participation as important in fostering a self-sustaining impetus of growth in a specific capacity. Likewise, Rahman (1987:37) noted that "participation intensifies the effectiveness of developments as mechanisms of community development." He further claimed that, if partaking permits people to have an influence in "influencing objectives, supporting project administration and making their local knowledge, skills and resources more available, it will result in more effective projects".

The respondents noted that when their family members were initially diagnosed with HIV, care givers were ignorant of the disease and some of the care givers were even discriminated against. However, this stance has since changed and their involvement in community health services has significantly improved their knowledge about HIV/AIDS and skills in dealing with people living with HIV/AIDS, thereby strengthening their ability to determine their own values and priorities, and to organise themselves to take action regarding health matters. For the remaining 20%, employment was the overriding motivation for participating in community health.

However, 100% of the caregivers interviewed indicated that they had not participated in any decision-making process concerning the establishment of the partnership during either the implementation or the construction of the soup kitchen. When asked if they participated in any decision making at all, they stated that they never attended any of the planned meetings organised by the directors of Heavenly Promise. Most of the information they received only became available after the directors had held meetings with other relevant stakeholders.

The spaces in which individuals are capable of participating are of essential importance in development and democratisation. These findings are in line with what Cornwall and Pratt (2003) referred to as "closed spaces", where that many decisions are made by actors behind closed doors, without pretence of broadening the boundaries for inclusion. Closed spaces are selectively restricted to bureaucratic power-holders, whereas others are excluded.

Furthermore, the organisational structure of Heavenly Promise is clearly hierarchical and follows a top-down approach in terms of decision making within the organisation. Arnstein (cited in Baum 2008:479) voiced her concern in this regard and stated that "the idea of

hierarchical participation has often been used in health to distinguish genuine from pseudo-participation." Baum (2008) argued that a bottom-up decision-making approach is a decisive form of participation and has great potential for power sharing. The benefits of true participation lead to the empowerment of communities through the building of skills and capacity and enhance the sustainability of projects. These findings are in line with Rifkin and Cassels's (1996:39) belief that participation in development initiatives can lead to the following:

- Compliance: people are motivated to accept interventions, or act according to the advice of professionals.
- Contribution: the community supplements the contributions of professionals.
- Collaboration: the community participates in planning and introducing initiative.
- Control: the community controls the activities and available resources by the communities.

5.2.1.2 The relationship among the Dunoon Clinic and local community

During the observation phase, it was notable that there was minimal collaboration between the HBC and the local municipal clinic of Dunoon. This is not in accordance with the National Health Act No 61 of 2003 (DOH, 2003), which specifies that local municipalities should engage with the community and community organisations to ensure effective planning, provision and evaluation of health services. All the caregivers reported having an essentially negative relationship with the staff at the Dunoon clinic. One respondent stated that HBC-givers are not treated as professionals and they have to queue for hours even while wearing their visible HBC identification badge: "*They treat us as patients and it is not a pleasure to go into the clinic, and we only go there because of our patients*." These findings are of concern as, besides the fact that the Dunoon Clinic has shown no interest in joining the partnership, it should be playing a prominent role in the community as a government instituted health provider in terms of supporting the Heavenly Promise HBC.

The reports from the Department of Health (DOH, 2001), in contrast, have clearly stated and documented its commitment to participation in healthcare by all stakeholders. DOH policy documents highlight its members' determination to incorporate communal healthcare in its approach and its aim which is to inspire local groups, families, fellow citizens or volunteers

to support on-going household needs, thus inspiring involvement in communities. In addition, the Alma-Ata Declaration (cited in Oakdale & Kahssay, 1999) promotes the maximum community participation in the preparation and procedure of primary healthcare through education, thereby enabling communities to contribute to healthcare. Thus, these research findings reveal that the Dunoon Clinic is not following the guidelines and objectives promoted by the Department of Health.

However, all the caregivers of Heavenly Promise have built trust between themselves and the community and are held in high esteem. One family member of a HIV patient exclaimed, "*The care givers shaped us as a family, as they are very people orientated. They have made a lot of friends here in the community and we are proud of them*." Yet another respondent echoed, "*They are trying to resolve some of our difficulties we are experiencing, and are hands on with the people"*.

This was evident to the researcher while conducting home visits with a group of caregivers in an area notorious for muggings. A group of young men had identified the researcher as a potential victim, but after interacting with the caregivers, they desisted from any wrong-doing and allowed the researcher to complete the home visits unhindered.

5.2.1.3 Inspirations and challenges within the HBC Programme

The caregivers reported that they were inspired about the work they conducted in the community for various reasons. It was clear that they all found their work very rewarding and desired to see real change and to assist the community through their involvement in Heavenly Promise. One interviewee mentioned that "*to experience the radiance on my patients' faces and seeing them out of bed every day makes me happy*". Another caregiver indicated that attending to her patients' problems helps her to deal with her own stress. Another caregiver enthusiastically stated, "*They speak to us, inform us, the moment we come; when they see us, they get re-vitalised. They get strength. They get power. That's where they get their enthusiasm from. They get it from us*."

She further explained that her patients' problems are far greater than her own. A different caregiver indicated that to observe patients getting healthy after they had all but given up hope inspires her even if she does not receive her monthly stipend.

Interviews further revealed that some of the greatest challenges facing the caregivers are that they are not able to holistically support the patients in their needs by, for example, rendering financial assistance to those living in extreme poverty. The caregivers also have to deal with the growing youth problem, such as drugs and alcohol in the community and the increase in unemployment and prostitution in the area. The caregivers all agreed that there is a great need for a hospice centre to be established in the community as a holistic approach is needed to effectively render services such as home-based care in Dunoon.

The respondents suggested that, upon entering the HBC programme, caregivers should already have been provided with three months of training in basic home and community healthcare. The majority feel that they do not have adequate training and there needs to be on-going training as home-based caregivers should be kept informed about the rapid change in AIDS-related infections.

Not only does a lack of collaboration between the local clinic and caregivers exist, but during observation, it was clear that the City of Cape Town's Health Department in Dunoon lacks the capacity for effective engagement with the home-based caregivers. Another challenge is the low monthly compensation that caregivers receive. One interviewee stressed that the monthly R780 stipend is inadequate as it is her only source of income. During discussions, it was revealed that caregivers often apply to other HBC organisations, which offer higher stipends, in order to sustain their families. However, they all agreed that better health-care facilities should exist for all in the community: "*They* [the community] *need us and we cannot let them down; we are their hope*".

5.2.2 The role of the supervisor of Heavenly Promise

In-depth focused interviews were conducted with the supervisor of the HBC project, who is the chief spokesperson for the home-based care project in Dunoon. Exploratory and open-ended questions were used to elicit information relating to the length of the programme, the overseeing role and responsibilities of the respondents, the selection criteria in terms of appointing home-based caregivers, the training of caregivers, the caregivers' level of supervision, debriefing, and the strengths and weaknesses of the programme (see Appendix D).

5.2.2.1 Role and functions of the supervisor

The supervisor is responsible for the daily monitoring of the HBC programme, disseminates information to caregivers and other stakeholders, and ensures that the monthly stipends are allocated to the caregivers. In addition, she is responsible for dealing with any queries the community or patients of the caregivers have pertaining to their various needs, and acts as the link between the caregivers and the directors of Heavenly Promise. She stated that caregivers are "*nurses on the go*" and that she is responsible for counselling the caregivers: "*Whenever they have problems, we would have a round table and discuss personal problems and I'm able to debrief and assist them in any matter*".

The supervisor stressed the importance of the soup kitchen, which is one of the projects managed by the programme to provide food to community members. She noted that the community sees the soup kitchen as a resource centre and any problems regarding grants, food parcels and other health matters are reported at the centre. Observation of the supervisor's participation in daily maintenance revealed that it pertains mainly to decision making, planning and monitoring the work of HBC staff employed in the soup kitchen.

5.2.2.2 Validity of the home-based care programme

In terms of the validity of the HBC programme, the supervisor averred that it has had a very positive effect in the community and has made a huge difference to the lives of residents. It is a resource centre, where advice is given and workshops are conducted. The respondent explained that the home-based care programme is less expensive for families as care is provided at home. She noted further that the cost of hospitalisation and transportation to and from a hospital would be financially crippling, adding that "we *observed that sick people are comforted by being in their own homes with community members and friends around them*".

The supervisor stated that participation in the programme has a life-changing effect on the caregivers. Having lost loved ones in their own families to HIV/AIDS-related illnesses, the caregivers are able to assist the affected members of the Dunoon community in their plight. She emphasised that the caregivers go out of their way to serve the community, as is evident whenever they return from their daily visits: "*Our caregivers return from their home visits with harrowing reports of the appalling conditions of their clients. It has shaped their characters and made them strong leaders in Dunoon*." This reinforces opinions expressed in

the literature that affirm that people who are sick or dying prefer to stay at home so that they can spend their last days in familiar surroundings (Frölich, 1999; Peu, 2008; Uys, 2003: Van Dyk, 2005).

The supervisor also observed that "*the home-based care programme has made the caregivers more sensitive to the culture and value system of the local community*", adding that they gain "*a sensitivity that is often missing in clinical hospital settings*". Commenting on the value of the programme for the caregivers, she maintained that "*home-based care for the caregivers is empowering; we observe how our caregivers are able to identify the needs of children who are affected by the illness of parents, and to assess whether the child is attending school or not*".

The supervisor said that there had been notable successes within this programme, for example, the recovery of patients who were on the verge of death and whose CD4 count had been stabilised. Other successes concerned patients who had completed their tuberculosis (TB) treatment and recovered, and previously bedridden patients who had been reinstated at their respective workplaces and were earning an income for their families. The value of the service that the HBC programme offers was explained as follows: "*We experienced how this programme allows the patient and family to come to grips with the illness and to prepare them for the impending death of the patient. Our patients are comforted by being in their own homes and communities with family and friends around them*".

The respondent also explained that the ambience of the home prevents the patient from feeling isolated and rejected. "*Our focus is therefore on a patient-centred approach; this programme is supported by the community, which includes the neighbours and extended family who focus on caring for the patient and family*," she added. She stressed further that that the programme is operational and effective.

In accordance with the findings of caregivers, the supervisor stated that there was no relationship or communication between the local NGO and the municipal clinic of Dunoon: "*The staff at the clinic does not recognise us as health workers; our home-based caregivers have to wait in the line even if they wear their HBC uniform*," she explained. Although there have been noteworthy successes in the community, the challenge is that Heavenly Promise cannot supply the patients with food parcels. Another challenge is the high unemployment

figure in Dunoon and that the NGOs are unable to assist the patients with employment after they have recovered. This affects the schooling of the patients' children, as children cannot go to school on an empty stomach.

The South African DOH (cited in Van Dyk, 2005:229) recommends the following guidelines for supervisors for the care of caregivers:

- Guide the process of case management and ensure that counselling is helpful and not harmful to the client.
- Provide the counsellor with continuing education, updates and input relevant to counselling by introducing journal articles, techniques and strategies related to HIV/AIDS/STIs and TB.
- Act as a sounding board for the counsellor in terms of perceptions, interpretations and understanding of the issues and problems presented by the clients and how these should be addressed.
- Recommend sources of referral to the counsellor and advise the counsellor on when to employ these.

5.2.3 The role of the directors of Heavenly Promise

This section will provide the results of an interview conducted with one of the directors of Heavenly Promise. The section will also conceptualise the role and function of the partnership in terms of common interest and complementary capacity. Questions were focused on the tasks, functions and challenges of the directors. The director interviewed for the study is a co-founder of the organisation and has been actively involved in the project from its inception.

5.2.3.1 The role and responsibilities of the directors

The directors' role in the organisation is to take responsibility for the maintenance of the projects within the community. The interviewee affirmed that the supervisor of the centre reports to the directors and that it is their duty to assist the supervisor in the appropriate execution and functioning of the programme. Reciprocally, the directors, in collaboration with the board, are responsible for developing strategic plans with regard to the HIV/AIDS

projects. The director explained, "*We also select the home-based caregivers who apply as candidates for home-based care work. A minimum of Grade 10 is required for every potential candidate and three months training in home-based care*."

According to Fox et al. (2002), caregivers in South Africa attend a three-month programme on elementary skills of home-based care and palliative care. The training is centred on the DOH curriculum for home-based care. Relevant material on STIs, HIV/AIDS and TB is incorporated into these workshops. Additional skills incorporated during the training are communication and teaching skills, spiritual and traditional issues, community assistance and infection control.

The director viewed the partnership between Heavenly Promise, Chevron and the Department of Social Development, as involving people who have a co-operative relationship with one another and who agree to share responsibility for achieving their particular objectives. She further explained that the members of the partnership have respect for another's differences and work in harmony in order that the community as a whole can benefit from them as a group networking together. The respondent explained that

> *Although Chevron plays an instrumental role in contributing financially to this project, they don't dictate the partnership. There is a perceived need for this partnership in terms of common interest and complementary capacity. In this partnership we are willing to share ideas, resources, influence and power to strengthen our relationship. As this partnership grew we observed that there is a core group of skilled and committed staff that have continued to mature within the partnership*.

Lastly, the respondent explained that there are regular opportunities for informal and voluntary contact between staff from the different agencies and other members of the partnership.

Verzuh (2008) explained that the directors are the substance and the motivators who support the entire project and put it into action. Couture (2003) also thought that the principal charge of the directors is to lead all the shareholders, the patrons, management and project team and inspire them to work collectively throughout the progression of the project.

5.2.3.2 Challenges of the HIV Programme

The director noted a high incidence of HIV/AIDS in the economically depressed refinery community, with many patients being bedridden and malnourished. She estimates that the prevalence of HIV/AIDS could be as high as 50%: "*The number of people affected with HIV/AIDS has inspired us ordinary women to be actively involved in community health in Dunoon. However, there is still a great deal of ignorance amongst the residents of Dunoon regarding aspects of community participation*," the interviewee explained, adding, "*Our people are still battling with primary issues such as housing, unemployment and lack of water; therefore they don't regard participation as an important function in the community."* This confirms the findings of the caregivers whose responses revealed that as the community focuses mainly on survival, the importance of participation in community matters is minimal.

The interviewee pointed out that often when patients' CD4 count improved, their relatives would take them back to the Eastern Cape without medication: "*These patients sadly return just to die here in Cape Town. That is one of our greatest challenges*." However, the interviewee pointed out that one of the achievements of their group's intervention is that they manage to work together as a unified group. She mentioned that, on completion of their treatment, some of the patients send their CVs to companies and are currently employed.

Another important challenge was the care of orphans affected by the death of both HIV/AIDS parents. The respondent stated that "*planning for the future of bereaved children before the death of their parents is important and this includes aspects like the making of a will and ensuring the aspirations these parents have for their children's future*". Orphan-care options should be looked into and the best option chosen, whether extended families, family type groupings, child-headed families, or orphanages (Fox et al., 2002; WHO, 2002).

5.3 Partner Organisations: Project Management 4 Africa, Chevron Refinery and Department of Social Development

The third category of respondents included representatives from the partner organisations of Project Management 4 Africa (PM4 Africa), Chevron Refinery and the Department of Social Development. The scheduled interviews with both organisations focused on gathering data relating to their involvement as partners in the Heavenly Promise Home-Based Care Project

and their role and responsibility within the partnership (see Appendices F, G and H). This category also included an interview with a representative the Department of Social Development in order to highlight its contribution to the HBC programme and partnership.

5.3.1 The role of Project Management 4 Africa

An interview was conducted with a representative from Project Management 4 Africa (PM4 Africa) in order to gather information about the organisation's partnership role with Heavenly Promise and its contribution to the Dunoon community. The respondent indicated that his role as a partner in this project is to act as an implementer of the HBC community engagement programme. In addition to managing the HBC project, PM4 Africa offers project management and life skills training to all project participants, especially those from disadvantaged communities. The representative explained that there is a "*perceived need for the partnership in Dunoon so that areas of common interest and complementary objectives can be achieved.*" PM 4 Africa believes that a healthy community in Dunoon will involve joint activity, have joint goals and show a commitment to achieve this through healthy partnerships.

Consequently, the respondent sees community participation as "*community members working together to achieve community benefit*", and believes that "*continual achievements, as a consequence of learning and applying the correct methods of community participation, ensure sustainability*".

Concerning the accomplishments of and challenges faced by the partnership, the respondent believed that there is a "*lack of commitment*" on the part of the local clinic in Dunoon. This has resulted in the caregivers not receiving adequate refresher training, which is vital when dealing with health issues in the community. The PM4 Africa representative noted that from the beginning of this project, the local clinic failed to show any interest in joining the partnership and does not collaborate with the partnership in any way.

The respondent claimed their partnership has been relatively successful, although they have experienced a few setbacks He added that, considering the modest beginning of Heavenly Promise, the organisation has every reason to be proud of its achievements since the inception of the NGO four years ago. He indicated that achievements included the

establishment of the soup kitchen; the provision of capacity training and the important training provided by the DSD in minimum norms and standards and, most importantly, the assistance rendered to HIV/AIDS patients to regain a sense of hope and strength. The respondent confirmed that PM4 Africa will continue to be a partner in 2011 and 2012 and that there is no real threat to this programme.

5.3.2 The role of Chevron Refinery

An interview was also conducted with the other partner within the HIV/AIDS Programme, namely Chevron Refinery, whose contribution to the partnership and Dunoon community is crucial in that it contributes significantly to the operation of the programme. Chevron Refinery is the main sponsor and, as such, plays a critical role in the partnership. Scholars such as Verzuh (2008: 43) stated that the main contribution of sponsors is their authority and there are numerous concrete methods through which sponsors can apply their authority to projects, such as

- Prominently supporting the organisation by issuing a project charter, which describes the purpose of the project,
- Assisting in developing a responsibility matrix. The responsibility matrix shows how different shareholders will be involved in the project,
- Reviewing and approving the project plan. The sponsor must endorse the cost-schedule quality equilibrium represented in the plan.

In the section below, information gathered about the organisation's partnership role with Heavenly Promise and its contribution to the Dunoon community is presented.

5.3.2.1 Chevron's role in the partnership

The respondent is a manager and responsible for community projects supported by Chevron South Africa. He explained how the partnership started:

> *Women in the community approached us through the Community Advisory Panel and discussed the pressing need to render community health services to HIV/AIDS patients and this community. In response, Chevron, in conjunction*

with the DSD and PM4 Africa, collaborated to establish the Dunoon community home-based care centre in 2009.

The interviewee indicated that Chevron's role in the partnership is to train caregivers from the community and to provide between 100 and 150 meals each week to homebound HIV/AIDS patients. He explained that over and above supplying funding to build and stock the Heavenly Promise centre, Chevron and its partners provided project management training to community women to run the centre. Thus, the community has taken ownership of the centre and keeps it sustainable. "*We provided Heavenly Promise with a soup kitchen facility, and also provided the NGO with project management skills*," he added.

The interviewee further elaborated that "*project management is so important because it helps Heavenly Promise in their skills to run the project properly, the way it should be done; I think that's the very simple thing that we can do and we'll have a big impact*". The respondent held the view that the idea of partnership is fundamental to everything Chevron embarks on, and that healthy partnerships are based on collaboration and corporate trust. He explained that Chevron will continue to access resources and invest in infrastructure for the community. He further indicated that partnerships ensure the long-term health of the company, benefit the Dunoon community, and contribute to economic growth and human progress for the future generations.

5.3.2.2 Contextualisation of community participation and ownership

The interviewee viewed participation as the "*involvement by the community, and in some instances additional stakeholders, in the conception, content and executing of a programme to change lives within the community*". The respondent stated further that the community themselves take ownership of the centre and that the centre belongs to them. He added that Chevron is very proud of the HBC programme, and that one of its highlights is that it is being led by women, which is in line with one of the national mandates in South Africa, namely to empower women.

5.3.2.3 Chevron's evaluation of and expectation for the partnership

The respondent explained that for Chevron, this programme is about life and death every single day for many in the Dunoon community. Chevron's expectation is that in the near

future, communities will no longer talk about HIV/AIDS as a life-and-death situation, but local communities will understand how to prevent it and have effective medication to treat the condition. The respondent stated that Chevron will continue to network with Heavenly Promise and this will be an on-going process in the community. Lastly, he pointed out the following achievements of the partnership:

- the construction of a new multi-purpose mobile facility;
- the supply of soup to between 100 and150 people daily;
- the creation of a monitoring and evaluation plan for the operation of the soup kitchen and the home-based care programme; and
- the development of a scoreboard based on the Department of Social Development's norms and minimum standards for home- and community-based caregivers.

5.3.3 The Department of Social Development

A representative from the Department of Social Development (DSD) was interviewed in order to gather information on the DSD's role in the HBC programme. The interview for the DSD representative focused on descriptive criteria such as the duration of the DSD in the HIV/AIDS programme and the type of training it provides (see Appendix H).

5.3.3.1 Department of Social Development's role in the partnership

The DSD representative is the district officer and co-ordinator of the HIV/AIDS programme in Dunoon and other allotted areas in the Western Cape. Consequently, the respondent is responsible for the official liaison between the DSD and the partnership, and is responsible for the monitoring and evaluation of the project. It is the task of the supervisor of Heavenly Promise to forward all the monthly reports, such as a progress report and the minimum norms and standard report, to her department.

The DSD's involvement with the Heavenly Promise NGO was instigated because of government's commitment to supporting home- and community-based care to mitigate the socio-economic impact of HIV/AIDS at community level. The DSD was initially part of the established Heavenly Promise organisation that was conceptualised in 2007. The respondent commented that a group of women first gathered in an RDP house in the community and distributed soup to HIV/AIDS patients in 2007. This pivotal role the women played was

invaluable in that it prompted the DSD to commit itself to offering its support and guidance in the fight against HIV/AIDS.

5.3.3.2 Significance and aims of the partnership

The interviewee indicated that it is the desire of the DSD to see the community themselves taking the initiative for active programmes. She further mentioned that the DSD wants to ensure that communities are empowered in order for them to deal with their own challenges and find their own solutions. The respondent pointed out that HBC programmes should be developed, implemented and monitored by the community to ensure full community ownership. She has confidence that these programmes will empower and strengthen families and communities to care for those affected by HIV/AIDS.

The respondent specified that external organisations sometimes do not understand the term *partnership*. She observed that often, when there is a partnership, small organisations want to dictate the terms, not realising that government needs to comply with legislation. "*Usually it is us (the DSD) who often provide the necessary funding; but certain protocols need to be in place, for example rules, guidelines and accountability obligations. Furthermore, certain targets need to be met, and government requires that partners adhere to this*." She mentioned that NGOs often regard this as a threat, believing government wants to dictate to them. She stressed that this programme does not involve shifting the responsibility of government to families and communities, but that it recognises the value of partnerships between governments, communities (the public) and the private sector.

The DSD representative highlighted the importance of the minimum norms and standards training workshop which each HBC caregiver has to attend, and noted that the two-day training workshop is important as it contributes to the success of the partnership. Table 3 briefly outlines the benefits of having minimum norms and standards in HBC training. The motivation for having minimum norms and standards is that they ensure that quality services and funds are utilised effectively, with a clear correlation between funds invested and the quality of services rendered.

The respondent stated that, during the conception phases of the NGO, the women had no guidelines for interventions to facilitate the implementation of the HBC programme. There

was no record of any patients, bookkeeping, staff ratios, and no clear system for referrals. Feedback on referrals was not in place. She stated that the kind of training workshops assists the DSD in dealing with the ever-increasing number of NGOs offering HBC programmes. The training highlighted in Table 3 informs the development toolkit for starting and running HBC programmes, thus ensuring standardisation of practice.

Table 3

National norms and standards (Department of Social Development, 2007)

Norms	Standard
Compile and submit reports timeously to relevant stakeholders including sponsors.	Host weekly staff meetings and monthly Management Team meetings with caregivers and ensure that weekly, monthly, quarterly and annual reports are available.
A procedure for recruitment, selection, engagement and disengagement of community caregivers is in place.	Written documentation that outlines recruitment, job descriptions, code of conduct and exit strategies for community caregivers should be maintained.
Every caregiver to have one supervisor.	The programme supervisor to ensure the efficient running of the organisation. Supervise community caregivers on a regular basis. Develop job descriptions for all staff.
Each organisation to have at least 10 caregivers.	Caregivers to render comprehensive services to vulnerable groups in the community.
Each caregiver to render services to a minimum of 15 households at least once a week.	Each HBC to maintain a care plan for each household and individual. Community caregivers should keep record of their clients.

5.3.3.3 The accomplishments and successes of the partnership

The respondent specified that, in retrospect, since the origin of the partnership when the particular group of women met in an RDP house to render assistance to the community, it has

become increasingly successful. In the commencement phases of the NGO, there was no visible structure. Heavenly Promise as a programme emerged from humble beginnings but evolved into one of the integrated parts of the DSD Western Cape's interventions. Their aim is to build the capacities of communities and to ensure that members of these communities are able to access integrated support and care within their communities. The DSD appointed a supervisor to this programme to ensure that a high work ethic within the NGO will be maintained.

The Department of Social Development (2009) claims that government recognises the necessity for the sustained complete provision necessary to reach the appropriate level of service customary as set in the norms and standards. Additionally, it recognises that improved consistent and continual HBC programmes will only be safeguarded through rigorous determination by all partners involved, particularly NGO's, within an efficient supportive setting.

This programme is also designed to ensure that a minimum comprehensive package of care and support service is rendered within the home-based care programme. The training of the caregivers in the norms and minimum standards workshop was notably the success of the partnership. The approach of the DSD, according to the respondent, is to place people at the centre of development, thereby increasing the effectiveness of development:

> *We, as partners in this programme, would desire to see this project extending and filtering through to as many HIV/AIDS patients and their families in the future as possible. The DSD will throughout 2011 render our support and services to Heavenly Promise so as to ensure they are effective in their community*.

5.4 Conclusion

The findings presented in this chapter have demonstrated that, thus far, the awareness of community participation and the role of home- and community-based health services came about as the result of the rapid spread of the HIV/AIDS pandemic in Dunoon. Initially, there were some weaknesses in the levels and types of participation displayed by the organisational

structures within Heavenly Promise and the community members of Dunoon. Similarly, weaknesses were revealed in the inability of the City of Cape Town's health department to implement and facilitate a strong participation programme. However, it was revealed that through the strength and vision of ordinary women in the community, an effective HIV/AIDS programme has been designed and implemented in the Dunoon.

Furthermore, community members demonstrated weak areas in capability regarding awareness and knowledge of HIV/AIDS. However, members who have been directly affected by family members living with HIV/AIDS display a high level of awareness and knowledge of operational issues in community participation and social sustainability, as well as a strong capability in terms of enthusiasm and interest in maintaining the HBC project. Financial resources are limited, but Heavenly Promise has sustained the project with limited funds and donations from individuals and partner organisations.

Also, a high level of collaboration is displayed and demonstrated by the commitment of the partnership (Chevron, PM 4 Africa and DSD) as they are willing to share ideas, resources, influence and power to strengthen their critical function within the community. Therefore, using these exploratory findings as a base, the following chapter will present the general conclusions of the study and recommendations for the future.

CHAPTER SIX: RECOMMENDATIONS AND CONCLUSION

6. Introduction

In this chapter, the general findings of the research conducted are set out. A number of theoretical considerations are outlined to provide a critical reflection on community participation, and recommendations for improving the community's involvement in health and meeting the HBC challenges to various stakeholders in the Dunoon area are presented.

6.1 General findings

The purpose of this study was to focus on investigating the nature and extent of HBC as an alternative strategy to institutional care at grassroots level in the Western Cape in order to ascertain its value and contribution to the overall development goals of primary healthcare. It is evident from analysis of the study results that the main barriers to successful active participation among residents in Dunoon are unemployment, poverty, lack of housing, no sense of belonging in the area and a lack of pride apparent in the community.

This section also includes general findings regarding the nature and extent of participation among Heavenly Promise NGO and the collective partnership, to gain an insight into the community's knowledge and understanding of the concept. The findings from the research in the case study areas are summarised in this section.

6.1.1 The Dunoon community

The research findings indicate that the Dunoon community is faced with enormous challenges, which contribute to passive or, in some cases, no participation. Housing, unemployment and crime are the three main concerns in the community. Poverty in Dunoon has produced a large number of people living in shacks, which is the only alternative in the absence of housing. During the interviews, most people reported that they consider not having a house as their greatest problem. Home ownership therefore, is considered an aspect of healthy living by many and provides secure tenure.

The findings also highlight that many women enter prostitution for economic reasons in order to provide for their families. Regrettably, men in Dunoon are willing to offer a higher price if they have sex without condoms, which increases the risk of sexually transmitted infections.

All these factors have contributed significantly to the residents of Dunoon's lack of participation in their community health matters.

Furthermore, widespread marginalisation of informal settlement people from community development has led to a lack of confidence and to a mood of despair. The dependent mentality that still exists within the community of Dunoon is further strengthened by the fact that mere existence is, for the majority of informal dwellers, their major goal and consumes a large portion of their energy, leaving them little time to participate in health matters (Oakley, 1991). Many of the informal dwellers therefore tend to accept the status quo and their destitute position, in which economic and social arrangements remain in the control of bureaucrats whilst the majority remain poverty stricken.

6.1.2 Heavenly promise home-based care

The research findings reveal that caregivers play a very important role in HIV/AIDS treatment at Dunoon. They also indicate that the HIV/AIDS pandemic has placed a large burden on public health facilities. Therefore, the Heavenly Promise HBC programme needs to respond to the demands identified and to be more involved in decisions pertaining to the community. In addition, the study results reflect an increasing acknowledgment by institutionalised organisations that community participation is essential to the main task of renewing democracy, changing service distribution and constructing effective communities.

Throughout this research study, Heavenly Promise was found to display a dynamic, vigorous, and energetic degree of participation in the community. Unfortunately, HBC establishments are facing a combination of demands which indirectly affects their ability to deliver adequate services to their clients. Consequently, the HBC programmes are limited in their ability to carry out activities such as proper anti-retroviral treatment (ARV) adherence and support.

6.1.3 The Partnership

The findings show that there is a need for strong partnership support to the HIV/AIDS programme. Without this support, the programme cannot function to its fullest potential. The findings also revealed that the partnership between Heavenly Promise, Caltex, Project Management 4 Africa and the Department of Social Development in Dunoon has the potential to deal with the complications and variations that represent most health-related

matters. An effective networking system appears to exist between the partnerships as they are interested in trading information for their common benefit. Chevron's financial contribution is essential; however, it appears not to dominate the partnership.

Also a healthy co-operation seems to exist between the members of the partnership as they are able to exchange information and share resources, and this appears to entail a considerable amount of time, together with a high level of commitment by the partners. Finally, collaboration within the partnership seems relatively good because elements of teamwork are visible, which, additionally, increases the capacity of the other associates to gain mutual advantage and follow the collective objective.

6.2 Theoretical reflections

This section provides reflections on existing models, legislation and frameworks for participation in terms of the empirical fieldwork results.

6.2.1 Participation

Proponents of participatory development, Slocum, Witchart, Rocheleau and Thomas-Slayter (1995) contended that this method requires the involvement of beneficiaries in all phases of a project. Furthermore, active participation is an important means to secure sustainability; it places emphasis on beneficiaries as initiators, owners and controllers of a development process based on their needs as a self-organised community (Groenewald, cited in Theron, 2005; Rahman, 1993).

The researcher observed that the caregivers have a strong interaction with all the people with whom they deal, are optimistic about the future and show a positive behaviour change toward the HIV/AIDS pandemic. Although caregivers are actively involved in community participation, they never attend meetings or formally arranged gatherings pertaining to decisions and matters concerning the partnership. It was observed, during operations management of the home-based care project, that decision making lies with home-based care staff and the partnership and not with the caregivers. Cornwall and Pratt (2003) maintained that hidden power may be present not only inside political processes but also in management and other group contexts, such as in the working force, in NGOs or in community based establishments. Furthermore, scholars such as Brock et al. (2001), Gaventa (2002), and VeneKlasen and Millers (2002) identified this form of power as the "mobilization of

partiality", where some issues are structured into management level whilst others are structured out.

However, as Kroon (1995:111) pointed out, upper management is occupied with strategic design such as planning, which requires adequate information on those variables that may have a direct influence on the efficient functioning of the organisation. Moreover, critical decision making at upper management level determines the condition, affairs and expected outlook of the organisation. Kroon (1995:112) further explained that those at the lower level are primarily responsible for the operational implementation of the planning of the organisation.

The results of the study, however, indicated that caregivers who were personally affected by HIV/AIDS displayed strong levels of participation, even from the conceptualisation of the project. Heavenly Promise has been constituted essentially to focus on the HIV/AIDS pandemic in Dunoon, and in addition, the centre is staffed by women openly committed to the radical changes that participation implies.

From observing the caregivers throughout the various home visits, it was clear that home-based care was preferable to institutional care. The caregivers' patients who are sick or dying prefer to stay at home in familiar surroundings, especially when they cannot be cured in hospital. The caregivers were mindful of the culture and ethical code of the patient and family, an important consideration that is often overlooked in institutional settings.

Caregivers displayed a high degree of compassion as they were in touch with potential orphans and family members who really need help. The findings demonstrated how caregivers were able to recognise the necessities of children who are affected by the illness of parents and to assess issues such as whether the child is attending school or not. Participation for the caregivers involved having strong leadership skills and character traits, which distinguished them among the community.

Active participation, however, amongst the majority of community members in terms of networking and collaborating in health services is unheard of in Dunoon. The local community shows a lack of enthusiasm and some resistance to taking part in participation matters. Overall, the assessment indicated that if a community has no sense of belonging or

taking pride in its community, participation will be considerably weakened and inevitably passive. The research has shown the reasons for this lack of pride relates to some degree to the polluted environment in the community.

Moreover, throughout the observation period, it was noticeable how residents conducted themselves by dumping their garbage, waste material and household refuse in the streets. Respondents were clearly very disgruntled with service delivery processes in the community. Another factor that contributed to the lack of a sense of belonging was the crime rate in the area. Respondents mentioned their desire to move to other areas due to the high incidence of crime. Burglary, theft and assault were reported to be common offences in the community. Poverty in Dunoon was also seen to be a clear reason for passivity in the community, as many households are ignorant of their legal rights, which make them an easy target for exploitation. Their deprivation increases their inability to participate in community affairs.

However, it was observed that all employed respondents actively participated in community matters, compared to those who are unemployed. The findings clearly indicated that employed respondents with a secure financial income had a far greater sense of hope and optimism about the community than the unemployed respondents. Unemployment and lack of income in Dunoon led to despair, feelings of hopelessness and to young people resorting to crime and prostitution.

6.2.2 Capacity building

Brynard and De Coning (2006) confirmed the concept that *capacity building* refers to support rendered to organizations or communities which lack particular expertise or capabilities or to the improvement of their capability to execute their objectives. With regard to capacity building, areas in which the home-based care project demonstrated either strong or weak capacity were identified in the course of the study.

Strong capacity was demonstrated in the area of resource capacity, which includes a commitment and passion to caring for PLWA, their knowledge, commitment to and determination to provide home-based care programmes in Dunoon. The study also revealed that there is sufficient training of home-based caregivers in the HIV/AIDS project. This is due to sufficient resources available to conduct training and the expertise available, such as support from PM4 Africa and the Department of Social Development, which play a vital role

in the HIV/AIDS programmes. Burke (2001) affirmed that capacity building encompasses human resource development, which is regarded as the method of training people in understanding their roles, in acquiring skills and accessing information, and cultivating knowledge, all of which empower community members to perform effectively.

However, weaknesses were also evident in capacity building with regard to technical expertise in key areas of ongoing primary health training, due to a lack of collaboration between the partnership and the City of Cape Town's Health Department. Furthermore, weaknesses were identified in capacity building with regard to the community members' attempt to gain knowledge and skills in the participatory process concerning health matters. Barely any support is given to the community by the City of Cape Town's Health Department to provide expertise or skills or to improve their ability to accomplish their task in active participation in health matters.

6.2.3 Constitutional framework

South Africa is regarded as having the most advanced constitution in the world. Regrettably, implementation of participatory healthcare and compliance with community participation in the City of Cape Town's Health Department (particularly in the Dunoon local clinic) is fraught with a number of challenges. One of these challenges can be related to Weaver's (2004) estimate of 48,000 migrants moving into Cape Town every year.

The mere existences of a legislative framework, though essential as a basis for action, does not in itself provide a solution to community participation, particularly in health matters. Furthermore, the goal of the HIV/AIDS and the STI Strategic Plan 2007-2011 is to plan co-operation with stakeholders independent from government, such as the community, thereby constructing and expanding efficiency in combating HIV/AIDS (DOH:2007). From observations, it was apparent that the local health clinic was not involved in partnership with the home-based care programmes in the Dunoon community.

This research disclosed the City of Cape Town Health Department's lack of effective engagement with the public through using health committees, in the community. The local municipality facilities accessed at this community clinic are inadequate and only include child care, family planning, TB treatment, HIV inspection, cervical smears and therapy, and analysis of sexually transmitted infections. Other aspects such as the shortage of personnel

and an uncaring, unfriendly approach of the professional personnel at the Dunoon municipal clinic are of great concern.

Subsequently, no long-term mechanisms have been established to keep the community actively involved in health, which plays an important part in the life of any community. This coincides with the opinion of De Kadt (1982: 174), who stated that the notion of community involvement as presented in the South African legislation "has popularity without clarity and is subject to growing faddishness and a lot of lip service."

6.3 Recommendations

The following is a list of recommendations based on the findings of this research, which should be implemented to help substantiate community participation in Dunoon. This community participation should also be considered to help strengthen the existing HBC programmes and pave the way for a higher level of services to PLWA.

6.3.1 Dunoon residents

There should be a concerted effort to build community participation from one of passivity to a community that takes responsibility for its own health. Public participation is fundamentally about empowering people. Decisions pertaining to the health system should be clearly communicated to the public in an open and transparent manner.

The public needs to be simultaneously provided with the opportunity to give feedback or to alter the decision-making process or its outcome if necessary. This process of capacity building should be coupled with broader civic education initiatives. Communities should have the opportunity to be trained by their local health professionals to read policy documents, interpret health indicators and be able to provide constructive feedback.

The community is only passively involved in health services at local government level. This is evident as they have no sense of belonging and are not proud of their community. Poverty and unemployment also play a role in passivity in community participation. There needs to be practical participation as part of the deeper agenda of building a local democracy. A wide range of skills needs to be developed, including the protocols of public meetings, negotiations and conflict resolution skills, especially for stakeholder groups. Gaventa (2002) postulated that visible power presumes that decision-making arenas are unbiased playing fields, in

which any actors who have concerns to raise may contribute without restraint. It also assumes that actors are conscious and aware of their grievances and have the resources, organisation and agency to make their voices heard.

The Health Department of Western Cape should develop a proper budget for community participation in health. This budget should go a long way in ensuring that community participation in the health plan is effectively carried out. In order to create a climate of active participation, adequate health facilities should be catered for. The Dunoon community lacks other health facilities, such as a day hospital, hospice and a 24-hour emergency centre.

6.3.2 Heavenly Promise home-based caregivers

The HIV/AIDS pandemic has resulted in local community members, in particular the caregivers of Heavenly Promise, becoming involved in health matters in Dunoon. Hence, a renewed effort and commitment in community home-based care support is needed. Due to a lack of collaboration between the local clinic and Heavenly Promise, there is a lack of on-going health training. If home/community-based care is to be sustained, the providers of home-based care should receive a comprehensive education. The WHO (2002) affirms that *providers* include families, health and social welfare authorities, community health employees and volunteers.

Nemathaga (cited in Peu, 2008: 140) was of the view that the future of HBC should be planned carefully and adjusted according to the development needs of the different communities. Van Dyk (2005: 266) agreed and highlighted that it is important to train home-based caregivers accurately and thoroughly to provide a high standard of holistic care.

6.3.3 Partner organisations

The partnership in this home-based care programme should consider preventative measure strategies. Although not a primary finding of this research, numerous HBC programmes have integrated prevention and voluntary counselling and testing education as a central activity of their work. Prevention education and the functioning of support groups for people living with HIV/AIDS should be increasingly documented to encourage their implementation within HBC activities/services. For example, the correlation between HIV/Aids and alcohol use should be investigated and special awareness campaigns should be targeted at shebeens, youth groups, and local soccer and netball clubs in the community.

Shebeens or taverns are the most commonly cited places where men and women meet with friends for recreation in informal settlements. In the course of this research, respondents reported that most of the youth in Dunoon increased their drinking of alcohol at weekends. Clients at shebeens also meet new sexual partners there.

Awareness and strategy campaigns such as the ABC approach of the South African government need to be revised. Questions about the effectiveness of the Love Life Campaign in reducing HIV/AIDS statistics in South Africa need to be asked. The partnership should co-operate with these strategy campaigns and consider a call for strong family values and abstinence from sexual intercourse before marriage as viable options in the fight against the spread of HIV/AIDS.

It is important to ascertain if the Heavenly Promise HBC project has accomplished any objectives and if these are replicable. Various HBC programmes have authenticated best practices in the quest to attain and sustain a high level of service. A thorough investigation of these programmes is needed for substantiating a step-by-step approach to achieve the goals and deal with the challenges.

6.4 Conclusion

There is a characteristically fallible referral structure between the home-based care organisations in Dunoon and the local public sector of the Western Cape. Therefore, purposeful interaction between patients, caregivers and health professionals is required. This will destroy barriers between health professionals and the Dunoon community and improve the understanding of each role-player's function. Consequently, it will improve the exchange of information to generate more networks for the client in the community and develop efficient service delivery, which is essential in Dunoon.

Nonetheless, a good level of co-operation exists between HBC programmes and larger, experienced NGOs and authorities that have a vast knowledge of socio-economic and nutritional services for people living with HIV/AIDS. The disregard for ongoing health training is a fundamental problem encountered by HBC programmes and requires immediate attention and technical expertise.

Lastly, the approach to development at the local and national levels should be holistic in order to confront the challenge of community participation. Similarly, there should be a persistent enhancement of the recognition and progression of the community of Dunoon. Participation is, above all, a governmental procedure, which should incorporate the general population, the elite, bureaucrats and the political rulers of government. Without substantial commitment at the highest level of national government, it is unlikely that development programmes and projects will be designed to achieve community participation and mobilisation, particularly in informal settlements.

REFERENCES

Akintola, G. 2004. *Home based care: A gender analysis of informal caregiving for people living with HIV/AIDS in a semi rural South African setting*. Unpublished PhD Thesis. Durban, RSA: University of KwaZulu-Natal.

Allen, T. & Thomas, A. (Eds.) 2000. *Poverty and development into the 21st century*. London, UK: Oxford University Press.

Allender, J.A. & Spradley, B.W. 2005. *Community health nursing: promoting and protecting the public's health*. 6th ed. Philadelphia, PN: Lippincott Williams & Wilkins.

Arnstein, S.A. 1969. *A ladder of citizens' participation in USA. A Journal of American Institute for Planners, **57***(4), 176-182.

Babbie, E. & Mouton, J. 2001. *The practice of social research*. Cape Town, RSA: Oxford University Press.

Baum, J. 2008. *The new public health.* 3rd ed. London: Oxford University Press.

Beechey, S. 2004. *A viable alternative for HIV/AIDS treatment*. *Target*. ***4***:76.

Brenner, M.H 1993. *Mental illness and the economy*. Cambrigde, MA: Harvard University Press.

Brock, K.,Cornwall, A. & Gaventa, J. 2001. *Power, knowledge and political spaces in the framing of poverty policy*. IDS Working Paper 143. Brighton, UK: IDS

Brynard, P. & De Coning, C. 2006. *Policy Implementation*. In F. Cloete, H. Wissink, & C. De Coning (Eds). *Improving public policy: From theory to practice.* Pretoria, RSA: Van Schaik.

Burke, R. 2001. *Project management: Planning and control techniques*. 3rd ed. Cape Town, RSA: Rustica Press.

Burkey, S. 1993. *People first: A guide to self-reliant, participatory rural development.* London, UK: Zed Books.

Cardoso, F.H. 1972. *Dependency and development in Latin America.* University of Los Angeles. Los Angeles, CA: California Press.

Chambers, R. 1984. *Rural development: Putting the last first*. London, UK: Longman.

Chambers, R. 1992. *Rural appraisal: Rapid, relaxed, and participatory*. Institute of Development Studies Discussion Paper 311. Brighton, UK: University of Sussex.

Chambers, R. 2003. *Whose reality counts? Putting the first last*. London, UK: ITDG.

Clemen-Stone, S., McGuire, S.L. & Gerber Eigsti, D. 2002. *Comprehensive community health nursing.* 6th ed. St. Louis, MO: Mosby.

Coetzee, J., Graaff, J., Hendricks, F. & Wood, G. 2001. *Development: Theory, practice and policy.* Cape Town, RSA: Oxford University Press.

Conyers, D. & Hills, P. 1990. *An introduction to development planning in the Third World*. New York, NY: John Wiley & Sons.

Cornwall, A. & Pratt, G. 2003. *Pathways to participation*. London, UK: ITDG publishing.

Couture, D. 2003. *Enterprise product management*. New York: John Wiley & Sons

Davids, I., Theron, F. & Maphunye, K.J. 2005. *Participatory development in South Africa: A development management perspective.* Pretoria, RSA: Van Schaik.

De Beer, F. & Swanepoel, H. 1998. *Community development and beyond: Issues, structures and procedures.*Pretoria, RSA: Van Schaik.

De Beer, F. & Swanepoel, H. 2006. *Community development: Breaking the cycle of poverty*. 4th ed. Cape Town, RSA: Juta.

De Kadt, I. 1982. *Community participation for health: The case of Latin America*. *World Development*, ***10***(7): 573-584.

Dennill, K., King, L. & Swanepoel, T. 1999. *Aspects of primary health care: Community health in South Africa.* 2nd ed. Cape Town, RSA: Oxford University Press.

Department of Health. 2001. *National Guidelines on home-/community care and community based care*. Pretoria, RSA: Department of Health. Retrieved on 28 August 2010 from www.dsd.gov.za

Department of Health. 2002. *Comprehensive home/community based training manual*. Pretoria, RSA: Department of Health.

Department of Health. 2003. *National guidelines on home/community care and community-based care.* Pretoria, RSA. Department of Health.

Department of Health. 2007. *HIV/AIDS and STI national strategic plan, 2007-2011*. Pretoria, RSA: Government Printer.

Department of Health. 2008. *Progress report on declaration of commitment on HIV and AIDS.* Pretoria, RSA: Government Printer.

Department of Provincial and Local Government and Housing. 2007. *Guidelines for public participation: A third draft for feedback. Government Gazette* No 30137 Pretoria, RSA: Government Printer.

Department of Social Development. 2007. *National Norms and Minimum Standard. Home and Community Based Care (HBCB) and Support Programme*. Pretoria, RSA. Department of Social Development

Department of Social Development. 2009. *HIV/AIDS Programme Concept Paper.* Retrieved on 14 June 2010 from http://www.capegateway.gov.za/other/2009/10/concept_paper_ programme_hivAIDS.pdf

Dreyer, N. 2004. *Most of city's 164 informal settlements to have piped water in a week*. In M. Barry & H. Rüther. 2005, *Vol. **17***(1): 1-5 *Data collection techniques for informal settlement. Upgrades in Cape Town, South Africa.* Retrieved on 25 June 2010 from http://www.cybertracker.co.za/Barry.pdf

Fawcett, J. 1989. *Analysis and evaluation of conceptual models of nursing.* 2nd ed. Philadelphia, PA: Davis.

Flynn, B. 1995. *Measuring community leaders perceived ownership of health education programs: Initial test of reliability and validity*. London, UK: Oxford University Press.

Fonaroff, A. 1983. *Community involvement in health systems for public health services. Geneva, Switzerland*: World Health Organisation.

Fox, S., Fawcett, C., Kelly, K. & Ntlabati, P. 2002. *Integrated community based care in South Africa.* Cape Town: CADRE.

Frank, A.G. 1969. *Latin America: Underdevelopment or revolution*. New York, NY: Monthly Review Press.

Freire, P. 1972. *Pedagogy of the oppressed*. New York, NY: Herder and Herder.

Frolich, J. 1999. *Draft guidelines for community home-based care and palliative care for people living with AIDS*. Pretoria, RSA: Department of Health-Directorate, SDDs and HIV/AIDS.

Gardner, K. & Lewis, D. (1996). *Anthropology, Development and the Post-modern Challenge, Vol. **16***(1): 13-21. London, UK: Pluto Press.

Gaventa, J. 2002. *Introduction: Exploring citizens, partnership and accountability, IDS Bulletin **33***(2): 1-18, Brighton, UK: IDS

Graaff, J. 2003. *Poverty and development*. Cape Town, RSA: Oxford University Press.

Haug, M.R.1985. *Home care for the ill elderly: Who benefits*? *American Journal of Public Health, **75***: 127-128.

Hennessy, D. & Spurgeon, P. 2004. *Health policy and nursing: Influence, development and impact.* London, UK: MacMillan.

International Association for Public Participation. 2010. *IAP2 core values*. Retrieved 28 June 2010 from *http://iap2.affiniscape.com/displaycommon.cfm?an=4*

Korten, D.C. 1990. *Getting to the 21st century: Voluntary action and the global agenda.* West Hartford, CN: Kumarian Press.

Kotze, D.A 1997. *Development administration and management: A holistic approach.* Pretoria: Van Schaik.

Kroon, J. 1995. *Planning and Plans in General Management*. Pretoria, SA: Kasgiso.

Lankester, T. 1994. *Setting up community health programmes: A practical manual for use in developing countries*. London: Macmillan.

Lasserve, A.D 2006. *Informal settlements and the millennium development goals*: *Global policy debates on property ownership and security of tenure. Global Urban Development Magazine, **2**(1): 1. Retrieved on 9 September 2010 from http://www.globalurban.org/GUD Mag06Vol2Iss1/Durand-Lasserve.htm

Lefebvre, H. 1991. *The production of space*. Oxford. UK: Wiley-Blackwell.

Long, C. 2001. *Participation of the poor in development initiatives: Taking their rightful place*. London, UK: Earthscan.

Louden, M. 1999. *South Coast hospice's community-based HIV/AIDS home care model*. *HIV/AIDS Best Practice Series*. Pretoria: Department of Health.

Masango, R. 2002. *How can public participation in local government policy formulation be improved?* Pretoria, RSA: UNISA.

Marquis, B.L. & Huston, C.J. 2000. *Management functions in nursing*. 3rd ed. Philadelphia, PN: Lippincott, Williams and Walkins.

Marston, J. 2003. *Doing a home visit*. In L. Uys & S. Cameron (Eds). *Home-based HIV/AIDS care*. Cape Town, RSA: Oxford University Press.

Mantzaris, E & Ngcobo , I. 2007. *Public participation, local government and HIV/AIDS. Critical Dialogue,* pp. 24-30. Centre for Public Participation.

Menda, M.D. 2006. *Assessment of sexual behaviour and knowledge of HIV amongst adolescent schoolgirls in a rural district in Zambia*. Bellville, Cape Town, SA: University of Western Cape.

Midgeley, J. 1987. *Popular participation statism and development. Journal of Social Development in Africa. **2***(1): 5-7.

Midgley, J., Hall, A., Hardiman, M. & Narine, D. 1986. *Community participation, social development and the state.* London, SA: Methuen.

Moodley, S. 2006. *Public participation and deepening democracy; experiences from Durban, South Africa. Critical Dialogue*, pp. 3-8. Centre for Public Participation.

Mouton, J. 2001. *The practice of social research*. London, SA: Oxford University Press.

Narayan, D. 2002. *Empowerment and poverty reduction*. Washington DC: World Bank.

Neuman, W. L. 2000. *Social research method: Qualitative and quantitative approaches*. 4th ed. Boston, MA: Allyn and Bacon.

Oakley, P. 1991. *Projects with people: The practice of participation in rural development*. Geneva, Switzerland: International Labour Office.

Oakdale, P. & Kahssay, M. 1999. *Community involvement in health development: A review of the concept and practice*. Geneva, Switzerland: World Health Organisation.

Paul, S. 1987. *Community participation in development projects*. Discussion paper No. 6. Washington, DC: World Bank.

Pearson, A., Vaughan, B. & Fitzgerald, M. 1996. *Nursing models for practice.* 2nd ed. Oxford: Butterworth-Heinemann.

Penderis, S. 1996. *Informal settlements in the Helderberg Basin: People, place and community participation*. MA Thesis, University of Stellenbosch, RSA.

Peu, M. 2008. *Home/community based care*. Pretoria, RSA: Van Schaik.

Pieterse, J. 2009. *Development Theories/Strategies: Deconstructions/ Reconstruction* 2nd ed. London, UK: Sage and TCS Books,

Rahman, M. A. 1987. *The concepts of community participation through family units.* Geneva, Switzerland: International Labour Office.

Rahman, M.A. 1993. *People's self-development--perspectives on participatory action research: A journey through experience*. London, UK: Zed Books.

Rahman, M.A. 1998. *People's self-development: Perspectives on participatory action research.* London, UK: University Press.

Rappaport, J. 1987. *Terms of empowerment? Exemplars of prevention: Toward a theory for community psychology*. *American Journal of Community Psychology*. ***15***(2): 121-148.

Rifkin, S. 1996. *Paradigms lost: Towards a new understanding of community participation in health programmes*. London, UK: Chapman and Hall.

Rifkin, S. & Cassels, A. 1996. *Training managers for primary health care: Teaching about community involvement.* Liverpool, UK: Department of International Community Health.

RSA (Republic of South Africa). 1996. *The Constitution of the Republic of South Africa, Act 108 of 1996*. Government Gazette No 32549. Pretoria, SA: Government Printer.

RSA (Republic of South Africa). 1998. *Local Government: Municipal Structures Act (Act 117 0f 1998)* Pretoria, SA: Government Printer.

RSA (Republic of South Africa). 2000. *Municipal Systems Act (Act 32 of 2000)* Pretoria, SA: Government Printer.

RSA (Republic of South Africa). 2003. *Constitution National Health Act, Act 61 of 2003*. Government Gazette No 26595. Pretoria, SA: Government Printer.

Russell, M. & Schneider, H. 2000. *A rapid appraisal of community based HIV/AIDS care and support programmes.* Johannesburg, RSA: University of the Witwatersrand: Centre for Health Policy.

Saff, G. 1996. *Claiming a Space in a changing South Africa: The "squatters" of Marconi Beam, Cape Town. Annals of the Association of American Geographers*. ***86***(2): 235-255. Retrieved on 8 August 2010 from http://www.cybertracker.co.za/Barry.pdf

Sen, A. 1999. *Development as freedom*. Oxford, UK: Oxford University Press.

Slocum, R., Wichhart, L. Rocheleau, D. & Thomas-Slayter, B. 1995. *Power, processes and participation: Tools for change.* London, UK: Intermediate Technology Publications.

Spier, J & Edwards, C. 1990. *Models of community/home-based care for people living with HIV/AIDS in southern Africa. Journal of the Association of Nurses in AIDS care*. ***16***, 3: 33-40.

Strategic Development Information (SDI) and Geographic Information Department (GIS) - City of Cape Town. 2010. Retrieved on 22 July 2010 from www.capetown.gov.za/en/stats/pages/default.aspx

Swanepoel, H. 1992. *Community development: Putting plans into action*. Cape Town, RSA: Juta.

Todaro, M.P. 1987. *Economic development in the Third World*. 3rd ed. Singapore, Malaysia: Longman.

Todaro, M. 1992. *Economics for a developing world: An introduction to principles, problems and policies for development*. London: Prentice Hall.

Theron, F. 2005. *Public participation as a micro-level development strategy*. In I. Davids, F. Theron, & K.J. Maphunye (Eds). *Participatory Development in South Africa: A Development Management Perspective*, pp. 112-114. Pretoria, RSA: Van Schaik.

Tshabalala-Msimang M. 2004. *Launch of community health workers programme*. South African Government Information. Retrieved on 17 June 2010 from http://www.info.gov.za

UNAIDS. 2002. *Report on the global HIV/AIDS epidemic*. Geneva, Switzerland: Joint United Nations Programme on HIV/AIDS. In Van Dyk, A. 2005. *HIV/AIDS care & counselling: A multidisciplinary approach*. Cape Town, RSA: Pearson Education.

UNICEF. 1990. *The Bamako Initiative: Reaching goals through strengthening service delivery.* New York, NY: F.A.D.L.

Uphoff, J. 1986. *Improving international irrigation management with farmer participation: Getting the process right*. London, UK: Westview Press.

Uys, L. 2003. *A model for home-based care. In* L, Uys. & S, Cameron (Eds). 2003. *Home-based HIV/AIDS care*, p. 13. Cape Town: Oxford University Press.

Uys, L. & Cameron, S. 2003. *Home-based HIV/AIDS care.* Cape Town, RSA: Oxford University Press.

Van Dyk, A. 2005. *HIV/AIDS care & counselling: A multidisciplinary approach*. Cape Town, RSA: Pearson Education.

Van Rensburg, H. C. J. 2004. *Health and health care in South Africa*. Bloemfontein, RSA: Van Schaik.

VeneKlasen, L. & Millers. V. 2002. *A new weave of power, people and politics. The action guide for advocacy and citizen participation.* Oklahoma City, OK: World Neighbours.

Verzuh, E. 2008. *The fast forward MBA in project management*. New York, NY: John Wiley & Sons.

Wallerstein, N. 1993. *Empowerment in health: The theory and practice of community change*. London, UK: Zed Books.

Walt, G. 1990. *Community health workers*. Philadelphia, PN: Open University Press.

Weaver, A. 2004. *48,000 a year pour into city*. *Cape Times*. In M. Barry. & H. Rüther, *Data collection techniques for informal settlement upgrades in Cape Town, South Africa.* Retrieved on 12 August 2010 from http://www.cybertracker.co.za/Barry.pdf

World Bank. 1994. *The World Bank and participation*. New York: Cornell University Press.

WHO (World Health Organisation). 1978. *Declaration of Alma-Ata. Report on the International Conference on Primary Health Care, Alma-Ata, USSR*, 6-12 September. Retrieved on 2010/08/15 from http://www.who.int/hpr/NPH/docs/declaration_almaata.pdf

WHO. (World Health Organisation). 1985. *Community involvement in health development: Challenging health services.* World Health Organisation Report. Geneva, Switzerland: World Health.

WHO. (World Health Organisation). 2002. *Community home/community-based care in a resource limited setting*. Geneva, Switzerland: World Health Organisation.

Williams, G 2004. *Towards a repoliticization of participatory development: Political capabilities and spaces of empowerment*. In S. Hickey & G. Mohan (Eds.) *Participation: From Tyranny to Transformation? Exploring New Approaches to Participation in Development*. pp 92-107. London, UK: Zed Books.

World Health Report. 2000. *Health systems: Improving performance*. Geneva, Switzerland: World Health Organisation.

World Health Report. 2008. *Primary health care: Now more than ever*. Geneva, Switzerland: World Health Organisation.

Appendix A: Consent to participate in study

Dear Participant

I, Abraham Warren am currently studying for a master's degree at the above university in the Department of Social Development. I am interested in doing a study on the importance of community participation in health-care programmes, focusing on home-based care projects as an alternative strategy to institutional care, within the Dunoon community (Western Cape Metropole). Your participation will be highly appreciated.

Terms and condition of the agreement

Should you agree to participate in this study please note the following:

a) Your participation is voluntary.

b) The interview will be conducted with respect for your privacy.

c) Your information will be treated with confidentiality.

d) With your permission, this interview will be recorded on tape.

e) You will remain anonymous (i.e. your name will not be mentioned to anyone).

f) You are free to withdraw from the study anytime should you feel uncomfortable.

g) The information obtained will be used for research purposes only.

h) All information will be kept secure by the researcher at all times.

Thank you for your participation.

Abraham Warren Signature (Participant)

I agree/do not agree to participate in the study **Witness**

Appendix B: Semi-structured interview with community members of Dunoon

1) Are you proud of Dunoon community?

If *yes* please state

If *no*, please state

2) Do you have a sense of belonging in the community?

Please state in which way

3) Do you participate in any community activities in Dunoon?

Please list a few of activities

4) Who is responsible for the upliftment and the future of this community?

5) What are your aspirations and dreams for this community?

6) Who should have the final say in public participation processes pertaining to health services?

7) Have you ever attended an HIV/ AIDS awareness campaign in Dunoon?

If *yes*, how many?

8) Do you think HIV/AIDS is a threat to your community?

If *yes* why is it?

9) Have you ever spoken to a HBC worker in Dunoon?

10) What can be done to reduce the incidence of HIV/AIDS in Dunoon?

Appendix C: Semi-structured interview with home-based carers of the HBC Program

1) Please state the reason you became involved in the HBC programme?

2) How long have you been involved in the program?

3) As a home-based carer:

- What motivates you to volunteer?
- What are your needs/expectations as a home-based carer?
- How have your needs/expectations changed over time?
- How must the partnership manage the project to sustain this programme?

4) Participatory participation:

- Has your decision to be active in the development of appropriate health services increased your knowledge of health?
- Are you part of the decision-making process within the partnership?
- Do you have a good relationship with the local health services in the community?
- Do you have a good relationship with the local people in the community?
- Is there a sense of community involvement in health matters?
    - If *yes* please state.
    - If *no,* please state.

- If answer is *no,* what needs to be done to improve the community involvement in health?

5) What have been the obstacles carers have experienced within the HBC programme?

6) What are the challenges that you are facing as an HBC?

7) What are your aspirations and future plans for this program?

Appendix D: Semi-structured interview with supervisor of the HBC programme

1) How long has the HBC programme been running?

2) What is your length of service in this programme?

3) Please describe your role as overseer in this programme?

4) Please describe the criteria in recruiting HBC to this programme?

5) How does the community see the role of HBC?

6) How has this programme had a positive effect on the community?

7) Please describe if the programme has had a life-changing effect on the personal lives of carers.

8) Who is responsible for the counselling of the carers?

9) What have been the successes of this home-based care programme?

10) Please list some threats to the sustainability of this programme?

Appendix E: Semi-structured interview with director of the HBC Program

1) What is your length of service in this programme?

2) Describe the HIV/AIDS pandemic your organisation faced within the Dunoon community.

3) Describe the challenges the community has addressed in assessing the needs of home-based care for HIV/AIDS patients in Dunoon.

4) Describe the importance of the role of home-based caregivers.

5) How would you define *community participation*?

6) What does your organisation understand by the term *partnership*?

7) What role does the director play within the Dunoon partnership?

8) What has been the success of this partnership?

Appendix F: Semi-structured interview with PM4 Africa Partner

1) How did PM4 Africa become involved in this partnership?

2) Please state how long (duration) PM4 Africa has been involved in the programme.

3) What does your organisation understand by the term *partnership*?

4) What is PM4 Africa's role in this partnership?

5) How would you define *community participation*?

6) How important is participation to your organisation and where does it fit into the department structure?

7) What has been the success of this partnership?

8) What are your aspirations and future plans for this partnership?

9) Are there any possible threats to this home-based care program?

Appendix G: Semi-structured interview with Caltex/Chevron partner

1) How did Chevron/Caltex become involved in this partnership?

2) Please state how long (duration) Chevron has been involved?

3) Describe the role of partnership and level of collaboration?

4) Describe Chevron's global commitment to HIV/AIDS and illustrate how Dunoon HBC supports the Global Fund initiative?

5) How would you define *community participation*?

6) How important is participation to your department? Where does it fit into the department structure?

7) What does your company understand by the term *partnership*?

8) What have the successes of the Caltex/Heavenly Promise partnership been?

9) How do you define *community ownership*?

10) What are your aspirations and future plans for this partnership?

11) Are there any possible threats to this home-based care program?

Appendix H: Semi-structured interview with the Department of Social Development (DSD)

1) How did DSD become involved in this partnership?

2) Please state how long (duration) DSD has been involved?

3) How would you define *community participation*?

4) How important is participation to your department? Where does it fit into the department structure?

5) Does your department see participation as a means to an end, or as an end in itself?

6) What does your department understand by the term *partnership*?

7) What has been the success of this partnership?

8) What type of training does the department offer the HBC?

9) Describe why the training is an important element of this partnership.

10) What are the department's aspiration and future plans for this partnership?

Appendix I: Request to undertake research in the Department of Social Development Western Cape

DEPARTMENT OF SOCIAL DEVELOPMENT FOR SUSTAINABLE COMMUNITIES | DEPARTEMENT VAN MAATSKAPLIKE ONTWIKKELING VIR VOLHOUBARE GEMEENSKAPPE | ISEBE LOPHUHLISO LOLUNTU KUNIKWA ULUNTU INKXASO YOKUHLALA

Verwysing:
Reference: **Research into Home based care as an alternative strategy to Institutional Care: A case study on Dunoon home based caregivers**
Isalathiso:

Navrae:
Enquiries: **Ms P. Brink**
Imibuzo:

Telefoon:
Telephone: **+27 (21) 483 4512**
Ifowuni:

Mr A. Warren
Warrenac1@gmailcom

Dear Mr Warren

Request to undertake research in the Department of Social Development, Western Cape

It is a pleasure to inform you that your request to undertake research in the Department of Social Development has been approved by the Research Ethics Committee of the Department. Please liase with Ms Petro Brink on 021 4834512 or pebrink@pgwc.gov.za regarding arrangements for the interviewing of Departmental officials.

Yours sincerely

Head of Department.....

Directorate Research and Population Development
Private Bag X9112, Cape Town, 8000
Union House, 14 Queen Victoria Street, Cape Town, 8001
Tel: (021) 483 4595, Fax: (021) 483 5602
www.capegateway.gov.za/social_services

Appendix J: Letter of Introduction

Private Bag X17, Bellville 7535, Cape Town, South Africa
Telephone :(021) 959 3858/9 Fax: (021) 959 3865 /49
E-mail: pkippie@uwc.ac.za

To whom it may concern

Mr Abraham Warren is a registered master's student at the Institute for Social Development at the University of the Western Cape. Part of the requirements of the master's degree is that candidates complete a mini-thesis which documents research in a particular case study area.

Mr Warren has recently presented a research proposal to the Post Graduate Board of Studies entitled *Home/community-based care as an alternative strategy to institutional care: A case study in Dunoon home-based caregivers*. The Post Graduate Board of Studies has approved his proposal and ethical commitment. Mr Warren has now been given consent by the University of the Western Cape to commence with his research.

It is Mr Warren's responsibility to consult with the relative organisations and committee representatives in his selected case study area and gain permission to conduct the research and to explain the purpose of the intended investigation. Should you require any additional information, please do not hesitate to contact me.

Sharon Penderis

Senior Lecturer

Institute for Social Development, University of the Western Cape: 084 510 2772

Appendix K: Aerial Photo of Dunoon

Source: Strategic Development Information and GIS Department- City of Cape Town (2010).