

**PROFESSIONAL NURSE PERCEPTIONS OF THE ROLE OF HOME AND  
COMMUNITY-BASED CARERS PROVIDING CARE TO THE COMMUNITY IN  
THE CAPRICORN DISTRICT OF THE LIMPOPO PROVINCE**

by

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## DECLARATION

I declare that **PROFESSIONAL NURSE PERCEPTIONS OF THE ROLE OF HOME AND COMMUNITY-BASED CARERS PROVIDING CARE TO THE COMMUNITY IN THE CAPRICORN DISTRICT OF THE LIMPOPO PROVINCE** is my own work and that all the sources used or quoted have been indicated and acknowledged by means of complete references and that this work has not been submitted before for any other degree at any other institution.

SIGNATURE

(MRS CR JACKSON)

DATE .....

# **PROFESSIONAL NURSE PERCEPTIONS OF THE ROLE OF HOME AND COMMUNITY-BASED CARERS PROVIDING CARE TO THE COMMUNITY IN THE CAPRICORN DISTRICT OF THE LIMPOPO PROVINCE**

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## **ABSTRACT**

The study sought to explore professional nurses' perceptions of the roles of home and community-based carers in the Capricorn district of the Limpopo province as well as the problems they experienced and make recommendations to improve the quality of home and community-based care.

A qualitative approach with non-probability, purposeful sampling was used in this study. The sample consisted of professional nurses serving as focal points for home-based care in the area of the study.

The findings indicated that professional nurses believe that carers have a role in providing care to the community and serve as the extended hands of their services. However, challenges exist, which impact on the quality of service delivery.

Recommendations included the strengthening of existing elements, such as improving relationships, communication, and the care of carer's programme, carer training, reporting, and monitoring and carer distribution.

### **Key concepts**

Capricorn district; carers' roles; home and community-based care; professional nurses

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## List of abbreviations

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AIDS	Acquired immuno-deficiency syndrome
ARV	Antiretroviral therapy
CBC	Community-based care
CBO	Community-based organisation
CBW	Community-based workers
CBWS	Community-based worker systems
CHBC	Community home-based care
CHW	Community health worker
DOTS	Directly observed treatment short course
HCC	Home and community care
HBC	Home-based care
HCBC	Home- and community-based care
HIV	Human immune virus
ICHC	Integrated community-based home care
MMAAK	Movement of Men Against AIDS in Kenya
NGO	Non-government organization
NPO	Non-profit organisation
PLHA	People living with HIV/AIDS
RHM	Rural health monitors
TB	Tuberculosis
TASO	The AIDS support organisation
SA	South Africa
STD	Sexually transmitted disease
UNAIDS	United Nations Program on Acquired Immunodeficiency Syndrome
WHO	World Health Organization

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# **CHAPTER 1**

## **Orientation to the study**

### **1.1 INTRODUCTION**

Home and community-based care (HCBC) has been practised throughout the ages. Care at home was provided mostly by women and initially for their family members. In fact, ancient Hebrew nurses participated in planned visitation programmes of sick people in their homes (Dolan 1978:15).

During the first century of the Christian Church, deaconesses provided care at home. They were called visiting nurses and were the forerunners of community health nursing of which home-based care forms a part (Dolan 1978:45). St Francis de Sales was instrumental in the establishment of a voluntary organisation who visited the sick in their homes. These women dressed patients' wounds and performed basic physical and household care (Dolan 1978:91). This thread can be traced throughout history and is evident today in most countries, including North America and Europe (Uys & Cameron 2003:3). It has taken different forms in different countries based on the availability of resources, cultural issues and context.

Due mainly to the inability of the health care system to meet the ever-increasing demand for services to the chronically ill and disabled, the need has once again arisen for HCBC. This has been exacerbated by the advent of the HIV/AIDS epidemic and the increasing aged population (Health and Development Networks [HDN] 2001:13).

The Department of Health (DOH) (2001:1) defines home care as "the provision of health services by both 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". Home care is a comprehensive service and includes preventive, promotive, therapeutic, and rehabilitative, long-term maintenance and palliative care (DOH 2001:4; Van Dyk 2005:260).

The goal of such care is to ensure that clients and families maintain their independence through receiving high quality care that meets their needs so as to ensure a quality life (World Health Organization [WHO] 2002a:6). In addition, the goal is to provide the organisational structures, resources and frameworks that will enable the family to look after its own sick members. This includes empowering and educating the community to provide holistic care, support to sick members and prevention of transmission as well as reducing the social and personal impact of living with HIV infection (Van Dyk 2005:267).

In the South African context, the shortage of hospital beds resulting in overcrowding, the inadequate number of medical, nursing and allied health professionals in the public sector and the cost of institutional care have increased the need for home care (DOH 2001:2; Van Dyk 2005:259). Moreover, the vast rural nature of the country, the large population of unemployed (26,7%) and poverty stricken people, especially women, has popularised HCBC in that it is seen as a means of educating oneself with a view to the possibility of one day finding employment as well as meeting the health needs of the community (Van Dyk 2005:259). In the deep rural areas, there is a community/social orientation where people support one another, thus HCBC meets their needs and is found to be acceptable. The good of the community is highly valued and thus HCBC supports traditional values (Ejiza 2000:1; Van Dyk 2005:260). The WHO (2002a:8) emphasises that community-based care is care that the consumer can access nearest to home, responds to the needs of people and encourages traditional community life.

In the Capricorn district of the Limpopo province, conditions are very similar to those mentioned above. Limpopo has a population of 5 273 637 with 1 154 693 people living in the Capricorn district (Department of Statistics 2005).

HCBC was commenced in this province in approximately 1998 by non-governmental organisations (NGOs). The government became involved in HCBC in 2000 and employed a provincial coordinator in 2001. Communities were mobilised and HCBC services increased with non-profit organisations (NPOs) and community-based organisations (CBOs) establishing programmes throughout the district. At present, fifty (50) funded HCBC organisations operate in the Capricorn district (Limpopo Department of Health and Social Development 2006:1).

According to Bopape (2006), Capricorn District HIV and AIDS Coordinator within the Limpopo Department of Health and Social Development (2006), the programme was not

initially formally introduced to the health sector in this district. The roles and responsibilities of all the role players, particularly the caregivers and nurses, were not clarified. Dealings with current HBC carers and nurses found that, in some instances, health professionals view the service with suspicion in terms of quality of service provided and the possibility that this category of health worker, home-based carer, may take over their work, as many carers do aspire to become health workers.

For HCBC to be effective and a quality service provided to the community, then, it was decided that perceptions and clarity regarding roles should be established. This study therefore endeavoured to examine and determine these perceptions.

The roles of nurses and caregivers have been researched in the United Kingdom (UK), Botswana, the United States (USA) and in the hospice context in South Africa, but no studies have been done in the Capricorn district, Limpopo (Mooka 2004:10; Rice 2001:24; Uys & Cameron 2003:119:7; Van Dyk 2005:263).

## **1.2 BACKGROUND TO THE PROBLEM**

The majority of HCBC services in South Africa have been established through communities identifying needs and developing strategies to address these needs. Initially, this was done informally and led by NGOs (Bopape 2006).

The escalating HIV/AIDS epidemic has increased the need for home care and resulted in a more programmatic approach (WHO 2002a:8). According to the National HIV and Syphilis Antenatal Sero-Prevalence Survey in South Africa 2006, the prevalence rate in South Africa declined from 30,2 % in 2005 to 29,1% at the end of 2006. In Limpopo, the rate decreased from 29,5% to 29,0% (DOH 2006:13). It was noted, however, that the prevalence rate in the Capricorn district rose from 22,2% in 2005 to 24,2% in 2006. This resulted in an increase of AIDS-related conditions requiring care and support. The inadequate number of medical, nursing and allied health professionals in the public sector, the cost of institutional care, and overcrowding of hospitals compound the problem.

The DOH (2001:1) has built on the groundwork done by NPOs, scaling up and formalising the programme through the development of guidelines and a training course.

As indicated earlier, community members originally initiated HCBC to assist family and community members in need. Consequently, the care provided was basic and limited to the skills that carers had and was not guided by professional nurses. Thus, community professional nurses were initially excluded and may not have been aware of the importance of their role. This exclusion may have resulted in a lack of cohesion and coordination between carers and professional nurses as well as the quality of care being unclear.

Home care is a fragile, new field in South Africa requiring support and standardisation so as to ensure quality care (Van Dyk 2005:260, 263). This is a problem because case management is essential in order to ensure the provision of quality care. The professional nurse, as the health professional and team leader with the competence to identify needs and develop plans accordingly, must do this. Research into nurses' roles stresses the importance of nurses leading and guiding carers in their work. In Botswana, Mooka (2004:10-11) found that community nurses are needed to assess the needs of patients and supervise caregivers. In addition, they need to be permanently employed to run HBC programmes.

According to Rice (2001:13), quality patient care is accomplished through a multidisciplinary approach where home care nurses functioning as case managers develop the plan of care. Moreover, nurses must recognise and value their pivotal role in determining what home care will become. Rice (2001:25) and Van Dyk (2005:263) identify the roles of nurses in home care as patient educator, case manager and patient advocate.

The DOH (2004:12,13) and Van Dyk (2005:331) emphasise the professional supervision of carers and family caregivers and the right of patients and people living with HIV/AIDS (PLHA) to expect quality care by trained supervised caregivers, supported by a home care team coordinated by a professional nurse.

### **1.3 STATEMENT OF THE PROBLEM**

The role of home-based carers in providing care to the community in the absence of community health services and inadequate hospital care has become vital (HDN and AIDS-Care-Watch Campaign 2005:1).

These carers, due to their limited skills and training require support from health professionals, particularly professional nurses so as to provide appropriate quality care. It has been noted that some professional nurses do not support home-based carers, thus resulting in carers providing a service to the best of their ability but without the guidance of professional nurses (Bopape 2006).

It is within the scope of professional nurses trained in community health to develop care plans based on a nursing diagnosis. Carers could carry out the nursing plans with their support (Regulation R2598, 1984, Paragraph 2a) (South Africa (Republic) 1989).

Home-based carers experience stress as a result of the lack of support. Faced with a patient requiring assistance, they may operate beyond their scope of training and competence, resulting in dangerous situations (Andrews & Darby 1995:174; Van Dyk 2005:325).

The DOH (2000b:22) supports home-based care (HBC) and views it as a mechanism for providing care to the community and empowering community members through the process as well as strengthening community partnerships. Accordingly, a care and support unit has been established to support the programme. This involves the provision of funds for stipends for carers through NPO funding (DOH 2007c:84).

Due to the already large public service and scarcity of skilled professionals, however, the DOH has not appointed nurses or a health team to support the HCBC programme at health facility level to manage the carers' work. This is currently done through informal systems set up within the primary health care (PHC) setting. Professional nurses based at clinic and community centre level have the additional function of supporting HCB carers. This puts additional pressure on already overburdened nurses who then are reluctant to support the carers. Importantly, nurses have not been consulted regarding these carers and their extended role (Bopape 2006).

This situation raised the following questions in the researcher's mind:



- What do nurses think about the work done by HCB carers?
- How do nurses perceive their role in this regard?
- Would this influence the quality of care provided?
- What systems would nurses recommend for improving the situation?
- What do carers perceive as their role and that of the nurses?
- How could these relationships be strengthened?

The research results may benefit health care policy makers as well as staff, clients and patients, as possible strategies may be developed based on the findings to address the current situation. Clarity may be gained on professional nurses and carers' roles thereby resulting in strengthening relationships and improving quality of care. Accordingly, the researcher wished to examine professional nurses' perceptions of the role of home-based carers.

#### **1.4 PURPOSE OF THE STUDY**

The purpose of the study was to examine and determine professional nurses' perceptions of the role of home and community-based carers providing care to the community in the Capricorn District of Limpopo.

#### **1.5 OBJECTIVES OF THE STUDY**

The objectives of the study were to

- determine professional nurses' perceptions of the roles of home-based carers in providing care to communities
- ascertain the problems that professional nurses experience in implementing HCBC
- make recommendations for strategies to improve the quality of HCBC and for further research

#### **1.6 SIGNIFICANCE OF THE STUDY**

The study was expected to provide insight into professional nurses' perceptions of the role of home-based carers. This would lead to an understanding of challenges encountered in the implementation of the programme by professional nurses. The findings could lead to the improvement of relationships and help to reduce barriers between nurses and carers. Moreover, the findings would add to existing knowledge because similar studies have not been conducted, particularly in the Limpopo province where home-based care services are mostly informal, lack professional supervision, and the quality is undetermined (Bopape 2006).

The findings would contribute to nursing knowledge and provide direction for further investigation as limited research has been done on home-based care. Moreover, possible concerns regarding role encroachment by informal carers on professional nurses are sensitive and warrant description and exploration. The findings would provide direction for further investigation as limited research has been done on home-based care.

The findings would also assist policy-makers to develop policies to address identified issues. Finally, the beneficiaries, that is, community members, would also benefit from the study, as better understanding would result in improved service delivery.

## **1.7 RESEARCH DESIGN AND METHODOLOGY**

A qualitative approach was selected because the study focused on professional nurses' perceptions. A qualitative approach was best suited, therefore, to determine the respondents' views and beliefs regarding the phenomenon of the role of home-based carers. The essence of qualitative research is a belief that multiple realities do exist and thus create meaning for individuals studied. Individuals who participate in social actions come to know and understand phenomena through these interactions (Streubert & Carpenter 1999:16).

A descriptive qualitative design was appropriate for this study. The purpose of the study was to explore the respondents' perceptions. This method would bring language to these human experiences and was suited to offering nursing an opportunity to describe and clarify phenomena important to practice (Streubert & Carpenter 1999:62).

A descriptive qualitative design involves direct exploration, analysis and description of particular phenomena. It stimulates perception of the lived experience and emphasises the richness, breadth and depth of these experiences. It contains three steps, namely intuiting, analysing and describing (Streubert & Carpenter 1999:59). Intuiting is the process whereby the researcher becomes totally immersed in the phenomenon under investigation. The researcher remains open and avoids all criticism, evaluation or opinion and pays strict attention to the phenomenon as described (Streubert & Carpenter 1999:49).

During analysis, the researcher rereads the data several times in order to identify the essence of the phenomenon under investigation. Describing the phenomenon is an integral part of the intuiting and analysing processes. Its aim is to communicate the verbal and written descriptions of the critical elements of the phenomenon. The description is based on the groupings of the phenomenon. Premature description is a common error and should be avoided (Streubert & Carpenter 1999:52).

## **1.8 POPULATION AND SAMPLE**

The population consisted of professional nurses working at government health facilities in the Capricorn district of Limpopo and who serve as focal points for home-based carers.

Non-probability, purposeful sampling was used to ensure that the respondents were selected based on their knowledge of the phenomenon. Purposeful sampling is done when researchers select the sample based on existing knowledge of the population and the purpose of the research (Babbie & Mouton 2002:166). This is a method of choice in qualitative studies as its use provides information-rich cases for in-depth study. The advantage of this form of sampling is that it is possible to acquire rich data from informed participants (Streubert & Carpenter 1999:58).

The sample consisted of professional nurses currently placed at health facilities in the Capricorn district of Limpopo, who were linked to home and community-based services and had served as the focal point for these carers. The respondents thus had experience and knowledge of working with them.

Professional nurses from the sub-districts in the district were invited to participate. The District HBC Coordinator provided a list of health facilities, names of professional nurses and their contact details. The researcher contacted the respondents and invited them to participate in the study.

## **1.9 DATA COLLECTION AND ANALYSIS**

Data was collected by means of two focus group discussions. A focus group is a semi-structured group session moderated by a group leader and held in an informal setting. Focus groups are well suited to the collection of qualitative data as they are inexpensive and flexible.

This method is effective in gaining insight into people's opinions and is capable of producing rich data (Streubert & Carpenter 1999:24). The disadvantage of this method is the possibility of *group think* occurring. This occurs when stronger members of the group have control or influence over the inputs/verbalisations of the other participants (Streubert & Carpenter 1999:24).

This limitation of this method was addressed by using a skilled group leader who could overcome this tendency by remaining mindful of this during the data-collection process (Streubert & Carpenter 1999:24). This method was chosen for the study as it enabled the researcher to determine the respondents' perceptions of the roles of home-based carers.

Data analysis is conducted to reduce, organise and give meaning to the data. Data analysis usually begins when data collection begins. In this study, descriptive and inferential analysis techniques were used. The analysis techniques implemented are determined primarily by the research objectives, questions or hypothesis (Burns & Grove 1999:43).

In this study, data analysis commenced in the data-collection phase, as is characteristic in qualitative research. The researcher listened carefully so as to discover meanings. A period of immersion followed at the conclusion of the data-collection phase when the researcher dwelt on what had been discovered. The cyclic nature of questioning and verifying is important in qualitative research. The data was analysed by means of clustering similar data into themes, which are structured meaning units of data. This

helped the researcher cluster information and discover the meanings intended in what she had observed and heard (Streubert & Carpenter 1999:28).

The total experience was described, including the respondents' responses to the questions. The interviews were tape-recorded and the data transcribed verbatim. The researcher read and re-read the transcriptions to identify themes and categories.

### **1.10 VALIDITY AND RELIABILITY**

The quality of a research instrument is determined by its validity and reliability. Validity is the degree to which an instrument measures what it is supposed to measure (Uys & Basson 1995:80). Reliability is the degree of consistency or dependability with which the instrument measures the attribute it is designed to measure. If the instrument is reliable, the results will be the same each time the test is repeated (Polit & Hungler 1997:308). Trustworthiness, credibility, dependability, transferability and confirmability are measures to ensure validity.

- **Trustworthiness**

Trustworthiness is the process whereby the researcher confirms that the findings accurately reflect the respondents' experiences and views and not the researcher's perceptions. This was done by the use of triangulation and returning to the respondents for confirmation. The researcher tape-recorded the interviews and took field notes (Polit & Beck 2004:36, 57).

- **Credibility**

The categories, themes and sub themes were confirmed with the respondents at a follow-up group session after completion. According to Streubert and Carpenter (1999:29), credibility is required to ensure that the people who have lived the described experience have an opportunity to validate the reported findings that describe their experience.

- **Dependability**

This criterion was met once the credibility of the findings had been determined (Streubert & Carpenter 1999:29).

- **Transferability**

Transferability refers to the probability that the findings will have meaning to others in similar situations (Streubert & Carpenter 1999:29).

The researcher must provide sufficient thick, descriptions so that consumers can evaluate the applicability of the data to other contexts (Polit & Beck 2004:435). Sufficient data must be generated for other researchers to judge transferability, if so desired.

- **Confirmability**

Confirmability was ensured through leaving an audit trail of all processes and documentation throughout the study. This will ensure that another individual may follow the activities and processes followed by the researcher. The objective is to illustrate the evidence and thought processes that led to the conclusions. However, this criterion may be problematic, as one researcher may not agree with the conclusions of another (Streubert & Carpenter 1999:29).

## 1.11 ETHICAL CONSIDERATIONS

Ethics deals with matters of right and wrong. *Collins English Dictionary* (1991:533) defines ethics as “a social, religious, or civil code of behaviour considered correct, esp. that of a particular group, profession, or individual”.

The researcher obtained approval from the Ethical Committee of the Limpopo Department of Health and Social Development to conduct the study. The researcher explained the purpose and significance of the study to the respondents before obtaining written informed consent from them. The respondents were briefed on their role and estimated time commitments, assured of confidentiality and anonymity, and informed what would be done with the findings. In addition, as is deemed acceptable in qualitative research, the respondents were given the option throughout the study to withdraw at any time, if they so wished. Confidentiality was ensured by not linking inputs to individual respondents (Streubert & Carpenter 1999:38). Scientific honesty on part of the researcher was ensured through establishing a relationship of trust with the respondents (Streubert & Carpenter 1999:36, 37). The researcher endeavoured to keep presuppositions or personal biases set aside throughout the investigation. This was done by returning transcriptions to the respondents for verification so as to ensure the accuracy of their inputs (Streubert & Carpenter 1999:41).

## 1.12 DEFINITION OF KEY TERMS

For the purposes of this study, the following terms were used as defined below.

- **Care**

The *Oxford Advanced Learner's Dictionary of Current English* (2000:163) defines care as “to watch over, to attend to and to provide for. It is the process of caring for somebody and providing what they need for their health or protection”. In the context of home care, it is comprehensive and includes basic physical, emotional, psychological and spiritual support.

- **Carer**

A carer is a person who looks after a sick person at home (Van Dyk 2005:164, 323).

- **Case management**

Case management refers to a formal process involving assessment of needs, service planning, service co-ordination and monitoring (Van Dyk 2005:331).

- **Community-based care (CBC)**

CBC is the care that “the consumer can access nearest to home, which encourages participation by people, responds to the needs of people, encourages traditional community life” (DOH 2001:1; Van Dyk 2005:262).

- **Community-based organisation (CBO)**

A CBO is an organisation situated at community level and addressing community identified needs at this level.

- **Community**

Stanhope and Lancaster (2004:342) describe a community as “a social group determined by geographical boundaries and/or common values and interests. Its members know and interact with each other.”

- **Home-based carers**

Van Dyk (2005:323) describes home-based carers as “people who may be from the formal or informal sector and provide care to community members as required”.



- **Home-based care (HBC)**

The WHO (2002a:6) and Van Dyk (2005:260) define HBC as 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 and health towards a dignified death.

- **Non-profit organisation (NPO)**

An NPO is an organisation operating not for profit and registered with the Department of Social Development.

- **Perception**

The *Oxford Advanced Learner's Dictionary of Current English* (2000:864) defines perception as "the ability to understand the true nature of things; an idea, belief or image that you have as a result of how you see or understand things". In this study it refers to professional nurses' perceptions of home-based carers and their role.

- **Professional nurse**

A professional nurse (PN) is a registered nurse who practises the profession of nursing (Searle 2000:70).

- **Quality**

Quality is a degree of excellence. It is the standard of something when compared to other things (*Oxford Advanced Learner's Dictionary of Current English* 2000:953). In the context of HBC it is the meeting or exceeding of the customers needs (Biggs 1996:305) and providing care according to set standards.

- **Role**

The function or position that a person has or is expected to have in an organisation, in society or in a relationship (*Oxford Advanced Learner's Dictionary of Current English* 2000:1021).

### **1.13 OUTLINE OF THE STUDY**

Chapter 1 outlines the problem, purpose and significance of the study, the research design and methodology, data collection and analysis, and defines key terms.

Chapter 2 covers the literature review conducted for the study.

Chapter 3 describes the research design and methodology.

Chapter 4 discusses the data analysis and interpretation.

Chapter 5 concludes the study, presents the findings, and makes recommendations for practice and further research.

### **1.14 CONCLUSION**

This chapter presented the background to the problem, the purpose, objectives and significance of the study; described the research design and methodology, including the population and sample, data collection and analysis, and ethical considerations; defined key terms and presented an outline of the study.

Chapter 2 deals with the literature review conducted for the study.

In this chapter the key issues relating to the study were discussed. This included the statement of the research problem, the background to the problem, the research objectives as well as the study design to be employed. Additionally, the ethical considerations were addressed.

## **CHAPTER 2**

### **Literature review**

#### **2.1 INTRODUCTION**

A literature review is “a systematic process whereby a search is performed to determine the existing body of knowledge relating to the proposed topic under study” (Ganga-Limando 2004:2).

#### **2.2 PURPOSE OF THE LITERATURE REVIEW**

The purpose of a literature review is “to determine the extent to which the topic under study is covered in the existing body of knowledge” (Babbie & Mouton 2002:565).

In qualitative research, extensive literature reviews are not generally done prior to the study as this might result in the researcher leading the participants in the direction of what had previously been discovered. However, in this study, a full review was done at its commencement and bracketing was applied (Streubert & Carpenter 1999:20).

#### **2.3 SCOPE OF THE LITERATURE REVIEW**

The researcher conducted a traditional literature review. The literature review covered the key concepts of and available information on professional nurses' perceptions of the role of home and community-based carers providing care in the community, thus indicating the researcher's understanding of the topic. The review also included the theory or conceptual framework underpinning the study (Ganga-Limando 2004:2).

## **2.4 THEORETICAL LITERATURE RESOURCES**

Concepts in theories refer to studies underpinned by one identified theory whereas a research model refers to a diagrammatical representation of concepts or theories to guide the study (Ganga-Limando 2004:5).

Watson's (2002:100) theory of human caring emphasises that caring is central to the provision of home care. Nurses or carers participate in human caring to protect, enhance and preserve life by assisting individuals to find meaning in illness and to gain self-knowledge, self-control and self-determination in health decisions, life style management and self-healing. A holistic approach to patient care is fundamental to home care (Watson 2002:100). Rice's (2001:19) model of dynamic self-determination for self-care was also relevant to this study, as home care is mostly about realisation of the available potential of the patient so as to regain health.

## **2.5 THE ROLE OF HOME AND COMMUNITY-BASED CARERS PROVIDING CARE TO THE COMMUNITY**

The study wished to determine the perceptions of professional nurses of the role of home and community-based carers providing care to the community. Although home and community-based care has been around for a long time, it nevertheless appears to remain an informal community service in which a team approach and the implementation of a comprehensive quality service to communities has not generally been realised. The researcher sought reasons for this in order to develop strategies to address these challenges. Key issues included defining care and caring; how it is understood; whose responsibility it is to provide care, and what the various role players' roles are. This would have major implications for the quality and type of care provided.

*Collins English Dictionary* (1991:244) defines *care* as "to provide physical needs, help, or comfort (for); to look after someone and keep them in a good state or condition". A critical feature of care is one person's responsibility for another, which involves looking after someone in need of help. Care is a general term used to indicate what is done for others, it does not specify why care is needed and what actions or resources are required (Orem 2000:25). Care is provided to assist patients reach their potential for optimal health (Watson 2002:100). To take care is seen as an act of justice in every life

situation, which is particularly important in the context of caring for others (Searle 2000:213).

The *Oxford Advanced Learner's Dictionary of Current English* (2000:163) defines *caring* as “the act of showing compassion, being thoughtful, considerate, concerned and sensitive to another's needs”. Orem (2000:29) and Watson (2002:10) emphasise that caring is a complex human phenomenon that may be viewed as an attitude, an ability, an attribute or characteristic or a complex of interrelated behaviours.

Cara (2003:53) refers to Watson's caring theory, which introduced *clinical caritas processes* as key to caring. Watson did this as her theory evolved from caritas factors to caritas processes. The word *caritas*, which originates from the Greek and Latin, means to cherish and give special loving attention. A few of the caritas processes which clearly depict the essence of caring include developing and sustaining a helping/trusting, authentic caring relationship; the creative use of self to engage in the artistry of caring healing practices; creating a healing environment, and assisting with basic needs (Cara 2003:53).

In addition, both Watson (1999:129) and Cara (2003:55) view caring as a moral imperative, an interpersonal interaction and a therapeutic relationship. The act of caring is integral to the holistic human health experience. Caring is valued by the majority of people in society and is essential to healing and health. It is also the essence of nursing (Chen 2001:1).

All the above definitions comprise relevant key elements of care. In the context of this study, care was seen as comprehensive, addressing basic physical, emotional, psychological and spiritual needs as identified by the patient and the carer in an effort to assist the patients to reach their full potential. Furthermore, caring was regarded as a holistic process whereby a caregiver provides comprehensive care, based on the client's needs as determined jointly by both client and carer. The extent of caring in home care has not been determined and is possibly linked to perceptions of the concepts.

*Home care* involves the provision of health services by both 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 according

to the DOH's (2001:1) guidelines on home-based and community-based care. Home and long-term care has become necessary due to the advent of HIV/AIDS as well as the increase in chronic illnesses. This is compounded by the spiralling costs of institutional care and the lack of adequate hospital beds. Thus home care is provided to replace acute care to prevent the need for institutionalisation and maintain individuals in their own homes and communities, which are familiar to them so that they can enjoy quality in their lives (WHO 1999:11).

The Department of Health's (DOH 2001:1) guidelines indicate that home care is comprehensive and includes provision of basic physical, emotional, psychological and spiritual support as well as a preventive, promotive, therapeutic, rehabilitative and palliative care services in the home environment.

Home care aims at assisting the client and family return to an optimal level of health and independence. This should be done in accordance with the client's needs. A primary objective of home care is to facilitate self-care, as care is not available twenty-four hours a day (Stanhope & Lancaster 2004:963, 968).

In the United States of America (USA), home care has evolved to become a prominent sector in the health care system where managed care is provided by agencies (Rappaport 2000:15).

The findings and recommendations of the 1st Southern African Regional Community Home-based Care Conference (HDN 2001:5) defines HCBC as care given to individuals in their own natural environment by their families supported by skilled personnel and communities. Regarding the plight of AIDS patients in rural South Africa, Hardman (2001:13) found that volunteers visit ill patients in their homes and provide holistic care. In Uganda, terminally ill patients are cared for in their homes (Hardman 2001:13).

In a study on the experiences of and impact on young girls and older women caring for family members in Botswana, Lindsey, Hirschfield, Tlou and Ncube (2003:489) found that their families, supported by welfare officers and the community, provide care to individuals at home. The setting for the provision of care, the need for home care and what it involves as defined in the literature review served as a standard for the study.

A *caregiver* is a person who is responsible for caring for another in need and is known as a care agent or caregiver. Caregivers have a relationship with the person they care for, which is determined by the care required (Orem 2000:25). Caregivers may be professionals, laypersons or family members who provide care to those in need in the context of the home within the community.

In rural Swaziland, McCreary, Mkhonta, Popovich, Dresden and Mndebele (2004:19) found that family care givers provide home care services mostly and although this service is valuable they experience difficulty due to lack of resources. Mooka (2004:5) examined home-based care of terminally/chronically ill persons by family caregivers in Botswana, and found that family caregivers' needs were not known and they were not prepared for their role as caregivers. Lindsey et al (2003:495) found that older women and young girls were the main caregivers of family members in Botswana.

In a study in Kenya to determine the priority needs and interventions necessary to plan, develop and implement community home-based care and assess the impact of caring on women and children, the WHO (2001:31-37) found that caregivers are mostly uneducated and need psychological support and counselling. Furthermore, care to family members and siblings was provided by children, mostly girls but at times also boys. It was noted that elderly people mostly grandmothers had taken over the care giving role in the absence or death of adult children. Some caregivers did not know the cause of the illnesses of their clients and had little understanding of diseases. Caregivers mostly work on a volunteer basis and are often linked to NPOs and church groups. Many lack resources and supplies to provide the service and live in poverty themselves. Time spent providing care ranges from two to ten hours daily (WHO 2001:31-37).

Although men are generally traditionally excluded from providing HCBC, a group in Kenya, Movement of Men Against AIDS in Kenya (MMAAK), provide care to HIV-positive men, which includes group therapy and counselling (Home-based care: women ... 2004).

In Zimbabwe where men are not generally involved in soft care as this is traditionally not their role, they increasingly support HIV-positive men and use their influence to advocate for sustainable HCBC (Dongozi 2005).

In the context of this study, caregivers were people, both family and community members of all ages, motivated to provide care for others for religious reasons or from a sense of duty to their community and family members. This may not be from choice but rather of necessity as there may be no one else to do so. Many of these caregivers live in poverty themselves and have hopes that, if they are patient and dedicated enough, government employment may follow in time.

Regarding the *roles of caregivers*, in the USA, the nurse serves as the caregiver, and the nurse's roles include that of a patient educator, patient advocate and case manager (Rice 2001:24). In the hospice context in South Africa, the roles of caregivers vary depending on their background and position within the care network (Uys & Cameron 2003:119). In Botswana, Mooka (2004:10) found that family caregivers' roles are to provide care to sick members of their families. In Kenya, community health workers provide HBC to HIV/AIDS clients as well as prevention education to their communities (Johnson & Khanna 2004:497).

In a study on models of community/home-based care for people living with HIV/AIDS in southern Africa, Ncama (2005:35) found that roles of caregivers vary depending on the service model of home care offered. Caregivers providing home visiting, mainly visit patients and spend time talking to and educating them and their family. They also provide household support, such as cleaning and cooking, and accompany them to health facilities, whereas caregivers providing comprehensive HBC provide these services as well as basic health care, palliative care and DOTS (Ncama 2005:35).

In the African context, the family member as caregiver has traditionally been the accepted practice especially in the rural setting (Kiwonbojjo 2001:3; Mooka 2004:5). Similar practices are found in the UK and USA, although these primary carers are supported to some degree by professional staff, which is not generally the case in Africa (Nolan, Grant, Keady & Open 2003:131; Rappaport 2000:43; Rice 2001:24).



The role of caregivers includes the provision of basic health care, such as changing dressings; physical care including bathing, dressing, changing soiled linen, cooking, symptom management, fetching wood and water, and cleaning the home (WHO 2001:25; WHO 2002b:35).

The literature review indicated that the role of caregivers is to provide basic care and assistance as deemed necessary by the condition of the client. In addition, the support received differs widely (WHO 2001:25; WHO 2002b:35; Mooka 2004:5; Ncama 2005:35; Uys & Cameron 2003:119; Kiwonbojjo 2001:3).

In this study, the expected role of caregivers agreed with the literature, but professional nurses' perception of this role in the South African context was further explored.

## **2.6 THE ROLE OF NURSES**

In her study on the interaction between caregivers and professional care providers, Mooka (2004:10-11) stresses the importance of the nurse leading and guiding carers in their work. In Botswana, community nurses are needed to assess the needs of patients and supervise caregivers, and nurses need to be permanently employed to run HBC programmes (Mooka 2004:11).

Nurses are seen as a major resource in home care programmes. They perform a variety of roles which include assessment, case management, provision of chronic care and acute nursing care, preventative care, and collaboration with physicians, links with the broader health system and monitoring of community-based home care services. Additionally nurses provide pain relief, palliative care and facilitate referrals (WHO 1999:21, 25).

With regard to family care giving in rural Swaziland, McCreary et al (2004:18) highlight the value of the rural health monitors and how they link the carer to the clinic and nursing staff. Zimba and McInerney (2001:90) examined the knowledge and practices of primary caregivers regarding HBC in Malawi, and note the importance of preparation of carers for their roles. In Brazil, Gupta, Da Silva and Passos (2005:244) investigated the role of integrated HBC in patient adherence and found that HBC applied in a team context made valuable contributions to adherence to the provision of antiretroviral

therapy. Regarding the role of capacity building in CHBC, Kiwonbojjo (2001:3) stresses the need for an integrated approach.

Professional nurses' roles in HCBC also include coordinating the care team, conducting team meetings and providing training and resources, for example, equipment, medication and various supplies. Nurses may be dedicated to the HCBC programme or have dual functions of providing health services at clinics or hospitals as well as supporting HCBC services (WHO 2001:55).

There is a need for caregivers to be supervised, trained, supported and monitored in a team approach in the primary health (PHC) context in South Africa, Kenya, Nigeria and Botswana (Hardman 2001:12; Johnson & Khanna 2004:501; Ncama 2005:37).

## **2.7 QUALITY HOME-BASED CARE (HBC)**

Quality is a continual striving for excellence and a conforming to specific guidelines and standards. The definition rests largely with the perceptions of the client and provider, each having a different focus (Stanhope & Lancaster 2004:519).

Quality assurance is "the promise that the set standards of excellence are being met in the delivery of care. It is concerned with the accountability of the provider" (Stanhope & Lancaster 2004:519).

In the context of quality, HBC is meeting or exceeding the customer's needs and providing care according to set standards (Biggs 1996:305). In order to facilitate quality services, policy guidelines, standards and regulations to govern HCBC must be developed (WHO 2002a:70). Community coordinators and health professionals must ensure the implementation of these standards through sound, regular monitoring and evaluation practices. Members of the HCBC team are responsible to ensure that their practices conform to these standards. Team members and HCBC clients should participate in the development of these standards (WHO 2002a:70). In order to facilitate quality assurance, it is thus essential to develop practical guidelines based on these policies, determine the roles and responsibilities of all role players, and develop standards for monitoring performance (WHO 2002a:70).

It is vital to develop outcome measures for HCBC as well as to ensure the availability of adequate resources, namely staff, supplies, equipment, education and financing. In addition, the development of quality care indicators is needed. Beneficiaries and members of the HCBC team should assess these indicators. External assessors should also assess quality of care during outcome evaluation. Examples of quality care indicators in terms of the ill person would include access to health care, medicines, supplies and provision of basic nursing care, comfort measures, house cleanliness and satisfaction with quality of care provided, among other things (WHO 2001:67).

Quality assurance, monitoring and evaluation are essential elements of HCBC programmes and must be in place (WHO 2001:68). Quality indicators for HCBC team members include adequate educational preparation, psychosocial support, adequate supervision and monitoring and case management (WHO 2002a:70). Monitoring and supervision of HCBC programmes is integral to ensuring quality of care. This is usually done by a nurse and ensures adequate and effective care delivery. Activities may include conducting site visits and promoting peer supervision (WHO 2002a:73).

HCBC requires standards, policies and indicators in order to be acceptable and must be implemented by nurses to ensure quality, especially in resource-limited settings (WHO 2001:68; WHO 2002a:70-73). This, again, stresses the need for exploring and formalising the role of professional nurses in HCBC, which also leads to the need for discharge planning and case management.

## **2.8 DISCHARGE PLANNING AND CASE MANAGEMENT**

The purpose of case management is the identification of core tasks, setting achievement goals, assessing individual needs, care planning, implementation, monitoring and review (Cowen 1999:87).

Discharge planning is an essential element of HCBC and starts at the health facility. Tools should be used to ensure effective referrals to home-based carers and back to relevant health service (WHO 2002a:49). Health professionals often do not respect referrals from caregivers.

Case management should be effected by the HCBC team leader to ensure that care is well coordinated and to avoid gaps in the care provided (WHO 2002a:52).

There is concern over discharge planning, case management and the supervision of caregivers. According to Rice (2001:13), quality patient care is accomplished through a multidisciplinary approach in which home care nurses functioning as case managers develop the plan of care. Case management is a formal process involving assessment of needs, service planning, and service coordination and monitoring. Nurses must recognise and value their pivotal role in determining what home care will become. Rice (2001:25) identifies the various roles of nurses in home care as patient educator, case manager and patient advocate.

In order to determine priority needs and interventions necessary to assess, plan, develop and implement an effective CHBC programme in Kenya, the WHO (2001:71) found that there is a need for professional supervision of carers and family caregivers. With regard to the impact of care giving on older women and young girls in Botswana, the WHO (2002) examined the roles of all categories of workers involved in HBC. The WHO (2000:11-12) emphasises that nurses are to educate and support caregivers and coordinate the home care team consisting of various sectors, thus addressing discharge planning and case management.

Hardman (2001:13) stresses the rights of patients and people living with HIV/AIDS in rural South Africa to expect quality care by trained, supervised caregivers and supported by a home care team coordinated by a professional nurse.

Caregivers indicate the need for support and supervision of health professionals in caring for their patients, as this is generally absent (WHO 2001:34).

In Kenya, discharge planning is done through the use of a discharge summary card, which indicates what care is required at home (WHO 2001:36). Formal referral policies and protocols are generally lacking. Accordingly, nurses who work in the community should supervise HCBC and regular visits should be done to clients' homes. HBC kits stocked with basic supplies should also be available (WHO 2001:45).

Ideally, discharge planning, case management and the use of referral protocols and procedures should be part of HCBC programmes. However, this is not the case in all countries and settings, especially in Africa. Nurses' perception of whether their role extends to HCBC and carer support and supervision has not been explored adequately and may reveal key issues to expedite quality care in HCBC.

## **2.9 CARE OF CARERS**

Concerns have been raised over the care of carers as an area for attention. Home-based carers experience stress as a result of the lack of support, and when faced with a patient requiring assistance, may operate beyond their scope of training and competence.

Burnout and exhaustion of HBC carers occurs more often in the informal sector as formal policies and strategies are not in place to address this. The workload of caregivers continues to increase in intensity and volume with dire effects on caregivers' physical and mental health and thus in time resulting in them becoming recipients of care themselves (WHO 1999:11). In Kenya, for example, carers sometimes experience stigma, rejection, and even abuse by their clients, and often neglect their own health (WHO 2001:25).

Elderly carers suffer from hypertension, diabetes, arthritis and tuberculosis (TB), which makes it very difficult to provide effective HCBC. Moreover, this compromises their health and their ability to sustain the service (WHO 2000:29). Carers also suffer from depression and personal neglect. Many are malnourished, as they give the little food available to the sick (WHO 2000:29).

HCBC is mostly facilitated by NPOs, some of which are funded by government and other donors. There are few formal sector strategies to support informal carers (WHO 1999:12-13).

Caregivers must be nurtured and supported so as to maximise the care they deliver and avoid the stress that accompanies care giving in order to sustain the care giving role (WHO 2001:26-27). Strategies to support caregivers include individual and group debriefing sessions, counselling, ongoing education, support visits and attendance of support groups (Adebayo, Ironoye, Oladoyin & Fakande 2004:54; Lindsey et al 2003:499; Nolan et al 2003:121-123, 131; Uys & Cameron 2003:12).

The support of all caregivers is essential to the sustainability of the HCBC programme and its carers. Ideally, the role of nurses as part of the HCBC team is to alleviate stress and provide support. Accordingly, this study wished to explore the degree to which professional nurses perceive this as part their role.

## **2.10 CONCLUSION**

This chapter discusses the literature review conducted for the study. The literature covered Watson's theory of caring and Rice's model of self-determination; care, home care, caregivers, the role of nurses and carers, quality of care, discharge planning, case management and care of carers.

Chapter 3 describes the research design and methodology.

## **CHAPTER 3**

### **Research design and methodology**

#### **3.1 INTRODUCTION**

This chapter describes the research design and methodology including the population, sample, data collection and analysis, and the data-collection instruments, including the population, sample, data collection and analysis, and the data-collection instruments. A qualitative descriptive phenomenological approach was followed.

#### **3.2 PURPOSE OF THE STUDY**

The purpose of the study was to examine and determine professional nurses' perceptions of the role of home and community-based carers providing care to the community in the Capricorn District of Limpopo.

#### **3.3 OBJECTIVES OF THE STUDY**

The objectives of the study were to

- determine professional nurses' perceptions of the roles of home-based carers in providing care to communities
- ascertain the problems that professional nurses experience in implementing HCBC
- make recommendations for strategies to improve the quality of HCBC and for further research

### **3.4 RESEARCH DESIGN**

The study focused on the perceptions of professional nurses therefore the researcher selected a qualitative approach to determine the participants' beliefs regarding the role of home-based carers.

The essence of qualitative research is a belief that multiple realities exist and thus create meaning for individuals studied. Individuals who participate in social actions come to know and understand phenomena through these interactions (Streubert & Carpenter 1999:16).

A descriptive qualitative design was appropriate for this study. The purpose of the study was to explore the participants' perceptions of the role of home-based carers. A qualitative design offered them an opportunity to describe and clarify their perceptions (Streubert & Carpenter 1999:62). The findings would contribute to nursing knowledge and provide direction for further investigation as little research has been done on home-based care. In addition, the participants could describe possible concerns regarding role encroachment by informal carers.

A descriptive qualitative design involves direct exploration, analysis and description of a particular phenomenon. It stimulates perception of the lived experience and emphasises the richness, breadth and depth of these experiences. The three steps of descriptive phenomenology are intuiting, analysing and describing (Streubert & Carpenter 1999:59). Accordingly, the researcher became totally immersed in the phenomenon under investigation through intuiting; tried to remain open and avoid all criticism, evaluation or opinion, and paid strict attention to the phenomenon as described by the participants (Streubert & Carpenter 1999:49).

During analysis, the researcher reread the data several times in order to identify the essence of the phenomenon under investigation. Describing the phenomenon is an integral part of the intuiting and analysing processes. Its aim is to communicate the verbal and written descriptions of the critical elements of the phenomenon. The description is based on the grouping of the phenomenon. The researcher avoided the common error of premature description (Streubert & Carpenter 1999:52).

### **3.5 RESEARCH POPULATION**



The population consisted of 30 professional nurses working at government health facilities in the Capricorn district of the Limpopo province and who serve as focal points for home-based carers.

### **3.6 SAMPLE AND SAMPLING**

Sampling is “the process of selecting a portion of the population to represent the entire population” (Polit & Hungler 1997:278). Non-probability, purposeful sampling was used to ensure that the participants were selected based on their knowledge of the phenomenon. Purposeful sampling is done when the researcher selects the sample based on existing knowledge of the population and the purpose of the research (Babbie & Mouton 2002:166). This is a method of choice in qualitative studies as its use provides information rich cases for in-depth study. The advantage of this form of sampling is that it is possible to acquire rich data from informed participants (Streubert & Carpenter 1999:58).

The sample consisted of 30 professional nurses currently placed at health facilities in the Capricorn district of the Limpopo province, which are linked to home and community-based services. The participants had served as the focal point for these carers and thus had experience and knowledge of working with them.

Professional nurses were invited from the sub-districts in the district. The focus groups consisted of 13 and 17 professional nurses respectively per group. The district HBC coordinator provided the list of health facilities, the names of professional nurses and their contact details. The researcher contacted the participants and invited them to participate in the study.

### **3.7 DATA COLLECTION**

Data was collected by means of two focus group discussions. A focus group is “a semi-structured group session moderated by a group leader held in an informal setting. Focus groups are well suited to the collection of qualitative data as they are inexpensive and flexible. This method is effective in gaining insight into people’s opinions and is capable of producing rich data” (Streubert & Carpenter 1999:24). The disadvantage of this method is the possibility of *group think* occurring. This occurs when stronger members of the group have control or influence over the inputs/verbalisations of the other participants (Streubert & Carpenter 1999:24).

The researcher overcame this limitation by remaining mindful of this during data collection (Streubert & Carpenter 1999:24). This method enabled the researcher to determine the participants’ perceptions of the roles of home-based carers.

### **3.8 VALIDITY AND RELIABILITY**

The quality of research and research instruments is determined by their validity and reliability. Burns and Grove (1998:28) describe study validity as “a measure of the truth or accuracy of the claim and an important concern throughout the research process”.

Validity is “the degree to which an instrument measures what it is supposed to measure” (Uys & Basson 1995:80). Reliability is “the degree of consistency or dependability with which the instrument measures the attribute it is designed to measure. If the instrument is reliable, the results will be the same each time the test is repeated” (Polit & Hungler 1997:308).

Trustworthiness, credibility, dependability, transferability and confirmability are measures to ensure validity.

#### **3.8.1 Trustworthiness**

This is the process whereby the researcher confirms that the findings accurately reflect the participants’ experiences and viewpoints and not the researcher’s perceptions. This

was done by returning to the participants for confirmation as well as the use of triangulation (Polit & Beck 2004:36, 57).

### **3.8.2 Credibility**

The categories, themes and sub themes were confirmed with the participants at a follow-up group session after completion. According to Streubert and Carpenter (1999:29), credibility is required to ensure that the people who have lived the described experience have an opportunity to validate the reported findings that describe their experience.

### **3.8.3 Dependability**

This criterion was met once the credibility of the findings had been determined (Streubert & Carpenter 1999:29).

### **3.8.4 Transferability**

Streubert and Carpenter (1999:29) refer to transferability as “the probability that the findings will have meaning to others in similar situations”. Polit and Beck (2004:435) emphasise that the researcher must provide sufficient thick, descriptions so that consumers can evaluate the applicability of the data to other contexts. In this study, sufficient data was generated for other researchers to judge transferability, if so desired.

### **3.8.5 Confirmability**

Confirmability was ensured through leaving an audit trail of all processes and documentation throughout the study. This would allow other researchers to follow the activities and processes followed by the researcher. The objective was to illustrate the evidence and thought processes that led to the conclusions. However, this criterion may be problematic, as one researcher may not agree with the conclusions of another (Streubert & Carpenter 1999:29).

## **3.9 DATA ANALYSIS**

Data analysis commenced at the same time as data collection, as is characteristic in qualitative research. The researcher listened carefully to discover meanings. A period of immersion followed at the conclusion of data collection when the researcher reflected on what had been discovered. The cyclic nature of questioning and verifying is important in qualitative research. This helps researchers cluster information and discover the meanings intended in what they have observed and heard (Streubert & Carpenter 1999:28). Streubert and Carpenter (1999:28) point out that heightened awareness of the data is developed once total immersion in the data has taken place.

The data was analysed by means of clustering similar data or ideas into categories, themes and sub-themes, which are structured meaning units of data. The researcher did this by questioning and reflecting on the data and developing categories and corresponding codes to sort and organise the data. The researcher identified themes by noting salient categories of meaning held by the participants in the setting. Then the researcher manually searched for patterns and structures that connected the themes (Polit & Beck 2004:571, 573-575).

### **3.10 ETHICAL CONSIDERATIONS**

Ethics deals with matters of right and wrong. *Collins English Dictionary* (1991:533) defines ethics as “a social, religious, or civil code of behaviour considered correct, esp. that of a particular group, profession, or individual”. Accordingly, the researcher sought and obtained permission from the Ethical Committee of the Limpopo province: Department of Health and Social Development (see annexures A and B).

The researcher informed the participants of the purpose and significance of the study, their role as participants, estimated time commitments, and what would be done with the findings. Written informed consent was obtained from the participants (see annexure D). Furthermore, the participants were given the option to withdraw from the study at any time, should they so wish. Confidentiality was ensured by not linking inputs to individual participants (Streubert & Carpenter 1999:38).

Scientific honesty on the part of the researcher was ensured through establishing a relationship of trust with the participants by continually informing them of developments

in the research process and asking permission to adjust, when needed (Streubert & Carpenter 1999:36, 37).

The researcher endeavoured to set aside presuppositions or personal biases throughout the investigation. This was done by returning to the participants for verification to ensure the accuracy of their inputs (Streubert & Carpenter 1999:41).

### **3.11 TIME FRAME AND LIMITATIONS OF THE STUDY**

The study was conducted in the Capricorn district of the Limpopo province and was limited to professional nurses at health centres and clinics where HCBC care services are linked. The study commenced upon approval from the relevant authorities and took one year to complete.

### **3.12 CONCLUSION**

This chapter described the research design and methodology of the study, including the population, sample, data collection and analysis, and ethical considerations.

Chapter 4 discusses the data analysis and interpretation.

## **CHAPTER 4**

### **Data analysis and interpretation**

#### **4.1 INTRODUCTION**

This chapter discusses the data analysis and interpretation. A qualitative descriptive phenomenological approach was followed and non-probability, purposeful sampling used. Data was collected by means of two focus group discussions with 30 professional nurses working at government health facilities that serve as focal points for home-based carers in the Capricorn district of the Limpopo province.

The aim of the study was to determine the respondents' perceptions of the roles of home and community-based carers.

The objectives of the study were to

- determine the perceptions of professional nurses regarding the roles of home-based carers in providing care to communities
- ascertain the problems that professional nurses experience in implementing home and CBC
- make recommendations regarding strategies which could be established for improving the quality of home and CBC

The researcher asked the respondents in the focus groups the following three questions:

- What do you as professional nurses think are the roles of home-based carers in providing care to the community?
- What problems/challenges and needs have you as professional nurses experienced in implementing HCBC?
- What strategies would you recommend or suggest to improve the quality of HCBC?

Data analysis commenced in the data-collection phase and was done by means of clustering similar data in categories and sub-themes according to recurrent themes.

## 4.2 CODING

The researcher transcribed the data from tape recordings and field notes. This was followed by a period of immersion, questioning and reflection. The data was coded and analysed by means of clustering similar data or ideas into categories, themes and sub-themes (Polit & Beck 2004:573-575). The participants were also asked to validate the analysed data.

Three main categories emerged following the process of data analysis. This chapter discusses the categories, themes and sub-themes with relevant quotations from the transcribed focus group interviews. Reference is also made to the relevant literature reviewed as a control to the findings. The researcher coded the data to facilitate audit trailing. The coding system is presented in table 4.1.

**Table 4.1      Categorisation and coding of data from focus groups**

### **Category A: Role of carers**

<b>Category</b>	<b>Themes</b>	<b>Sub-themes</b>
A: Role of carers	A1: Extended hand of nurses	A1.1 Patient management A1.2 Campaigns A1.3 Train family members
	A2: Advocate	A2.1 Community advocacy A2.2 Health promotion
	A3: Projects	A3.1 Income generation projects

## Category B: Problems

Category	Themes	Sub-themes
B: Problems	B1 Financial problems	B1.1 Loss of carers B1.2 Nurse contributions
	B2 Carer knowledge	B2.1 Clinical practice B2.2 Professional conduct and accountability
	B3 Poor reporting	B3.1 Irregular reporting
	B4 Communication challenges	B4.1 Role confusion B4.2 Communication resources B4.3 Community trust
	B5 Transport problems	B5.1 Clinic transport
	B6 Shortage of staff	B6.1 Dedicated HCBC staff B6.2 Carer attrition

## Category C: Recommendations

Category	Themes	Sub-themes
C: Recommendations	C1 Role player education	C1.1 Carer education C1.2 Role clarification
	C2 Government support	C2.1 Dedicated HCBC posts C2.2 Stipend C2.3 Carer office accommodation C2.4 Policy guidelines C2.5 Government recognition
	C3 Communication strategies	C3.1 Relationship strengthening C3.2 Carer coordination
	C4 Debrief carers	C4.1 Carer support
	C5 Projects	C5.1 Income generation projects
	C6 HCBC Service coverage	C6.1 Carer distribution C6.2 Community liaison

### 4.3 CATEGORIES, THEMES AND SUB-THEMES

The categories, themes and sub-themes are discussed with accompanying quotations from the data, and supported by the literature control.

Table 4.2 presents the first category, namely, the role of the carer and theme A1.



**Table 4.2      Category A: Role of carers**

Category	Themes	Sub-themes
A: Roles of carers	A1 Extended hand of nurses	A1.1 Patient management A1.2 Campaigns A1.3 Train family members
	A2 Advocate.	A2.1 Community advocacy A2.2 Health promotion
	A3 Projects	A3.1 Income generation projects

#### **4.3.1    Category A: Roles of the carer**

The *Oxford English Mini Dictionary* (2007:480) defines role as “a function performed or a particular responsibility”. The participants described the role of HCBC as the extended hands of professional nurses at clinics. The *Oxford English Mini Dictionary* (2007:196) defines extend as “to stretch out; to enlarge or broaden one’s reach”. The extended hands of nurses thus denoted an enlarging of reach of the nurses and the services they provide.

##### *4.3.1.1    Theme A1: Extended hands of nurses*

The researcher identified this as a theme from the following comments:

*I think the roles of the home-based carers is to work as extended hands for the health facility, to care for vulnerable clients, for the HIV and AIDS affected clients and TB clients as well as the elderly.*

*They are the extended arm of the nurses, so we have to teach them about prevention and we have to order those materials or supplies so that they can prevent themselves from being infected when providing that care.*

The literature made no explicit reference to the concept of extended hands of nurses. Nevertheless, this concept does relate to the reason for the existence of home and community-based carers and the services they provide. Health services are overstretched due to the advent of HIV and AIDS and professional nurses as key workers at PHC level are mostly overworked and unable to move into the community to

provide home care. The DOH (2001:2) indicates that South Africa has limited health care resources and the AIDS epidemic impacts further on them.

The DOH (2007b:3) refers to persons delivering health and social services within communities, which includes carers, as community-based workers (CBWs). The Department (2007b:8) emphasises that CBWs should render services in support of health and social development programmes, thus supporting the notion of extended hands of health workers.

The sub-themes of patient management, campaigns, and training of family members emerged in respect of areas of care, diseases addressed and carer activities. According to the participants:

- *Patient management (A1.1)*

According to the participants:

*They help also the nurses to manage the TB patients at home by observing them swallowing their medication and by reporting if they don't take their medication correctly. In addition to that they are called DOTS supporters.*

*They are the ones who are assisting nurses to trace patients who don't come for treatment.*

*Their role is to trace defaulters. They usually trace those ones that are getting treatment of TB, if maybe the patient has been diagnosed with TB we usually monitor until they finish the course of the treatment, and then. If maybe, all of a sudden he not coming to the clinic to collect the treatment then we are asking the home-based carers to go and visit the patient so that he may come to the clinic again. Even children who don't come for immunisations, and the chronic patients eg hypertension, diabetics and mental patients.*

*If we have any child that has defaulted they can send the carers.*

*Supervising them when they take their treatment. For example DOTS (Directly observed treatment short course) for Tuberculosis (TB). They can provide support, supervise, complete records and ensure completion of treatment.*

*Tracing TB patients if they have defaulted the treatment.*

*Help us when collecting the sputum samples from the clients; if patients are too weak, go to their homes and collect sputum.*

*Some clients they do trace and other clients we do send them to trace. Sometimes we test a woman and you find that she is positive and she is no more availing herself to the clinic, and you find that maybe she already has delivered and as a health facility worker you do not have the chance to go there. You do send a worker but not mentioning the condition. You just say, go there and ask her to please come to the clinic.*

These findings were consistent with the types of activities expected of home-based carers, including administering the directly observed treatment short course (DOTS) programme for patients with tuberculosis (TB), sputum collection, daily observation of treatment taking and record keeping (DOH 2004:9). In addition, the Department (2000a:10, 23) stresses the need for DOT supporters who are part of a community-based system to provide TB support.

A paradigm shift has occurred from service provider approach to community-based approach in Africa and India through HBC programmes and the use of treatment supporters, as was reported in correspondent dialogues from the Stop- TB eForum facilitated by Health and Development Networks (HDN) and AIDS-Care-Watch Campaign, 2005. Examples cited include the TB referral system in Uganda and the use of women volunteers as DOTS care providers in India (HDN and AIDS-Care-Watch Campaign 2005:8). This once more concurs with the roles identified by the Limpopo carers relating to TB.

In a study on the role of integrated HBC in patient adherence to antiretroviral (ARV) therapy in Brazil, Gupta, da Silva and Passos (2005:244) recommend that home-based carers be used to provide support to patients.

In addition, the participants indicated that the carers assisted in patient management by doing door-to-door house visits and identifying patients in need of care, tracing social problems, referring orphans and reporting problems as follows:

*Moving house-to-house looking for the people that need help and those who are unable to reach the clinic.*

*Home-based carers are just like social workers as they are tracing the problem at the community for example social problems, poverty, child-headed families, abuse of the elderly, psychiatric clients and orphans.*

*For example they used to refer the orphans to the drop in centre. Also for the social grant.*

*They are the eye opener as far as the community's social lives are concerned. They are doing door to door then they come across a family, with a problem of, I am just giving an example, of any child who is deformed or any member of the family with some disability, they refer.*

*They also help in diagnosing the patient, because some of them if they don't go to the health centre they sit at home until the home-based carers notice the sign and symptoms of this conditions for example tuberculosis. They can observe the patients and refer the patients.*

*Report unmanageable complications to the nurse at the clinic.*

*Collect chronic medicines for the aged who can't come to the clinic; for example, hypertension drugs.*

Community-based workers (CBW) serve as a link between the community and other service providers as they refer the community to available services (DOH 2007b:27). Home-based carers serve an important purpose in drawing people who have slipped through the cracks of the formal health system, as they live in the communities and are able to identify people with needs and problems. Moreover, as caregivers become known in the community they serve as a point of reference for questions and referrals, such as pointing out the need of a neighbour (DOH 2002:24, 25). The CBWs should assist with the identification of minor or chronic illnesses; recognise ill health; identify children, youth and families at risk, including abused children; provide support, and refer people to appropriate services (DOH 2007b:9-10). Furthermore, the support of orphans and vulnerable children forms part of HCBC (Simon-Meyer 2002:17).

The participants' views that the carers' roles are to identify and refer physical and social needs within the community as they move from house to house concur with the literature.

The participants indicated further that carers also provide physical and emotional care (as well as orphan care) and basic support (including household chores) to patients at home:

*Bathing and feeding very ill patients.*

*Doing wound dressings and bed baths, they must first get consent from the patient and their family to do the bed baths.*

*Supervising them when they take their treatment.*

*Cleaning their rooms, utensils and washing their clothes.*

*They help the patients in their homes, by preparing food and cleaning.*

*I wanted to say that they also act as surrogate mothers.*

*Yes, as you can see with our explanations, they do care for every person more especially the orphans. In the case of the death of parents, they attend to those orphans, every time they go there to find out if the orphans will be covered. For example, they used to refer the orphans to the drop-in centre. Also for the social grant.*

*They also provide emotional support to the bereaved family of the client or the patient they are nursing. For example, when they are nursing this client, during the memorial service of the client they avail themselves. Even on the day of the funeral, you will see them there and they even ask for a slot to talk and tell the people that this was their patient and I think this is emotional support for the family.*

Hardman (2001:13) found that community volunteers visit chronic and terminally ill patients in their homes and provide holistic care. Johnson and Khanna (2004:499) found that during visits community health workers (CHW) assist HIV clients with

preparing meals, do household chores, give medications and conduct needs assessments.

The core activities of the home-based carer include basic nursing care, practical support for example household chores, childcare and arranging for social grants (DOH 2001:37; 2004:9, 14). In addition, they should assist with activities of daily living, like hygiene and nutrition (DOH 2007b:8).

As part of a home care project in Phnom Penh, Cambodia and Manipur, India, the carers' role in home visits is to teach families to manage the treatment of symptoms, to give emotional support, to encourage good hygiene and nutrition, and to refer patients to hospitals and other services where needed (UNAIDS 2001:17, 60).

The role of carers also includes the provision of basic health care like changing dressings and symptom management; physical care including bathing and dressing; changing soiled linen, cooking, fetching wood and water, and cleaning the home (WHO 2001:25; WHO 2002a:35).

- *Campaigns (A1.2)*

The second sub-theme that emerged related to carers providing assistance to nurses with mobilisation and organisation of the community during awareness and campaigns. According to the participants:

*They are helping us with the sorting of patients more especially during campaigns". Examples are for polio and measles.*

*They also help us to mobilise the community during awareness days. With the awareness days I mean if maybe we are having HIV awareness we always contact them so we are working well hand in hand with them to go to the Indunas (local traditional leaders) and tell them so that they are able to inform the community around there about the awareness.*

The DOH (2007:6, 27) emphasises that a general role of community-based workers is to mobilise the community for advisory, support and learning activities on behalf of government or other stakeholders.

- *Training family members (A1.3)*

The participants indicated that the CBWs assisted them by training and supervising family members to care for their family members:

*They can also supervise and train the family members to do bed baths.*

*They give support to the family and even to the client. By explaining the condition of the patient to the family so that they can understand or encouraging them to take treatment.*

Johnson and Khanna (2004:499) state that educating and training family members in safe and hygienic care giving is a role of CHWs. In Botswana, Mooka (2004:64) found that family caregivers require education in caring for their family members. Teaching family members how to care for the patient, including how to give bed baths and provide basic personal care, was part of the tasks done on a home visit (ICHHC 2002:19). Supporting family members who care for patients is part of home-based care (DOH 2004:9).

#### *4.3.1.2 Theme A2: Advocate*

The second theme identified is that the carer serves as an advocate for the community (see table 4.3).

**Table 4.3 Theme A2: Advocate**

Category	Theme	Sub-themes
Role	A2 Advocate.	A2.1 Community advocacy A2.2 Health promotion.

*Collins English Dictionary* (1991:22) defines advocate as “(v.) to support or recommend publicly; to plead for or speak in favour of; (n.) a person who upholds or defends a cause; supporter; a person who intercedes on behalf of another”. In the home-based care situation, the carer is seen as someone who pleads on behalf of the community where necessary; for example, for financial and social support. In addition, the carer educates the community. To educate means “to impart knowledge by formal instruction to (a pupil); to train for some particular purpose or occupation” and an educator is “a person who educates” (*Collins English Dictionary* 1991:496). The carer trains, teaches or develops members of the community and is seen as a health promoter. According to the participants:

*They advocate for the client.*

The DOH (sa:7) states that CHWs, who are defined as community-based generalists, should act as an advocate to improve health.

The sub-themes of community advocacy and health promotion emerged in this theme.

- *Community advocacy (A2.1)*

The participants indicated that carers advocate for social support regarding food, social grants, orphan support, funeral assistance and housing for the community:

*Yes, with the pauper's burial, they call it what? Pauper's funeral? Umm!*

*To add to this financial support, maybe the family is poor, they give money for condolences/donations from local businesses and then they can talk to the social worker to give advice to the family or to bury the patient (local authority regarding the funeral). So that the community can be aware that such a family has got a problem and they do not have money so the families as well as the village are asked to donate some cents so that we can run the funeral.*



*Yes, if they do have knowledge those home-based carers they can assist the family, they can assist the family to go to the social worker or giving advices to the family and go with them to the social worker in order to bury that person. As the home-based carer was taking care of that dying or ill patient willingly, not forcing.*

*I think the role of the home-based carers also is to advocate for the community, especially the needy ones for example the orphans, HIV positive and TB.*

*And even those who don't get enough food, they arrange for food parcels and social grants.*

*Assist those who don't have houses to have relocation development programme houses (RDPs).*

*They also sacrifice to transport their patients to the hospital with their own money.*

*People from the community rely on the home-based carers, in the case of transport problems to take the patient to the hospital or clinic.*

These roles are supported in literature as is indicated below:

Thomson (2001:12) found that carers assist with funeral arrangements of poor patients with no family members to assist.

The CHWs should assist community members to access services and link the community with resources and local services, namely social workers, social security and home affairs (DOH 2007b:8-9). Moreover, referrals for social grants are considered part of CHWs role (DOH sa:9).

Being a bridge/link person between the community and the facilitating agent is also a CHW role. The facilitating agent may be a non-profit organisation (NPO) or service provider (DOH 2007c:6).

The participants also stated that carers approached local business to provide financial assistance to the needy. The proceedings of the 1st Southern African Regional Community Home-based Care Conference (HDN 2001:34), indicated that the business sector has a role in supporting families and partnering with community organisations. Furthermore, a multisectoral response is required and the business sector should be involved in supporting community initiatives according to the proceedings of the 1st South African National Home/Community-based Care Conference (Simon-Meyer 2002:24).

- *Health promotion (A2.2)*

*Collins English Dictionary* (1991:1243) defines promote as “to urge the adoption of; work for” and a promoter is “a person or thing that promotes; a person who helps to organize, develop, or finance an undertaking”. The participants regarded the carers as people who promote health support, including health education to the community:

*The role of these home-based carers, we can say that they are the health promoters because they can educate people about the.... Let's say there is a cholera outbreak – they can educate them about dirty water, good sanitation and so forth (how to purify water), prevent cholera and diarrhoea.*

*Another role is that they give health education about preventative measures and communicable diseases. They could give health education on how to care for yourself; for example, bathing. If you have TB, you have to take treatment otherwise you will infect the other members of the family. Teach them about the prevention of accidents in the home. This could also be about the spread of cholera and teenage pregnancies.*

*Assist in giving to the community to improve their knowledge for example TB, HIV and caring for the elderly people at home.*

*They provide information about TB and HIV (Human Immune Virus), more especially the mode of spread.*

Johnson and Khanna (2004:499) found that one of the primary roles of Nyatike home-based carers is to provide HIV and AIDS education to their communities. This was

successful, as they have helped to shape a positive attitude towards HIV-positive individuals.

According to the DOH (2004:6), CBWs may be a conduit for information and technologies. They are expected to disseminate information that promotes family health and social well being, promote healthy life styles, educate and raise awareness on causes of disease and disability (DOH 2007b:10).

#### 4.3.1.3 Theme A3: Projects

**Table 4.4 Theme A3: Projects**

Category	Theme	Sub-theme
Role	A3 Projects	A3.1 Income generation projects

The final theme identified within the roles of carers was doing projects to generate income, such as greenery projects. A project is “a proposal, scheme, or design; a task requiring considerable or concerted effort” (*Collins English Dictionary* 1991). The participants indicated that carers were involved in work planned to generate funds so as to augment their stipends. A stipend is “a fixed or regular amount of money paid as a salary or allowance” (*Collins English Dictionary* 1991:1518). Carers receive a stipend for the work they do.

The sub-theme of income-generating projects was identified in this theme.

- *Income-generation projects (A3.1)*

According to the participants:

*Some of them are even involved in greenery projects. They grow vegetables and provide to the needy. Some of them even do chicken farming and take some eggs to the needy.*

*The question there was where do they get money, some of them are doing baking, they make vetkoek and sell them to raise funds, to transport clients, to go and attend meetings etc.*

*I think that at the same time it is their role so that they must increase their stipend also. Because, isn't it, if they are selling they are going to get some profit?*

In Kenya, Johnson and Khanna (2004:499) found that CHW engaged in income-generation activities to support their programme, including farming, agriculture and sale of care kits. The majority of the carers were volunteers living in extreme poverty yet continuing to provide these services. Carers should link with income-generating projects (DOH 2007b:8). In Abidjan, Cote d'Ivoire, income-generating projects are done to assist community members in need (UNAIDS 2001:24, 32).

#### **4.3.2 Category B: Problems**

Table 4.5 presents the second category and theme 1, namely problems experienced by nurses and carers relating to HCBC.

##### **4.3.2.1 Theme B1: Financial problems**

This was identified as a theme and impacts on both the nurse and the carer.

**Table 4.5 Theme B1: Financial problems**

Category	Theme	Sub-theme
B: Problems	B1 Financial problems	B1.1 Loss of carers B1.2 Nurse contributions

Financial relates to monetary or economic issues and in this case to problems experienced in this regard (*Oxford English Mini Dictionary* 1991:188).

- *Loss of carers (B1.1)*

The participants cited financial problems for the loss of trained carers, as they expect to receive a stipend immediately. In addition, they leave fieldwork to rather work in the drop-in centres to get food to take home. Due to lack of funding, carers cannot pay their office rent and thus meet under a tree. According to the participants:

*The thing is that they expect to be paid and then if they don't feel that they are employed they go away. They are saying that they want to be paid. They expect that maybe if you train them you are going to hire them. They get trained, they get stipends and then they don't link themselves to the clinic anymore.*

*Another problem we have identified is that once trained and active, they go and look for another job and there is a gap as they are no longer there and we have to train other people and the community are used to the first group. This is with the very certificate they received.*

*Carers leave work in the community to work in drop-in centres, which are funded by Social Development. These drop-in centres provide food for schoolchildren. Carers like to work there because they get food and leftovers, which they can take home to their children.*

The issue of the payment of a stipend to carers is important. The participants indicated that all carers should receive a stipend and that the lack of a stipend results in attrition of carers. They also indicated that due to the small amount of money allocated, carers seek to augment their stipend through projects mentioned and many leave for other jobs as a result of this. All these aspects impact on service delivery.

- *Nurse contributions (B1.2)*

The participants indicated that they did not know what to do as they frequently had to provide money for transport:

*There are also financial problems. We hear that maybe there is an HIV patient who wants to come for the ARVs (antiretroviral treatment) at our hospital, and that person doesn't have money. We find that the home carers, the home-based carers, they also don't have money at the time, that day. So they will come to you as the nurse who is working at the clinic, for example like myself who is dedicated to them, if they have problems they come to me and say that this person should go for the ARVs and he should not miss his treatment and so we don't have money. How can you help us? We find that sometimes I pop out my money from my pocket and give the patient, so, this is another problem that we are facing.*

Hardman (2001:12) refers to the plight of nurses in rural Mpumalanga and their frustration at carrying huge responsibilities, the extra burden of seeing people dying daily from AIDS yet frustrated by lack of resources.

#### 4.3.2.2 Theme B2: Carer knowledge

**Table 4.6 Theme B2: Carer knowledge**

Category	Theme	Sub-themes
Problems	B2 Carer knowledge	B2.1 Clinical practice B2.2 Professional conduct and accountability

Knowledge is “the facts, feelings, or experiences known by a person or group of people; awareness, consciousness, or familiarity gained by experience of learning; specific information about a subject” (Collins English Dictionary 1991:860). In this instance the lack of information and understanding results in the difficulties raised by the participants. Carers require training in order to perform a service and training needs regarding key areas require additional attention:

*But my point is lack of knowledge of home-based carers.*

- Carers lack skills (B2.1)

According to the participants:

*Carers lack practice skills for example if have taught them how to do bed baths, there are no patients to bed bath in the community so they tend to forget. It a problem for the nurse, as I shall have to repeat what I have taught them and I don't have time to do that.*

- *Professional conduct and accountability (B2.2)*

A professional is “a person who belongs to or engages in one of the professions; a person who engages in an activity with great competence” (*Collins English Dictionary* 1991:438). A professional nurse is a qualified expert who is certified or licensed to provide a service

Conduct refers to the way in which acts are carried out or performed (*Oxford English Mini Dictionary* 2007:111). The participants had problems with the way in which carers carried out their service. The participants indicated that this was not in line with expected behaviour, especially relating to dress codes, lack of confidentiality and not following expected protocols, specifically in regard to poor reporting, not reporting, fake reporting, and not performing duties, particularly DOT, as required.

According to the participants:

*For example, they disrespect culture, values, divulging information, the way they talk and dress, underclothes visible at times. Don't have uniforms.*

*Some of home-based carers don't have confidentiality. Don't understand confidentiality.*

*Some lack professional conduct.*

*Ja, like they don't follow protocol.*

*The other problem that we have with those home-based carers sometimes others not all they don't, they do not DOT the TB patients (directly observed therapy), they don't DOT them, they just like ask the patient if they have taken the treatment, the patient say yes, even though she is not sure, he is not sure about the treatment.*

*There is an impact too much on the health workers, because you find that time and time again they get new volunteers. The old ones, who know the secret, they must keep because we tell them that they have taken an oath of secrecy as they are already belonging to the health worker. So the new people, when they come in, they don't know the oath of secrecy, and we find that the person starts to divulge people's conditions in the community, so we find ourselves having problems.*

The participants also raised problem of frequently having to train new groups caused by the constant turnover of carers. As this takes time and untrained carers cannot practise, gaps occur in service delivery:

*Another problem is that we train them and then thereafter they don't have any interest and they leave a gap, and we find that we don't know what to do. So we have to look for the other group now so that we can train them, because to be a home-based carer we have to train them first. So if maybe we have trained them we find that they don't have interest anymore and then it's a problem to us.*

#### 4.3.2.3 Theme B3: Poor reporting

The participants experienced problems in terms of carer reports, in that they did not always report to the clinic or they submitted their reports late (see table 4.7). Moreover, the participants indicated that community members also failed to indicate when they left the area or when deaths occurred in their families who were on treatment.

**Table 4.7 Theme B3: Poor reporting**

Category	Theme	Sub-theme
Problems	B3 Poor reporting	B3.1 Irregular reporting



- *Irregular reporting (B3.1)*

The participants stated the following:

*They don't report if they are having problems with their home visits. Since 2005, I have never had any report from them saying they have encountered a certain type a problem and can we assist.*

*Some don't report at all, as they have an office outside the clinic yard.  
Late submission of home-based carer reports, and they fake some of the reports (may say they have 5 patients when they only have 2).*

*They also fake some of the reports.*

*Like maybe, the carers might say that they have 5 patients when they only have 2.*

*Community/family do not report to the carers, about the client when they have passed away, therefore we are unable to record in the register especially re TB.*

*The patient moves to another place without informing his DOT supporter and you find that it is difficult to be traced, and even the nurses in the clinics don't know if the patient is taking his medication or what, we know nothing about the patient.*

The community needs to be involved from the inception of the HCBC project so as to ensure ownership and understanding of roles (Gupta, Da Silva & Passos 2005:245; Adebayo et al 2004:49-55). The researcher is of the opinion that the problem of the community failing to report in Limpopo could be due to an inadequate understanding of roles and ownership.

#### **4.3.2.4 Theme B4: Communication challenges**

Communication involves providing and sharing information. The participants reported difficulty with communication with carers (see table 4.8).

**Table 4.8 Theme B4: Communication challenges**

Category	Theme	Sub-theme
Problems	B4 Communication challenges	B4.1 Role confusion B4.2 Communication resources B4.3 Community mistrust

- *Role confusion (B4.1)*

The participants noted difficulty with communication in terms of the carers as well as related to some role confusion:

*They get trained, they get stipends and then they don't link themselves to the clinic anymore.*

*Ja, I mean they can maybe bypass coordinator and shoot straight to the region regarding maybe their issues their problems or things.*

*And the working hours are not clearly stipulated, because you will never know what time are they supposed to knock off. Sometimes you will need them after hours, say, around 14 hours and then you find that they have knocked off at one o'clock.*

*Some of them are even collecting the medication at the mobile clients. For example, we find that the hypertensive client can walk and everything but the carers come to the clinic to take the medication for them whereas we, nurses, want to see the patients monthly for follow-up e.g. blood sugar, blood pressure.*

*It is those patients, the hypertensive ones, even the diabetics, we want to see them monthly. We want to make the follow-up of their blood pressure and do their sugar level with their urine.*

*At times it seems that carers see themselves as a separate entity to professional nurses. For example, we find that at times, when we ask them to put their records here at the clinic so that we as nurses can have access to those, we find that they don't keep them and when we need something we can't get them.*

*I just want to clarify about the role confusion. I think it is because they are confused about their roles, and that is why they want to take the medication right*

*to the client, so it is for us to tell them what to do because we want to please the client.*

*Some carers who receive stipends just come and collect the chronic treatment from the clinic and then leave.*

- *Communication challenges (B4.2)*

The participants also referred to the following addition difficulty:

Another challenge is, for example, we don't have a telephone when we get a problem and we want to communicate or convey a message to the home-based carer regarding a patient.

- *Community mistrust (B4.3)*

Finally, the participants raised the issue of the community refusing home-based carers:

*Some patients refuse to be helped by home-based carers.*

*Some of the community members don't have trust in home-based carers.*

#### **4.3.2.5 Theme B5: Transport problems**

Transport problems given by the participants related to the felt lack of transport resources to fulfil their role as supervisor to carers and to provide support to patients.

**Table 4.9 Theme B5: Transport problems**

Category	Theme	Sub-theme
Problems	B5 Transport problems	B5.1 Clinic transport

- *Clinic transport (B5.1)*

The participants indicated that nurses lacked transport to accompany carers to do support visits to patients, which resulted in further problems for the carers:

*Okay, we have experienced some problems of transport. Our home-based carers call us, nurses, to go and see some of their patients. So we find that the place is very far, and we can't go on foot, so we end up failing to support the carer.*

*People from the community rely on the home-based carers, in the case of transport problems to take the patient to the hospital or clinic.*

*They also sacrifice to transport their patients to the hospital with their own money.*

Stredwich, Mukumbi and Bernadette (2003:153) found that volunteer caregivers in the Democratic Republic of Congo experienced transport problems while providing HBC services. (Society for AIDS in Africa 2003:153). In Kenya, Johnson and Khanna (2004:498) found that lack of transportation was one of the biggest obstacles to providing HBC.

In Lusaka, Amisi and Hillary (Society for AIDS in Africa 2003:230) found that inadequate transport and insufficient resources were constraints for caregivers in providing quality care.

#### *4.3.2.6 Theme B6: Shortage of staff*

The participants had a serious problem with shortage of staff (see table 4.10).

**Table 4.10 Theme B6: Shortage of staff**

Category	Theme	Sub-themes
Problems	B6 Shortage of staff	B6.1 Dedicated HCBC staff B6.2 Carer attrition and turnover

According to the participants, shortage of staff at the impacted on HCBC service delivery:

*Even the shortage of staff, we find that at the clinic there is one sister and one enrolled nurse.*

- *Dedicated HCBC staff (B6.1)*

The participants pointed out that:

*And talk about the dedicated staff, because usually we don't have specific people to deal with the home-based carers at the clinics, as such it gives a problem, because today you find this nurse and tomorrow you get this nurse.*

*It a problem for the nurse, as I shall have to repeat what I have taught them and I don't have time to do that.*

- *Carer attrition and turnover (B6.2)*

According to the participants:

*There is an impact too much on the health workers, because you find that time and time again they get new volunteers.*

Mooka (2004:10) emphasises that adequate numbers of qualified nurses are needed to meet the needs of patients and carers requiring support. HCBC projects should recruit more volunteers than needed due to the high dropout rate of carers.

### 4.3.5 Recommendations made by professional nurses: Category C

The participants were asked to recommend strategies for HCBC (see table 4.11).

**Table 4.11 Category C: Theme C1**

Category	Theme	Sub-themes
C: Recommendations	C1 Role player education	C1.1 Carers education C1.2 Role clarification

#### 4.3.5.1 Theme C1: Role player education

- *Educate carers and coordinators (C1.1)*

The participant indicated the need to educate carers and coordinators:

*I think home-based carers should be given in-service training or workshops time and again regarding health issues.*

*Professional nurses should do in-service training for carers weekly for updates about new developments.*

*The home-based carers should be taught by the health workers that the protocol established should be followed satisfactorily, like now as they are having the coordinator and the managers who are getting more stipends than they get, they should respect those people so that the project should run smoothly.*

*I think they must be also taught correct channels of communication in case they have problems. Sometimes there are problems, and they bypass the coordinator. They must know how to refer.*

*Maybe, as we were saying, sometimes they bypass their coordinator straight to the region. At least they must just follow, they must know the channels of communication, so that if they experience a problem they must just go to the coordinator and then the coordinator will take their problems further.*

*I think that the coordinator also should be taught about their role, because most of the time they find they are enabling them to work and they do stigmatise them.*

Mooka (2004:64) maintains that the role of the community health nurse is that of a teacher, as education of carers and patients is required. Initial and refresher training is recommended for CBW and their supervisors (DOH 2007b:38, 39). In their study in Blantyre, Malawi, Zimba and McInerney (2001:90) emphasised that government and NGOs should work in collaboration to provide regular training sessions and refresher courses for HBC volunteers. Training would ensure quality and prevent burnout.

The participants also indicated the need to teach the community and nurses about their roles in HCBC:

*The community also must be taught about their role.*

*Yes, to enable them to work hand in hand with them. For example, some of them are stigmatising them, are saying those are the ones that are working with HIV clients. Whenever they see a home-based carer go to the house, they start talking that it means that somebody in that house is HIV positive. So we find that in future clients that are in need of them won't be able to call them or allow them to come to their house because they fear that they will also be stigmatised.*

*In-service training should be provided to professional nurses, as they don't know what they (the carers) are supposed to do.*

*We as professionals need to have an in-service because some of us don't know what carers are supposed to do.*

Stigma impacts on those providing care as well as patients and the education of the community is the key to reducing stigma. The participants pointed out that the community stigmatised the carers for working with HIV-positive patients. The DOH (2007b:20, 21) stresses the need for community sensitisation and role clarification to ensure success of community-based programmes. In a study on the role of capacity building in HCBC, Kiwonbojjo (2001:66) found that orientation of clinic personnel is done so as to ensure positive attitudes towards clients and carers.

#### 4.3.5.2 Theme C2: Government support

The participants indicated the need for support from the Government, namely the DOH (see table 4.12).

**Table 4.12 Theme C2: Government support**

Category	Theme	Sub-themes
Recommendations	C2 Government support	C2.1 Dedicated HCBC posts C2.2 Stipend C2.3 Carer office accommodation C2.4 HCBC policy guidelines C2.5 Government recognition

Participants indicated the need for support in terms of dedicated posts, stipends, and accommodation, as well as support from provincial management.

- *Dedicated HCBC posts (C2.1)*

The participants indicated the following in this regard:

*Seeing that these people are very helpful, I do suggest or recommend that the department must just create posts for the dedicated staff so that at the end of the day there could be a proper monitoring and supervision of these people.*

*For example, there must at least be a local coordinator who will be on post, so that he or she can be able to monitor and supervise these carers appropriately.*

*Support from provincial HCBC is needed to assist with problems experienced, as the room in the clinic yard may not help.*



- *Stipend for all carers (C2.2)*

The participants indicated the following in this regard:

*I do think that they should add more on the stipend so that they can work actively.*

*Okay, because on what they are getting now, most of them are complaining that is very little, because most of them are using their own money to transport their clients to the hospitals and clinics.*

*We wish that all carers received a stipend so that they can stay in the service.*

In her study examining HBC and their interaction with professional providers, Mooka (2004:15) points out that quality officers, who are permanently employed to run HBC, are needed. The DOH (2004:12, 13) indicates that a HBC team is needed which consists of a HCBC coordinator and professional services to support the programme. Furthermore, supervision, support and mentorship are required (DOH 2004:12, 13).

- *Carer office accommodation (C2.3)*

According to the participants:

*They have to get a room in the clinic yard so that they can meet together and arrange something their reports and submit them to the professional nurses.*

- *HCBC Policy guidelines (C2.4)*

A policy is “a document which indicates strategy, procedures and provides guiding principles” (Oxford English Mini Dictionary 2007:424). The participants stated the need for HCBC organisations to possess such guidelines:

*HBC organisations must have policies and rules to guide them.*

- *Government recognition (C2.5)*

According to the participants:

*I think also the government must have something like appraisal and appreciation so that they can motivate the home-based carers to do the job.*

The researcher found no literature clearly addressing the matter of appraisal and appreciation by government.

#### 4.3.5.3 Theme C3: Communication strategies

The participants recommended strategies to improve communication and relationships between nurses, carers and the community (see table 4.13).

**Table 4.13 Theme C3: Communication strategies**

Category	Theme	Sub-themes
Recommendations	C3: Communication strategies	C3.1 Relationship strengthening C3.2 Carer coordination

- *Relationships strengthening (C3.1)*

According to the participants:

*I think that there must be a good working relationship with between the home-based carers and nurses in the clinics.*

*Professional nurses' attitude should be good towards carers; they should not look down on them.*

*Ja, I think by being open to those home-based carers, welcoming them so that they should not feel that they are not part of us. They must feel that they are part of the health care workers.*

*I think in the case of the patient refusing to be assisted by a certain carer, the best thing is that we must ask the patient first if she or he can be comfortable to be helped by a certain carer. If he refuses, that is his right. We must just counsel them and tell them of course that the carer may not refuse, but a patient may refuse to be helped by a certain carer. So I am saying we must get consent from patient so that he must not refuse.*

*No, I'm saying that we had a challenge that some patients refused to be helped by certain carer due to some reasons we don't know. I think that the best thing is to get the consent for the patient whether to be assisted by 'Anna' or not. If the patient refuses, then it is his right. I am sure it is for lack of trust for certain people or persons. They stay together; they don't trust each other for some reasons that we don't know.*

*We must encourage the carers so that they must make records and report if the HBC is coming to assist the patient and the patient refuses. The HBC must have notes that "I went to Mrs So and So, and she refused treatment or refused dressings" in order to communicate with that patient.*

- *Carer coordination (C3.2)*

In terms of carer coordination, the participants recommended:

*The professional nurses must arrange meetings always with the home-based carers, in order that the home-based carers can manage to raise their problems, maybe once in a month or twice in a month.*

*Carers should be involved in the clinic meetings. This could help when discussing structural changes and the clinic year plan.*

*We (professional nurses) have to work together with the home-based carers. I can say that we can have some meetings once per month maybe so that they can say out their problems and help them solve them.*

*We need to have meetings with the carers and how to solve them.*

The importance of holding regular meetings to provide support to caregivers is stressed in the HBC guidelines (DOH 2004:13).

Regarding coordination, the participants further indicated that nurses should support carers and clarify their roles:

*Nurses should encourage carers to do health talks in the mornings at the clinic. The professional nurse should delegate the carer and be present during the talk to ensure quality of information. The talk could also be prepared by the nurse for the carer and then taught to present it.*

*I think they (carers) should report after each and every visit (daily) so that we can hear the condition of the patients.*

*Nurses need the time frame for receiving reports from carers.*

*It is also the role of the home-based carers to give the staff the carers' details so that the nurses can refer the patient to the carers.*

*Professional nurses should do follow-up in the villages to see if carers are implementing what they have been taught about quality of care.*

*We must order HCBC kits so that they can provide quality care.*

Motsepe and Williams emphasise that health clinics and providers should partner with community caregivers to enhance referral and adherence to treatment (The Society for AIDS in Africa 2003:25). McCreary et al (2004:22) point out that supplies should be available for caregivers. Home care teams in Phnom Penh, Cambodia carry home kits consisting of basic supplies and simple treatment (UNAIDS 2001:17). Mooka (2004:10-11) emphasises that community nurses are needed to assess the needs of patients and supervise caregivers.

In Swaziland, McCreary et al (2004:22) found that carers needed greater coordination between HBC and the hospital or clinic as well as more home visits from nurses to assess the patient. Public health facilities and professional health workers must support HCBC programmes. These linkages and partnerships should be incorporated into discharge planning to ensure good follow-ups and also stress the need for professional support of caregivers.

Professional nurses' roles in HCBC include coordinating the care team, conducting of team meetings and providing training and resources, for example, equipment, medication and various supplies. Nurses may be dedicated to the HCBC programme or have dual functions of providing health services at clinics or hospitals as well as supporting HCBC services (WHO 2001:55).

#### 4.3.5.4 Theme C4: Debrief carers

The participants recommended debriefing periods to discuss their roles, experiences and any problems with the carers (see table 4.14). According to the participants, this should be done to allow carers to talk about their experiences and to establish how they feel about the work done.

**Table 4.14 Theme C4: Debrief carers**

Category	Theme	Sub-theme
Recommendations	C4 Debrief carers	C4.1 Carer support

- Carer support (C4.1)

According to the participants:

*Yes, nurses must also arrange debriefing courses for the carers.*

*Um, debriefing is whereby you, we as nurses must arrange with maybe people like psychologists or even us as professionals, we can arrange with our home-based carers to debrief them. Do we understand what debriefing is?*

*Okay, debriefing maybe is where, isn't it, these people are working with ill people? Sometimes they are working with dying people.*

*Sorry, that's it, they are working with dying people then at some stage they become depressed also, so they need to be debriefed.*

*It can come in a way that maybe they let all the home-based carers, maybe only once in a year, maybe they go somewhere, I don't know, whether it's a resort or*

*whatsoever, just to let them encourage them so that they must do their work wholeheartedly.*

*They need to be supported emotionally. Yes that's it.*

The DOH (2004:13) stresses debriefing of carers to prevent burnout.

Moreover, carers must be nurtured and supported so as to maximise the care they deliver and avoid the stress that accompanies care giving so as to sustain the care giving role (WHO 2001:26-27). Strategies include individual and group debriefing sessions, counselling, ongoing education, support visits and attendance of support groups (Adebayo et al 2004:54; Lindsey et al 2003:499; Nolan et al 2003:121-123, 131; Uys & Cameron 2003:12).

The participants also recommended the formation of carer support groups to come together to help or to encourage one another in terms of providing HBC. The participants indicated the necessity of this activity:

*Yes, we can also assist them as professionals to form support groups.*

*The support group whereby at least maybe once a week or maybe per fortnight they come together and then share their problems, isn't it they are people of the same goals and same interest so sitting together and sharing their problems will relieve stresses from them.*

Carers in the Eastern Cape meet monthly to touch base and offer some kind of support to one another (Painstakingly building ... 2002:31). The proceedings of 1st Southern African Regional Community Home-based Care Conference convened by the Botswana government (2001:22) stressed that regular forums and support groups be established for carers where carers can exchange experiences and let off steam.

#### 4.3.5.5 Theme C5: Projects

The participants held that income-generating projects were helpful to carers (see table 4.15).

**Table 4.15 Theme C5: Projects**

Category	Theme	Sub-theme
Recommendations	C5 Projects	C5.1 Income-generation projects

- *Income-generating projects (C5.1)*

According to the participants:

*Carers could do greenery projects to push stipend.*

*The home-based carers I think can be encouraged to form or to do the project so that they must push their stipend.*

*Maybe do the greenery project, so that they can boost their stipend.*

Income-generating schemes are necessary to provide resources for CHBC (Johnson & Khanna 2004:499). At the same time, many income generation projects are not sustainable and even successful ones struggle to find markets.

#### *4.3.5.6 Theme C6: HCBC service coverage*

The participants referred to the distribution of HBC groups in villages and the processes for establishment of new groups (see table 4.16).

**Table 4.16 Theme C6: Carer group distribution**

Category	Theme	Sub-theme
Recommendations	C6 HCBC service coverage	C6.1 Carer distribution C6.2 Community liaison

- *Carer distribution (C6.1)*

According to the participants:

*Each village should have more than one carer so that they can manage the work.*

*New groups should be established where carers have left to work in the drop-in centres.*

- *Community liaison (C6.2)*

The participants recommended that liaison and communication between should be improved and formalised:

*Professional nurses should liaise with stakeholders in the community, for example, local ward councillors, when establishing new groups, as carers may not be allowed to work in the area.*

The participants also recommended that carer selection should be addressed, by applying criteria when selecting carers:

*Selection tools could be used when recruiting carers to check if relevant. This could be a questionnaire or interview. Age should also be considered.*

The DOH (2007b:17, 33) stresses and supports the involvement of the community in determining carer selection and recruitment.



#### **4.4 CONCLUSION**

This chapter discussed the data analysis and interpretation, including coding, categories, themes and sub-themes. Data was collected by means of two focus group discussions. Data analysis commenced in the data-collection phase and was done by means of clustering similar data in categories, themes and sub-themes. The participants' inputs were presented with reference to the literature reviewed.

Chapter 5 concludes the study, presents the findings and makes recommendations for practice and further research.

## **CHAPTER 5**

### **Findings, conclusions and recommendations**

#### **5.1 INTRODUCTION**

This chapter presents an overview of the study and findings, and makes recommendations for practice and further research.

#### **5.2 AIM OF THE STUDY**

The aim of the study was to examine and determine professional nurses' perceptions of the role of home and community-based carers providing care to the community in the Capricorn District of Limpopo province.

#### **5.3 OBJECTIVES OF THE STUDY**

The objectives of the study were to

- determine professional nurses' perceptions of the roles of home-based carers in providing care to communities
- ascertain the problems that professional nurses experience in implementing HCBC
- make recommendations for strategies to improve the quality of HCBC and for further research

#### **5.4 RESEARCH QUESTIONS**

The researcher asked the participants the following questions:

- What do you as professional nurses think are the roles of home-based carers in providing care to the community?

- What problems/challenges and needs have you experienced as professional nurses implementing HCBC?
- What strategies would you recommend be established to improve the quality of HCBC?

## **5.5 RESEARCH DESIGN AND METHODOLOGY**

The researcher adopted a qualitative approach in the study.

## **5.6 SAMPLE AND SAMPLING**

Non-probability, purposeful sampling was used to ensure that the participants were selected based on their knowledge of the phenomenon. The sample consisted of professional nurses serving as focal points for HBC in the Capricorn district of Limpopo.

## **5.7 DATA COLLECTION**

Data was collected by means of two focus group discussions.

## **5.8 VALIDITY AND RELIABILITY**

The researcher confirmed that the findings accurately reflected the participants' experiences and views by returning the captured discussions to the participants for confirmation as well as the use of triangulation.

## **5.9 ETHICAL CONSIDERATIONS**

Ethical principles were taken into consideration and permission was sought and obtained from the relevant authorities and participants.

## **5.10 DATA ANALYSIS**

Data analysis commenced in the data-collection phase. The data were transcribed from tape recordings and field notes. Data were coded and analysed by means of clustering similar data or ideas into categories, themes and sub-themes manually (Polit & Beck 2004: 573-575). The participants were also asked to validate the analysed data.

Three main categories emerged from the data analysis. The categories, themes and sub-themes were discussed with relevant quotations from the participants, and with reference to the literature review as a control to the findings of this research. The coding system was presented in chapter 4, table 4.1.

## **5.11 LITERATURE REVIEW**

The literature review was conducted to gain insight into the key concepts and available information relating to the topic of the study. The literature review covered care and caring; how this is understood; whose responsibility it is to provide care, and the roles of the various role players. Furthermore, the literature concentrated on the categories, themes and sub-themes that emerged from the data (see chapter 4).

## **5.12 RELATING THE STUDY TO EXISTING THEORY**

To enhance the trustworthiness of the findings, the researcher related the findings to existing theory and identified the concept of caring, which is central to the role of carers as seen by the participants:

*Yes, as you can see with our explanations, that they do care for every person more especially the orphans. In the case of death of parents, they attend to those orphans, every time they go there to find out if the orphans will be covered.*

*Yes, they are mostly unemployed, we know, but you know good people have soft hearts. I can say, they feel for their clients very much.*

The researcher considered Watson's theory of human caring, as caring is central to the provision of home care. Nurses or carers participate in human caring to protect,

enhance and preserve health by assisting individuals to find meaning in illness and to gain self-knowledge, self-control, self-determination in health decisions and life style management and self healing. A holistic approach to patient care is fundamental to home care (Watson 2002:100).

## **5.13 FINDINGS**

### **5.13.1 The roles of home-based carers**

The participants' responses to the 'roles of carers' were further divided into four themes and six sub-themes. The four themes were extended hands of nurses at clinics; advocate, liase and educate the community; care for patients at home, and projects.

- **Extended hands of nurses at clinics**

The participants indicated that carers had a role in supporting health care services provided by nurses. For example, carers conducted home visits to identify physical ill health and social problems; assisted in the management of TB, HIV-positive and chronic patients at home, and collected and distributed medication for patients too sick to come to clinic. In addition, carers trained family members to care for their relatives and also assisted nurses with the arrangement of campaigns by mobilising the community.

The participants therefore believed that carers did have a role to play in providing health care to the community and that their role was seen as an extension of the services nurses provide.

Accordingly, it is recommended that this belief be strengthened by providing support to professional nurses and carers through the provision of training and resources.

- **Advocate, liaise and educate the community**

The participants indicated that the carer's role is to advocate for financial and social support for community members. Carers could do this by requesting donations from businesses for paupers' funerals and arranging food parcels and social grants. The participants also referred to liaising with local councillors regarding people requiring housing. Carers were seen as 'health promoters', as they improved the knowledge of the community regarding health issues.

Due to their proximity to the community and their ties with all spheres, therefore, carers are able to advocate and lobby for community members.

It is thus recommended that carers should continue with this activity, as it appears to provide support to the community.

- **Care for patients at home**

The participants stated that when visiting patients at home carers should provide basic physical and emotional care and perform household chores, when needed. This might include support to the bereaved family and acting as surrogate mothers to orphans.

The care provided by carers to community members therefore includes basic physical and emotional support as well as performing household tasks, when needed.

It is recommended that carers receive appropriate training and support in performing these activities.

- **Projects**

The participants indicated the need for carers to participate in income-generating projects to augment their stipends and assist patients with food. This would include greenery projects, poultry farming and baking.

Carers participating in income-generating projects supplement their financial position and enable them to sustain their work as well as producing food to support the poor in the community.

Carers should be encouraged to participate in such projects and receive training in business management and marketing so as to benefit fully from this activity. The continued support of the nurse in this regard is needed, for example, by allocating ground in the clinic yard.

### **5.13.2 Problems/challenges and needs experienced by participants**

The second question examined the problems/challenges and needs the participants had experienced in implementing HCBC. The participants' problems were divided into six themes and fourteen sub-themes.

- **Financial problems**

The participants indicated that both carers and nurses experienced financial problems in implementing HCBC. Carers left care giving after receiving training as they expected to receive a stipend and others moved over to drop-in centres, as they were able to access leftover food. The participants experienced problems as carers expected them to provide money to assist with the transport of patients to hospital when needed in the absence of government transport.

The study found that the participants experienced financial problems relating to HBC, and transporting patients to hospital was a problem for both carers and nurses. Both carers and nurses did not understand the criteria for the allocation of carer stipends. The participants reported keen competition among carers to work at drop-in centres where they had access to leftover food rather than community care giving.

The study recommends that transport for patients to hospital from clinic and community level be investigated, as this is a government function. This would greatly assist the nurses and carers, who often have to use personal funds to transport patients. Furthermore, nurses and carers should be taught the criteria for stipend allocation.

Regarding the competition for carers between drop-in centres and community care giving, both are government and necessary strategies. Consequently, if the carer turnover relates to leftover food, this should be investigated and addressed.

- **Carers' lack of knowledge**

The participants indicated that carers lacked clinical practice, as some did not have patients to practise their skills on and thus forgot. Some carers also lacked accountability and professional conduct. This was evident when confidential information was divulged, as they did not understand the oath of secrecy. Disrespect of conservative culture was not properly observed in that they sometimes spoke and dressed inappropriately. In terms of accountability, some carers were dishonest as they indicated visiting their DOT patients while in fact just recording the visit without observing the patients as required.

Furthermore, the attrition of carers resulted in gaps in the HBC service and the participants emphasised the problem that as only trained carers are able to provide the service, the community suffered and they as nurses had to train new carers.

The study found that there is a lack of training or understanding in respect of professional conduct and accountability in carers' training and that monitoring and supervision of home carers required strengthening.

It is recommended that the relevant government department implement measures for carers to practise their clinical skills. Education on code of conduct, accountability and responsibility should be urgently provided to carers. The routine inclusion of this material in their basic training should be strengthened, as this behaviour was evident in trained carers. The extent of their training should also be assessed and monitoring and supervision of carers in the field strengthened.



- **Poor reporting**

The participants indicated that some carers did not report as required. Reports were sometimes late and data might be faked. Some carers did not inform the professional nurses about problems in the community, which then resulted in a lack of continuity in service. In addition, community members did not always inform the nurse when relocating or when death occurred and were therefore lost to follow-up.

The study found that there were problems with the accuracy and punctuality of carers' reports and that carers did not always consult with nurses on problem cases identified in the community. Clients were sometimes lost to follow-up through lack of reporting movement or death of patients. This could be due to poor coordination, limited monitoring and perhaps strained relationships between nurses and carers resulting in carers not consulting nurses as required.

Strengthening of relationships between carers, nurses and the community is recommended. Training in record keeping and role clarification of both nurses and carers as well as strengthening of monitoring of HBC are required.

- **Communication difficulties**

The participants indicated that there were difficulties with communication between carers, the health facility and the community. In terms of carers, the participants stated that carers did not maintain links after receiving training and stipends; did not follow the correct channels of communication, bypassed the nurse and communicated directly with the district. The carers' working hours were not clearly stated and the participants frequently had difficulty contacting carers when needed. The participants also indicated that carers collected medication for mobile patients who should visit the clinic for reassessment.

The participants raised the problem of lack of telephones at the clinic resulting in difficulty in contacting the carers. A further problem was that some community members did not trust the carers and refused to be treated by them.

The study found that communication channels were not clearly defined between carers, nurses and the district office. The community also did not understand HCBC and carers' roles and responsibilities. This was worsened by the lack of the necessary infrastructure for communication being available at all clinics, such as telephones.

It is recommended that programmes be introduced to orientate community members, nurses and carers to HCBC, including role clarification. The relevant authorities should investigate and establish communication resources.

- **Transport problems**

The participants reported that nurses were unable to do support visits with carers, as transport was not available. Furthermore, carers used their own money to assist with the transport of patients to hospital.

The lack of transport at clinic level is an obstacle to provision of support to carers providing care in the community.

It is recommended that the Department of Health and Social Development and Department of Roads and Transport investigate the problem and its solution.

- **Shortage of staff at health facilities**

The participants indicated a lack of dedicated staff for HCBC at health facilities. Those who assisted performed that function in addition to other duties. Attrition of trained carers also impacted on service delivery in the community.

The lack of dedicated posts for coordination of HCBC at clinic level comprises the coordination of service delivery.

It is recommended that the DOH and Social Development and relevant authorities consider the appointment of HCBC coordinators.

### **5.13.3 Participants' recommended strategies to improve HCBC**

The participants were required to recommend strategies to improve the quality of HCBC. The recommendations were divided into six themes and seventeen sub-themes.

- **Educate carers, coordinators, professional nurses and the community**

The participants stated that carers, coordinators, professional nurses and the community required education regarding HCBC and role clarification.

It is recommended that joint sessions be held to re-orientate all parties to HCBC and role clarification.

- **Government support**

The participants stated that posts should be created for HCBC, policy guidelines on HCBC were needed, and government recognition for work done by carers would motivate carers. Office accommodation for carers at health facilities was also required.

The participants emphasised that the lack of dedicated coordinator posts at local level compromises the HCBC service and there was limited government recognition for the work done by carers.

Posts should be created for HCBC coordinators at local level. Provincial policy guidelines for HCBC need to be developed and made available to carers, nurses and the community. Carers require government recognition for the work done and stipends should be given to all carers offering a service. Furthermore, office accommodation should be provided on clinic premises to carer organisations in order to facilitate improved coordination and to address financial problems, as they are unable to pay rent for offices elsewhere.

- **Strengthen communication and relationships**

The participants recommended the strengthening of relationships and communication between all parties. This could be done through regular coordination meetings. They recommended that the role of carers should be clarified and nurses should support carers in their work.

The need to ensure good working relationships was noted as well as the support of carers in their work.

It is recommended that strategies to ensure good working relationships be introduced, such as carer coordination meetings, detailing carer roles at health facilities, and nurses supporting carers in their work by conducting support visits to patients, providing supplies and assisting with problem solving.

- **Debrief carers**

The participants recommended that as carers worked with the sick and dying on a daily basis, they required debriefing on a regular basis. There was also a need for nurses to facilitate support groups for carers. The participants stressed that 'care of carers' must be strengthened.

- **Do projects**

The participants recommended that carers should participate in income-generating projects, such as greenery projects, to augment their stipend.

The study found that there was a need for carers to participate in income-generating projects to increase their stipend and contribute to the sustainability of their projects.

It is recommended that assistance be provided to carers to facilitate income-generation projects, which could include business and marketing skills.

- **Carer group distribution and establishment**

The participants reported that the distribution of carers accompanied with the attrition of carers created problems in service delivery. They suggested that each village should have more than one carer and that new groups be established to deal with this problem. They recommended that carer selection criteria and tools be used and the community involved in this process.

The study found that due to attrition of carers and organisations as well as duplication of services in some areas, there was a need to improve strategies for carer distribution and establish new groups. Moreover, community members' lack of trust in and occasional rejection of carers highlighted the need for increased community liaison.

It is recommended that information sessions on criteria for establishment of organisations, carer selection criteria, and norms be held for managers, nurses, carers and community members.

#### **5.14 LIMITATIONS OF THE STUDY**

The researcher identified two limitations in this study. First, only focus group sessions were used to collect data. Individual interviews with respondents might have eliminated any possibility of the participants influencing each other's views.

Secondly, the study focused on professional nurses' perceptions of the role of carers in HCBC. The inclusion of other categories of nurses working with carers might have yielded broader valuable insights, as it appears that very often liaison with carers is delegated to them.

#### **5.15 RECOMMENDATIONS FOR FUTURE RESEARCH**

The study was limited to the Capricorn district of Limpopo, and thus reflects only the participants' perceptions and insights. It is therefore recommended that further research be conducted in the remaining districts as the lived experiences might differ and be influenced by culture and traditions predominant in those districts.

In addition, based on the findings of this study, the researcher recommends further research on the following topics:

- Carers' perceptions of providing HCBC to communities.
- The training received by carers and its ability to prepare carers for their work as caregivers, focusing on the concept of 'professional conduct'.
- Should carers exist as a discipline on their own, with their own controlling body or should they be considered part of the nursing fraternity and thus be accountable to the nursing council?

## **5.16 CONCLUSION**

This chapter discussed the findings in detail and made recommendations for practice and further research. The limitations of the study were also described.

The participants clearly indicated that carers did have a role in providing care to the community and served as the extended hands of their services. These services include conducting home visits, advocacy, health promotion, community liaison, and participation in income generation projects. However, existing challenges impact on the quality of service delivery. These may be attributed to improper orientation of key role players to the programme, a lack of role clarification for nurses, carers and the community, and inadequate training for carers and nurses.

There are also challenges to the overall support of the programme from government, including availability of physical resources, for example, office accommodation, and patient and nurse transport to follow up patients and support carers in the field. There is also a lack of human resources like coordinators at local and clinic level for HCBC.

Existing elements should be strengthened, including improving relationships, communication and the "care of carers" programme, carer training, reporting, and monitoring and carer distribution.

Finally, in conclusion, the words of the Honourable Joy Phumaphi, former Minister of Health, Botswana, in the opening address of the 1st Southern African Regional Community Home-based Care Conference held in March 2001 (2001:2), hold true

today, and remind us of the power of humanity to rise to meet catastrophic challenges throughout life:

HBC is taking us back to the root of human co-existence. It reminds us that we all have a responsibility to one another. If we hold hands through this tragedy, we will be able to retain our humanity and will come out of this epidemic as a stronger community.

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## **ANNEXURE A**

Mrs CR Jackson  
Postnet Suite 370  
Private Bag X9307  
Polokwane  
0700  
17/11/2006

Ms Malumane  
The Department of Health & Social Development  
Research/Ethics Committee  
P/B X 9302  
Polokwane  
0700

Dear Madam

### **RESEARCH STUDY: PROFESSIONAL NURSE PERCEPTIONS OF THE ROLE OF HOME AND COMMUNITY-BASED CARERS PROVIDING CARE TO THE COMMUNITY IN THE CAPRICORN DISTRICT OF THE LIMPOPO PROVINCE**

Herewith a request to conduct the above mentioned research study in the Limpopo province. Attached please find the research proposal detailing the study.

This study is towards the requirement for completion of a MA Cur Degree.

The proposal has been approved by the supervising university i.e. Unisa, see attached proof thereof.

In the event of any queries or clarifications please contact Mrs Colleen Jackson (0828031775).

Thank you for your support in this endeavor.

Yours sincerely

Mrs CR Jackson: Student Number: 4903447

Date: 17/11/2006

## ANNEXURE B



**LIMPOPO**  
PROVINCIAL GOVERNMENT  
REPUBLIC OF SOUTH AFRICA

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**DEPARTMENT OF HEALTH & SOCIAL DEVELOPMENT**

Enquirer: Malomane EL  
Ref: 4/22

18 May, 2007

Mrs C.R Jackson  
Postnet Suite 370  
Private Bag X9307  
Polokwane  
0700

Dear Ms C.R Jackson

The perceptions of Professional nurses regarding the role of professional nurses regarding Home based Carers in providing care to the communities in the Capricorn district in the Limpopo Province

- Permission is hereby granted to Mrs. C.R Jackson to conduct the study as mentioned above: Capricorn district Limpopo Province
- The Department of Health and Social Development will expect a copy of the completed research for its own resource centre after completion of the study.
- The Researcher/s should be prepared to assist in interpretation and implementation of the recommendations where possible
- The Institution management where the study is being conducted should be made aware of this,
- A copy of the permission letter can be forwarded to Management of the Institutions concerned

  
\_\_\_\_\_  
HEAD OF DEPARTMENT  
HEALTH AND SOCIAL DEVELOPMENT  
LIMPOPO PROVINCE  
Date: \_\_\_\_\_

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Private Bag x 9302 Polokwane  
Polokwane 0700. Tel.: (015) 293 6000 Fax: (015) 293 6211 Website: <http://www.limpopo.gov.za>



**Land of Southern Africa - development is about people!**

**ANNEXURE C**

**UNIVERSITY OF SOUTH AFRICA  
Health Studies Research & Ethics Committee  
(HSREC)  
College of Human Sciences  
CLEARANCE CERTIFICATE**

Date of meeting: 2006:03:2006

Project No: 04903447

**Project Title: Professional nurse perceptions of the role of home and  
community carers providing care to the community  
in the Capricorn District in the Limpopo Province**

Researcher: Mrs CR Jackson

Supervisor/Promoter: Dr UU Alberts

Department: **Health Studies**

Degree: MA(Cur)

**DECISION OF COMMITTEE**

**Approved**



**Conditionally Approved**



Date: 2006:10:30

**Prof TR Mavundla**

**RESEARCH COORDINATOR: DEPARTMENT OF HEALTH STUDIES**

**Prof SM Mogotlane**

**ACADEMIC CHAIRPERSON: DEPARTMENT OF HEALTH STUDIES**

## ANNEXURE D

**Research study: Perceptions of Professional nurses regarding the Roles of Home Based Carers in providing care to communities in the Capricorn district in the Limpopo province.**

I,..... hereby give consent freely and without coercion to participate in the study entitled ***Perceptions of Professional nurses regarding the Roles of Home Based Carers in providing care to communities in the Capricorn district in the Limpopo province.***

My role in the study has been clearly explained to me by the researcher.

My inputs will not be in any way linked to me personally and my rights to confidentiality will be at all times protected.

I understand that at any given point during this study I may withdraw if I so desire.

Name .....

Date:.....

Signature:.....



## ANNEXURE E

### FOCUS GROUP 1: TRANSCRIPTION NOTES AND CODING

<b>8. Research Question:</b>		<b>8.1. What do you as Professional Nurses think are the roles of Home Based Carers in providing care to the community?</b>  F: “So we are going to go to the actual questions. The first question that we are going to discuss is what you as professional nurses think are the roles of home based carers in providing care to the community. So it is very much your opinion, what to do you think the home based carers should be doing? What do you think their roles should be? They are providing care to our people; we need to find out what you think their roles should be.”
<b>8.1.1. Responses from participants re Question 1:</b>	A1.1 A1.1.b(i)  A1.3b  A.2.2.b  A1.1.a (iv) A1.1.f A1.3.a	P: (A.1.1) “They help the patients in their homes, by preparing food & (A.3.2.1.b) by supervising them when they take their treatment. (F: Would you like to elaborate a little?) e. g. DOTS (Directly observed treatment short course) for Tuberculosis (TB). They can provide support, supervise, complete records and ensure completion of treatment.”  P: “They give support to the family and even to the client. (F: Would you like to elaborate on the type of support?) By explaining the condition of the patient to the family so that they can understand or encouraging them to take treatment.”  P: “They provide information around TB and HIV (Human Immune Virus) more especially the mode of spread.”  P: “If we have any child that has defaulted they can send the carers.”  P: “Doing wound dressings and bed baths, (F: any additions?) They can also supervise & train the family members to do bed baths. They must first get consent from the patient and their family to do the bed baths.”

	A1.1.a(ii)	<p>P: “Their role is to trace defaulters. They usually trace those ones that are getting treatment of TB, if maybe the patient has been diagnosed with TB we usually monitor until they finish the course of the treatment, and then. If maybe, all of a sudden he not coming to the clinic to collect the treatment then we are asking the Home Based Carers to go and visit the patient so that he may come to the clinic again. Even children who don’t come for immunizations, and the chronic patients e.g. hypertension, Diabetics &amp; mental patients.”</p>
	A1.1.c	<p>P: “They are the eye opener as far as the community’s social lives are concerned. They are doing door to door then they come across a family, with a problem of, I am just giving an example, of any child who is deformed or any member of the family with some disability, they refer.”</p>
	A1.1.a (iii)	<p>P: “They are the ones who are assisting nurses to trace patients who don’t come for treatment.”</p>
	A2.2.a	<p>P: “Another role is that they are giving health education about preventative measures and communicable diseases. They could give health education on how to care for yourself for example bathing. If you have TB you have to take treatment otherwise you will infect the other members of the family. (F: Any additions?) Teach then about the prevention of accidents in the home. This could also be about the spread of cholera and teenage pregnancies.”</p>
	A1a	<p>P: “We (Professional nurses) even order materials for the home based carers for example gloves, soap, diapers, aprons and linen savers. (F: Explain their (carers) role?) They are the extended arm of the nurses, so we have to teach them about prevention and so we have to order those materials or supplies so that they can prevent themselves from being infected when providing that care.”</p>
	A1.2b	<p>P: “They are helping us with the sorting of patients more especially during campaigns”. (F: What type of campaigns?) “Examples are for Polio and measles.”</p>

	A1.2a	<p>P: “They also help us to mobilize the community during awareness days. With the awareness days I mean if maybe we are having a HIV awareness we always contact them so we are working well hand in hand with them to go to the Indunas (local traditional leader) and tell them so that they are able to inform the community around there about the awareness.”</p> <p>F: “Welcome back from the short break. We are now going to look at the second question”.</p>
<b>Research question 2:</b>		<b>8.2. What are the problems/challenges &amp; needs you have experienced as a Professional Nurse implementing Home and Community Based Care?</b>
<b>8.1.2. Responses from participants:</b>	<p>B4.3.1</p> <p>B2.3.</p> <p>B4.1.5</p> <p>B2.3.a</p> <p>B2.5.</p> <p>B1.1.1.a</p>	<p>P: “Some of the community members don’t have trust in Home Based Carers.”</p> <p>P: “Some of Home Based Carers, don’t have confidentiality.” (Don’t understand confidentiality)</p> <p>P: “At times it seems that Carers see themselves as a separate entity to Professional Nurses; (F: Tell me more about something separate?). For example, we find that at times, when we ask them to put their records here at the clinic so that we as nurses can have access to those, but, we find that they don’t keep them and when we need something we cant get them.” (Agreement by one of the group members indicated by mmm).</p> <p>P: “Another problem is that we train them and then thereafter they don’t have any interest and they leave a gap, and we find that we don’t know what to do. So we have to look for the other group now so that we can train them, because to be a home based carer we have to train them first. So if maybe we have trained them we find that they don’t have interest anymore and then it’s a problem to us.”</p> <p>P: “They thing is that they expect to be paid and then if they don’t feel that they are employed they go away. They are saying that they want to be paid. They</p>

	B4.1.1	expect that maybe if you train them you are going to hire them. They get trained, they get stipend and then they don't link themselves to the clinic anymore."
	B1.1.1.b	P: "Another problem we have identified is that once trained and active, they go and look for another job and there is a gap as they are no longer there and we have to train the other people and the community are used to the first group. This is with the very certificate they received."
	B4.1.4.a	P: "Some carers who receive stipend just come and collect the chronic treatment from the clinic and then leave."
	B3.1.1.	P: "They don't report if they are having problems with their home visits, since 2005, I have never had any report from them saying they have encountered a certain type a problem and can we assist."
	B3.1.2.	P: "Some don't report at all as have an office outside the clinic yard."
	B1.1.2.	P: "Carers don't have space to hold their meetings they do it under the tree."
	B2.1.1.	P: "Carers lack practice skills for example if have taught them how to do bed baths, there are no patients to bed bath in the community so they tend to forget. It a problem for the nurse as I shall have to repeat what I have taught them and I don't have time to do that."
	B6.2.	
	B1.1.1.c	P: "Carers leave work in the community to work in Drop Inn Centers, which are funded by Social development. These drop inn centers provide food for school children. Carers like to work there because they get food and left overs which they can take home to their children."
Research question 3:  8.1.3. Responses from participants:	C2.2c.	<b>What recommendations regarding strategies would you suggest be established to improve the quality of care of Home and Community Based Care?</b> P: "We wish that all carers receive stipend so that they can stay in the service."

	C1.7	P: “We as professionals need to have an in service because some of us don’t know what carers are supposed to do.”
	C3.2.1.c C3.3.2.a	P: “We need to have meetings with the carers and how to solve them.” P: “Nurses need the time frame for receiving reports from carers.”
	C2.3.a	P: “They have to get a room in the clinic yard so that they can meet together and arrange something their reports and submit them to the P/N’s. “
	C2.1.c	P: “Support from provincial HCBC is needed to assist with problems experienced, as the room in the clinic yard may not help.”
	C3.2.1.b	P: “We (P/N) have to work together with the home based carers. I can say that we can that some meetings once per month maybe so that they can say out their problems and help them solve them.”
	C3.3.2	P: “I think they (Carers) should report after each and every visit (daily) so that we can hear the condition of the patients.”
	C1.6	P: “In service training should be provided to P/N’s as they don’t know what they are supposed to do.”
	C6.1.a	P: “Each village should have more than one carer so that they can manage the work.”
	C6.1.b.	P: “New groups should be established where carers have left to work in the drop inn centers.”
	C6.2.a	P: “P/N’s should liaise with stakeholders in the community, for example, local ward councilors, when establishing new groups, as carers may not be allowed to work in the area.”

	<p>C2.3.1.</p> <p>C1.1.</p> <p>C6.2.a (i).</p> <p>C3.1.b</p> <p>C3.4.1</p> <p>C3.4.1a</p> <p>C3.2.1</p> <p>C3.3.1</p>	<p>P: "Home Based Care organizations must have policies and rules to guide them."</p> <p>P: "P/N's should do in service training for carers weekly for updates about new developments."</p> <p>P: "Selection tools could be used when recruiting carers to check if relevant. This could be a questionnaire or interview. Age should also be considered."</p> <p>P: "P/N's attitude should be good towards carers, they should not look down on them."</p> <p>P: "P/N's should do follow up in the villages to see if carers are implementing what they have been taught about quality of care."</p> <p>P: "We must order HCBC kits so that they can provide quality care."</p> <p>P: "Carers should be involved in the clinic meetings. This could help when discussing structural changes and the clinic year plan."</p> <p>P: "Nurses should encourage carer to do health talks in the mornings at the clinic. The P/N should delegate the carer and be present during the talk to ensure quality of information. The talk could also be prepared by the nurse for the carer and then taught to present it."</p>
<b>9. Way forward:</b>		<p>F: "Thank you very much we have now gone through each of the three questions, the roles, the problems and the recommendations and we have captured them. So thank you all for your inputs. What we are going to do now is to go back to our programme and the next point is the way forward. What will now happen in relation to the information that we have captured from the key experts. The first thing that I do is that I will now capture everything from the tape and I transcribe it. When I have done that there will be a time that I</p>

		<p>will either call you together as a group or if that is not possible due to your work pressure then I will make sure that you will each get a copy of what has been transcribed for you to verify if this is correct or not. So, that will depend on your availability as a group.”</p> <p>“The next step after the groups are completed is to analyze the data. When the whole process is complete and finalized then I will let you will get a copy so that you can see what the end result of the study was.”</p> <p>“Are there any more questions anything that you would like to ask or add?”</p> <p>Q: P “Is there anything that you are going to help with us to improve about this Home Based Care or just doing the research and that’s all?”.</p> <p>F: “As researcher my role is to do the research to capture and analyze. Once the report is complete and approved then it must come back so that the service can be improved. My personal role is to give feedback about the results but you have a provincial Home and Community Based Care co-coordinator who is Ms Johanna Rapakwana and it will be her role to take these findings and to assist you to improve the Home and Community Based Care. That would be the correct pathway. It is very important what we have learned here must come back and must be presented to everybody and the learning’s that we get from there if they are accepted should be implemented.”</p>
<b>10. Closure &amp; vote of thanks:</b>		<p>F: “It is just for us to close. Thank you so much for you coming today, for taking your time to come to Lonsdale clinic and to share your experiences and expertise with me so that in time we can improve our services.</p> <p>We are going to close and then have lunch. We started with a prayer so do you want to close with a prayer? Thank you, thanks very much ladies, much appreciated.” (Focus group closed with prayer in Sepedi).</p>

