AN EXPLORATORY STUDY OF THE REFERRAL PATHWAY OF PATIENTS DISCHARGED FROM A TERTIARY HOSPITAL TO HOME-BASED CARE IN THE WESTERN CAPE

A thesis submitted in fulfillment of the requirements for the degree of Master in Nursing (Full Research) in the School of Nursing, University of the Western Cape

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May 2012
DECLARATION

I declare that the full Masters in Nursing research study entitled “An explore study of the referral pathway of patients that have been discharged from hospital a tertiary hospital to home-based care in the Western Cape” is my own work, that it has not been submitted for any degree or examination in any other University, and that all the sources I have used or quoted have been indicated and acknowledged by complete references.

Lorna L Scheepers

May 2012

Signed…………………………..

Date: May 2012

UNIVERSITY of the WESTERN CAPE
DEDICATION

In loving memory of my late husband, Wilhelm. His legacy will continue throughout the generations.

To my mother Anne, my role model and inspiration.

Sustained by His Grace.
ACKNOWLEDGMENTS

To God be the Glory! Thank you for allowing this achievement. I bless your Holy Name!

A vote of thanks to:
My children, Juanita, Rovellen, Herscheline and Dreschel. Thank you for your unwavering support and the joy that you have brought to your belated father & my heart. God bless you always!

To my supervisor, Prof. M. Ganga-Limando. No words can describe how infinitely grateful I am for your guidance and input. Where others before you failed and disappointed me, you went the extra mile. Beneath your quiet disposition, you have the ability to inspire and instil the desire to “not give up.” You are a SUPER – supervisor, THANK YOU!

The Western Cape Department of Health, staff at all the sites including non-governmental organizations.

The National Department of Health for granting study leave to complete my research.
ABSTRACT

The purpose of the study will be to explore the discharge referral pathway for patients that have been discharged from hospital to home in the Western Cape Province. A mix of quantitative and qualitative research, using a descriptive design will be undertaken. Quantitatively, following the patient paper trail from Tertiary Hospital to grassroots level. Qualitatively, to identify whether the referral pathway was user friendly.

Records of discharged patients from the Tertiary Hospital will be used as the study population. Patient information will be accessed from patient files at the hospital. Interviews will be conducted with the relevant discharge liaison officers at the Tertiary Hospital, and Primary Health Care level. Relevant staff members within the non–governmental –organisations (NGOs), will also be interviewed in order to determine their perception of the discharge referral pathway. The findings of the study will be used to inform policy guidelines. Challenges encountered by staff members in referring patients for continuum of care, and the perception of consumers will also be described and documented.

KEY WORDS: Referral pathway, Home based care, Burden of disease, Management, Continuum of care, Primary health care, and Health for all concepts
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<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
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<tr>
<td>ADL</td>
<td>Activities of Daily Living</td>
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<td>AIDS</td>
<td>Acquired Immuno-Deficiency Syndrome</td>
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<td>CVD</td>
<td>Cardio Vascular Diseases</td>
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<td>CHC</td>
<td>Community Healthcare Centre</td>
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<td>DOT</td>
<td>Daily Observed Therapy</td>
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<td>DALYs</td>
<td>Disability Adjusted Life Years</td>
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<td>HIV</td>
<td>Human Immune-deficiency Virus</td>
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<td>HCBC</td>
<td>Home and Community Based Care</td>
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<td>IADL</td>
<td>Instrumental Activities of Daily Living</td>
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<td>M.O.</td>
<td>Medical Officer</td>
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<td>MRC</td>
<td>Medical Research Council</td>
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<td>MOH</td>
<td>Ministry of Health</td>
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<td>NDOH</td>
<td>National Department of Health</td>
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<td>NEPC</td>
<td>National Environment Protection Council</td>
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<td>NHA</td>
<td>National health Act</td>
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<td>NCD</td>
<td>non-communicable diseases</td>
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<td>NGOs</td>
<td>Non-governmental organisations</td>
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<td>PHC</td>
<td>Primary Health Care</td>
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<td>QALYs</td>
<td>Quality-adjusted life years</td>
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<td>SPSS</td>
<td>Statistical package for the social sciences</td>
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<td>SDHCBC</td>
<td>Sub-District Home Community Based Care</td>
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<tr>
<td>TA</td>
<td>Technical Assistant</td>
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<tr>
<td>TCA</td>
<td>Come back dates</td>
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VCT = Voluntary Counseling and Testing
WCDOH = Western Cape Department of Health
WHO = World Health Organization
UNICEFF = WHO & United Nations Children’s Fund
YLLs = Years of Life lost
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CHAPTER ONE:

OVERVIEW OF THE STUDY

1.1 INTRODUCTION

The provision of health care services prior to the 1994 democratically elected government was characterised by fragmentation and huge disparity mostly on racial basis. In an effort to correct the imbalances of the past, the new government implemented several measures including an integrated approach to health care service delivery; a decentralised health services management system; and the implementation of full package of primary health care services primary care level. One of the aims of these measures were to ensure reasonable access to effective, efficient and quality health care services to all South Africans in the respective health districts throughout the country. In order to ensure long-term sustainability, communities were engaged in local decision-making and encouraged to play an active role in the delivery of health and health related services (National Health Act (NHA), 2003).

The National Health Act of 2003 makes provision for equal access to basic health care for unemployed people and people from the lower income groups. It offers opportunity to people who could not afford private medical insurance to access free health care services at any clinic or Community Health Care Centre. These services included amongst others, basic health care services, management of chronic diseases of older persons, physical rehabilitation, psychosocial rehabilitation and care to individuals in their home environment or in the community (NHA, 2003).
Home or community based care is an innovative way whereby patients could receive quality care through the delivery of cost effective and affordable health care in the home environment. HCBC services are health and health related services provided to patients by lay health workers. Its specific purpose is to provide access to appropriate services as close as possible to the patient’s home / community. The service is enhanced through active participation of the patient, family and the community. Types of services rendered are health promotion, disease prevention, restoration / maintenance of health and care of the dying patient (National Department of Health (NDOH), 2001).

In the past, the biggest portion of the overall health budget in developing countries was allocated to large academic hospitals and controlled by the National Departments (World Health Organisation (WHO), 1999). Patients were admitted and remained in hospital for prolonged periods of time because it was perceived to be the best and / or preferred option. The reason for this phenomenon was due to the fact that the provision of health care was controlled and predominantly delivered by health care professionals (WHO), 1999).

In South Africa during the most recent years, reduction in the allocated health budget from the national health department caused severe financial constraints. In an effort to operate within budget, a number of hospital beds had to be closed. Vacant posts were not filled resulting in staff shortages, which caused a tremendous strain on the existing hospital staff. The length of hospital stay for patients was also drastically reduced and
patients were discharged as soon as their medical condition stabilised (Western Cape Department of Health (WCDOH), 2003).

The Western Cape Health Department developed a discharge referral mechanism to ensure appropriate and timeous follow-up care for patients at community-based level after hospital discharge. This referral system facilitated a process whereby the discharged patient was referred to a specific Primary Health Care (PHC) facility in the area where the patient lived. The responsible person at the health facility referred the patient to the relevant NGO. The NGO then delivered the required services in the patient’s home. This referral mechanism hinged on a paper trail that was created at the point of discharge and ended at the patient’s home when the NGO nursing manager completed the initial clinical assessment. The NGO nursing manager completed a nursing care plan and assigned a care worker to execute the plan. The nursing manager closely monitored the patient’s progress and provided feedback reports to the relevant health facility (WCDOH, 2003).

It is believed that compliance to the above referral pathway will facilitate smooth access to home / community based care services and continued nursing care after discharged from hospitals. However, it is not clear how these guidelines are being implemented from the hospital to the community and how user friendly are these guidelines from the perspective of health care workers. Hence the researcher intended to find out how the different agencies are implementing these guidelines and their perceptions about their user-friendliness. The research question that arose was whether
the proposed mechanism for the discharge of patients was adequate for the implementation of an effective referral system between hospital and home.

1.2 PROBLEM STATEMENT

The researcher’s personal experience and interaction with members of the community stimulated her interest to undertake this study. The researcher’s interaction with hospital staff identified that there were some challenges in the implementation of the discharge referral system from the hospital to home-based care. The perception was that some patients could have been discharged from hospital with inadequate information. Some staff members at the tertiary hospitals reported (to the researcher in her occupational capacity) that a number of patients referred for home based care, had not received the necessary treatment at home. Relatives have also reported that there were occasions when the NGO staff only arrived for the initial clinical assessment long after the patient had died. The researcher experienced a personal incident whereby a neighbour was discharged from a Tertiary Hospital with a gaping abdominal wound. No referral letter or any instruction to the patient or her relatives was given upon discharge.

These incidents highlight the importance of the referral system in ensuring the continuity of care. Ineffective referral may delay the provision of appropriate care. The lack of appropriate and timeous provision of care had serious implications for both the patient and the health department. Possible consequences of a mal-functioning discharge referral pathway were the increased risk of re-admission due to inadequate follow-up care. Re-admission may lead to prolonged bed occupation as the patient’s
health may have deteriorated very severely in the absence of care. This prolonged
admission further contributed to a financial burden for the health department because
of the major cost implications. It also added additional strain on existing services
because of staff shortages. Patients are also becoming more aware of their
constitutional right for access to an acceptable standard of care. The department could
be faced with serious litigation if the patient could prove that the department had
neglected its obligation in providing quality health care services.

1.3 AIM OF THE STUDY

The aim of the study was to explore and describe the referral pathway of patient
discharged from a Tertiary Hospital in Cape Town to home-based care and the
providers’ perceived user-friendliness of the referral pathway guidelines developed by
the Western Cape Department of Health.

1.4 RESEARCH OBJECTIVES

1.4.1 To explore and describe the discharge referral pathway of patients discharged
from a tertiary hospital in Cape Town to home-based care in the Northern parts
of the Metropole and Overberg Boland regions in terms of:

- documentation and record keeping,
- adherence to the steps outline by the provincial protocol.

1.4.2 To explore the experiences of the providers in the implementation of the
provincial referral to home-based care protocol pathway.
1.5 SIGNIFICANCE OF THE STUDY

*Nursing practice and education:* Healthcare managers in the targeted institution could use the findings to improve the quality of the referral and the continuum of care. Nurse educators can also use the findings to formulate need-based in service training.

*Body of knowledge:* the findings of the study will contribute to the body of knowledge on the implementation of policy guidelines with regard to referral to home-based care. The findings can also be used to inform further research on referral system and continuum of care.

*Policy implementation:* this study will highlight compliance and difficulties in the implementation of policies. The finding of the study has the potential to inform healthcare managers on the level of compliance of the healthcare providers with the policy guidelines.

1.6 ETHICAL STATEMENT

Ethical clearance was obtained from the University of the Western Cape, Senate Higher Degrees before the commencement of the research (see Appendix D). Further permission was obtained from the Head of the Health Department and the Chief Directors at the various sites (see Appendix A). Informed consent was obtained from the participants before the individual interview (see Appendix C).

The participants were fully informed about the study (see Appendix B). Further information is given under the ethical considerations in Chapter three.
1.7 DEFINITION OF KEY CONCEPTS

Referral pathway

The activities that facilitate a patient's movement from one health care setting to another, or to home. It is a multidisciplinary process involving physicians, nurses, social workers, and possibly other health professionals; its goal is to enhance continuity of care. It begins on admission (Mosby's Medical Dictionary, 2009).

The referral pathway in the context of the study refers to the process that was implemented to facilitate the discharge of patients from the Tertiary Hospital with adequate follow-up plans at community based level.

Home based care

Home based care is defined 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, function and health including care towards a dignified death. Home care services can be classified into preventive, promotive, therapeutic, rehabilitative, long-term maintenance and palliative care categories (NDOH, 2001).

Burden of disease

Disease burden is the impact of a health problem in an area measured by financial cost, mortality, morbidity, or other indicators. It is often quantified in terms of quality-adjusted life years (QALYs) or disability-adjusted life years (DALYs), which combine the burden due to both death and morbidity into one index. This allows for the
comparison of the disease burden due to various risk factors or diseases. It also makes it possible to predict the possible impact of health interventions (The Free Dictionary, 2012).

The Western Cape Government (2006), reports that chronic non-communicable diseases (particularly cardiovascular disease, hypertension, diabetes mellitus and chronic kidney disease) have now replaced the communicable diseases as the leading threat to public health and health budgets worldwide. The cost of treating these chronic diseases, already 80% of many health care budgets, represents a leading threat to public health and healthcare resources worldwide. The only feasible global response to this pending health and socio-economic crisis is chronic disease prevention.

**Continuum of care**

The extent of coordination of care as the client moves from one care setting to another (Mosby’s Medical Dictionary, 2009). It is envisaged that patients would be able to access continuous, uninterrupted healthcare services according to their specific home based care requirements once they have been discharged from the Tertiary Hospital.

**Primary health care**

The provision of basic health care that includes teaching people how to live healthily, eg, eating healthily and basic hygiene to prevent illness and disease. It includes programs directed at the promotion of health, early diagnosis of disease or disability, and prevention of disease. Primary health care is provided in an ambulatory facility to limited numbers of people, often those living in a particular geographic area. It
includes continuing health care, as provided by a family nurse practitioner (Mosby’s Medical Dictionary, 2009).

1.8 OUTLINE OF THE REPORT

Chapter one is an introduction into the study while chapter two reflects the literature review. The methodology of the study is presented in chapter three with its results reflected in chapter four. Discussion of the results is included in chapter five with recommendations for possible review of current policy guidelines.

1.9 SUMMARY

This chapter highlighted the perceived problems experienced by patients after their discharge from Tertiary hospital, the aim of the study and the research objectives. The significance of the study results for the Health Department had also been indicated in this chapter.
CHAPTER TWO:

LITERATURE REVIEW

2.1 INTRODUCTION

Information for the literature review was obtained from the following sources: The World Health Organisation (WHO). Policy guidelines from the National and Provincial health departments and Non-Governmental-Organisations (NGOs). Studies undertaken nationally and internationally as well as information obtained from books, abstracts, journals and presentations. The literature search revealed that most of the studies were done in developed countries. Some research relating to the topic was undertaken in developing and under developed countries. A number of studies in Southern Africa relating to patient care in the home and community setting have been done. However, very few studies have explored the patient trail between hospital discharge and management in the home setting.

2.2 REFERRAL MANAGEMENT SYSTEM

The referral pathway for patients through the health care system allows the system to track and follow the patient. These are well-designed plans, which are developed and executed by a multidisciplinary team. It should produce a single record of care whereby patient progress is monitored in hospital or in the patients’ home (Middleton and Roberts, 2000).

Appropriate mechanisms are designed to accelerate the recovery of the patient through an appropriate integrated care management system. “An integrated care management system focuses on the continuity of care, by examining the organisation and
management of patient care, facilitating the smooth transition between hospital and home” (Wilson, 1997). An integrated care management system benefits and focuses on the patient open discussions between clinicians and the patient regarding treatment plans reduce fears and anxiety for the patient / family. The patient / relatives become partners in health by actively engaging in the decision-making process, improvement and maintenance of their health status. Effective coordination between service providers reduces clinical risks and / or injuries and ensures better outcomes for the patient. Role clarification between team members eliminates duplication and overlapping of service delivery and thereby promotes effective and cost-effective use of resources (Wilson, 1997).

Referral management allows for proper planning and optimal use of health services / or resources to meet the individual needs of the patient. It directs patients and their families to the most appropriate levels / or location of care. Under-utilized health services are used optimally by re-directing patients to these under-utilized centres / services. A patient referral management system facilitates the discharge of the patient. Information regarding follow-up booking and access to service / service delivery points are provided to the patient before discharge. Mechanisms are implemented to track the patient and monitor compliance to follow-up visits and treatment regimes. Referral management is aimed at ensuring an effective and uncomplicated patient journey with the best possible outcome for the patient (The Scottish Government, 2007).

The guiding principles in referral management are to facilitate effective communication and co-ordination of care between the different care providers and
across settings. All role players collectively agree and support the patient outcomes. Referrals are based on the expert opinions of clinicians / or specialists. Role clarification regarding responsibilities and accountability are clearly outlined. Timeous consultation between relevant role players is facilitated to integrate tertiary or secondary care with primary care. Special emphasis is placed on treatment / management protocols available at local level. Education, training and capacity building are important elements in the referral management system. Continuous monitoring is important to monitor effectiveness, and to apply corrective measures, if necessary. Before a referral management system is implemented the impact on existing services or the possible benefits of such a system are to be carefully considered (British Medical Association, 2007).

The objectives and functions of a referral management system are to secure the best options available for the patient. To screen and facilitate referral of the patient to appropriate levels of care / or treatment interventions. To identify and form networks on behalf of the patient in order to facilitate access to other services (British Medical Association, 2007).

2.3 DISCHARGE PLANNING

In planning the discharge of a patient the different dimensions of continuity of care are carefully considered. The necessary resources needed by the patient upon discharge are well planned and well-coordinated. Proper discharge planning with the necessary follow-up at community-based level ultimately improves the patients’ prognosis (Erwin, 1999). Staff with special skills and advance knowledge plays an important role
in discharge planning. Intensive preparation and interaction with the patient and the prospective caregiver are needed before discharge (Erwin, 1999).

2.4 CONTINUUM AND CONTINUITY OF CARE

2.4.1 Continuum of care

A vast array of health problems is the probable cause of patients in need of health care over a prolonged period of time. Their health problems are due to: Ageing, chronic diseases, severe disabilities caused by accidents, postoperative / episodic care, physical or mental disabilities, congenital abnormalities or conditions of the nervous system etc (Evashwick, 1996).

Patients are admitted in hospital during the acute phase of their illness and discharged as soon as their condition is stabilized. Oftentimes, due to bed or staff shortages patients are discharged prematurely. The recovery process often requires care that is provided over a prolonged period of time. Long-term care is the provision of services beyond ninety days and will only be discontinued after the recovery or death of the patient. It also extends indefinitely over many months or years, for as long as the patient needed the service (Evashwick, 1996).

Functional disabilities in the physical, emotional or social aspects have been identified as the primary cause for patients in need of long-term care. According to a measurement tool developed by Katz, Ford, Moskowitz, Jackson and Jaffe (as cited in Evaswick, 1996) any inability to perform in the Activities of Daily Living (ADL) means that a patient’s physical function is compromised. Personal hygiene, toileting,
ability to move in and out of bed, bladder control, feeding oneself and drinking adequately are the most basic activities of daily living. It has been identified that the first sign of functional dependence is the patient’s loss of being able to bathe her/himself. The most severe sign of dependence is when the patient is unable to feed her/himself.

A different scale, the Instrumental Activities of Daily Living (IADL) is used to determine whether a patient is able to live independently in the community. This scale assesses issues such as the ability to prepare meals, budgeting, grocery shopping, the ability to make a phone call, housekeeping and other household chores. Lawton & Brody (as cited in Evaswick, 1996).

The inability to function independently could have other underlying causes i.e. the nutritional status of a patient suffering from a debilitating arthritic condition could be severely compromised because of the inability to eat. The reason for the nutritional status could be twofold. The patient could either be too sick to eat, or unable to hold a knife, fork or spoon. Continuum of care for this patient meant the provision of an assistive device to restore functional independence. The patient would then be able to eat independently and thereby fulfil his/her own nutritional needs (Evaswick, 1996).
2.4.2 Continuity of care

Continuity of care is a synonym for continuum of care. Continuum of care refers to the mechanism and method of service delivery to patients over a prolonged period of time and as long as the patient needed the service. It comprises of different role-players, resources and services to ensure that the physical, social and emotional needs of the patient are accommodated. These components / elements of care are available and accessible to patients whilst they transfer between the different levels of care. Evashwick 1987 (as cited in Evashwick).

Continuity of care has different dimensions in the delivery of health care services. It is a seamless transition for the patient between different settings with different staff members caring for the patient. At each setting, whoever manages the patient is accountable for the service provision. Continuity of care also means that resources such as information, health care service as well as health care providers are readily available. The other important aspect is to secure the next level or source of care. This level has to be adequately prepared and appropriately resourced to receive the patient (Brown University, 2004).

Continuity in a hospital setting differs from the above. The patient is managed in the same environment. The care is provided by different staff members / disciplines. Each discipline understands their role in the optimal management of the patient. Although different staff members are involved, the care of the patient is carefully coordinated by one person that is overall responsible for the hospital ward. The nursing
sister or doctor in charge of the ward is accountable for the patient’s progress (Brown University, 2004).

Record continuity refers to the availability of patient data. It can be manual or electronic access to patient data for continuous assessment and appropriate management. This is particularly important if the patient attends hospital or clinic on an outpatient basis. Loss of patient information (file) means loss of patient history. All previous treatment, tests done or test results received is then inaccessible. This could result in a severe setback in the necessary treatment and could adversely affect the progress of the patient (Brown University, 2004).

Clinic continuity refers to the fact that the whole range of primary care services is available at the nearest health care facility. The aim is to accommodate the physical, social and emotional needs of the patient. This is particularly beneficial to children. Medical visits become less fearful when the same clinician with empathy towards children examines them. Trust relationships are established between the patient / family and clinician (American Academy of Paediatrics, 1992 as cited in Brown University, 2004).

Site continuity refers to the availability and accessibility of the same site / premises for follow-up care. For an emergency admission however the patient is admitted to the nearest, most appropriate health facility. Site continuity promotes patient compliance. Patients are appropriately directed for follow-up care to a specific care centre in close
proximity to their residence, which promotes access to treatment (Brown University, 2004).

Patient records are an invaluable source of information to clinicians regarding the history of a patient. Clinicians generally have a large workload. They might frequently consult the same patients over a long period of time but clinicians cannot remember large amounts of information about their patients. Consulting a patient file assists clinicians to improve treatment for the patient. The information on the patient file ensures that there will not be a repeat of previous treatments such as a prescribed drug that did not produce the desired outcome, or proved harmful to the patient. Record continuity also means that information is accurately captured, and kept up to date at regular intervals. This information is then accessible and retrievable at all times. In a hospital setting record continuity is fairly successful. It becomes challenging when information has to be transferred to a different setting. There is a possibility that data could be misunderstood or misread which could prove to be very harmful to the patient’s recovery (Brown University, 2004).

In contrast to record continuity, which deals mainly with data, clinical continuity deals with patient information and the patient. Clinical continuity is profitable because the clinician has the advantage of getting to know his patient more intimately. This promotes the patient and doctor trust relationship that always has a positive effect on the healing process. This clinician and patient relationship is especially valuable to a dying patient because the clinician often becomes the patient’s only confidant. In other cases with frequent follow-up visits, the clinician might at times be able to
identify significant changes in the patients’ prior to clinical findings. The opposite effect is also possible. A clinician can become too familiar in assessing the same patient. He might then overlook important changes in the patients’ condition. Visits to different clinicians could be beneficial to the patient for various reasons. An older practicioner’s techniques might be outdated whereas a newly trained practtioner would probably use the latest treatment regimes and techniques. Practitioners are fallible human beings. It is therefore often better for the patient to have a service readily available irrespective of the on-duty clinician (Brown University, 2004).

2.5 HEALTH CARE DELIVERY SERVICES IN SOUTH AFRICA

2.5.1 The Alma Ata Declaration

The Alma Ata declaration confirmed that health is a fundamental human right and that the overall social goal for governments is to ensure the physical, mental and social wellbeing of the nations. Inequalities in the health status between developed and developing countries had to be reduced. To facilitate sustainable economic growth and social development so that quality of life and world peace could be enhanced. People had the right and responsibility to actively participate in the planning and management of their own health and wellness. The global community was given a target of attaining a level of health for its entire peoples to lead a socially and economically productive life by the year 2000. Primary Health Care was the key to the attainment of this goal (WHO, 1978).
2.5.2 Primary Health Care (PHC) Approach

PHC is the delivery of affordable, acceptable and scientifically sound basic health care services that are appropriate to the needs of the community. The service is to be globally accessible to patients and their families at grassroots level. Patients, families and communities are empowered through participation and interaction. They are consulted in decision-making regarding local issues that concerned them. Patients, families and communities are supported in order to become independent and self-reliant. They actively engage in decisions regarding their health and wellness status. PHC is the entry point for individuals into the formal health care system. Continuum of health care is ensured whenever necessary. Ownership and inter-sectoral collaboration between health providers, patients, families and communities ensures sustainability of the proposed model (WHO, 2002).

The PHC approach to the provision of health care services is a departure from the existing model. In the past, it was acceptable practice for patients to be admitted to hospital when they became ill. They remained in hospital until they had either died or completely cured. Those that recovered were then discharged to continue their lives as before. The management of the patient was exclusively the responsibility of health professionals. Patients were not always fully informed regarding treatment regimes, coping skills or how to prevent illness / relapse at home. The paradigm shift in this new approach is that the patient / family / communities are recognised as partners on the road to health and wellness. Patients and their families are now consulted, assisted and empowered in the process of recuperation and healthcare services are provided as close to home as possible (Tylee, n.d).
The PHC approach advocates that the patient, family and the community should be encouraged and empowered to be self-reliant. It recognises and respects the autonomy of the individual and allows for freedom of choice. It also recognises that access to health care does not necessarily have to be provided within the boundaries of the formal health care system. Community participation in decision-making processes is promoted and strengthened. Access to a larger pool of services is obtained through inter-sectoral collaboration and participation of individuals, their families and communities in the fight against/onset of disease. Integration of health care services secures the best outcome for the patient. Continuous care is ensured because care extends beyond the formal health system. Special emphasis is placed on vulnerable groups to reduce inequalities in the delivery of health care services. The use of technology is to be appropriate, acceptable, affordable and determined by the patient’s need.

PHC services are characterised by the provision and access to a range of comprehensive services delivered by a multi-disciplinary team. Continuum of care is ensured. Service providers understand health and illness in the social context of the individual/family. The different sectors involved in the provision of health care services are: the public sector, the private sector, local government, voluntary groups and non-governmental-organisations (Tylee, n.d).

The PHC package of services comprises health promotion, prevention and cure of disease, provision of basic care and rehabilitation of the individual after recovery from an illness (WHO & United Nations Children’s Fund (UNICEFF), 1978). Free access to
health care services is being provided to children less than six years of age and pregnant women and lactating mothers. The disabled and the aged or whoever is in need of the service. The provision of Voluntary Counselling and Testing (VCT) services as well as Home and Community Based Care (HCBC) has been adopted as part of the PHC package (Ministry of Health (MOH) 2003).

A review of twenty member states twenty-five years after the Alma Ata Declaration highlighted the fact that the PHC concept was fairly well understood. Implementation of PHC was at different stages and differed from country to country. In Mangolia and South Korea however, some professional groups misunderstood the concept and regarded PHC as cheap rural care with low technology. Japan and New Zealand regarded PHC as curative care both at primary and tertiary levels. Australia, regarded PHC as a mixture of medical and community based services (WHO, 2002).

Although it appeared that no specific legislation or PHC policies have been developed in the reviewed countries, the principles of the PHC concept had been clearly observed in the countries’ constitution and National Health Plans (WHO, 2002). Research revealed that although most countries received the PHC concept positively, resources have not been allocated appropriately. Funding and personnel had mostly been allocated to hospitals, which was a more expensive service. In smaller countries with smaller communities the hospital was the only health facility and therefore simultaneously provided different levels of care, due to limited resources (WHO, 2002). Malaysia was investigating the feasibility of decentralized management of health care services due to a growing demand by consumers, global changes in the
health status and increasing costs. Japan sought integration of their curative and public health services at community level (WHO, 2002).

2.5.3 Principles of PHC

Community participation

The involvement of communities in the care aspect ensured the sustainability of PHC. The implementation strategy however, differed from country to country. In some countries decisions were made at national and provincial levels, whilst implementation had been devolved to communities. Communities established local community steering committees to facilitate consultation and ensure participation in decision-making processes. Some countries involved all the relevant role players, including communities in policy making both at national and provincial levels. In many countries community groups and Non-Governmental-Organisations (NGOs) have been delivering health and health related services within communities prior to the adoption of the PHC approach. They were established because of a recognised need in the community that was not adequately addressed by the formal health care system. Unfortunately due to societal changes, lack of funding and increasing needs, many of these organisations no longer existed. Governments however realised the importance of the contribution made by these NGOs and were seeking mechanisms to revive community participation in the delivery of PHC services. (WHO, 2002).
Equity

The National Health Act provides a framework for the delivery of health services in the country. It recognizes the inequitable distribution of health services in the past. One of the most important developments for the country is the establishment of a district health system as the vehicle to implement PHC services in the country (Presidency, 2004).

Inter-sectoral collaboration

The conference report highlighted the fact that intersectoral collaboration remained challenging and needed to be strengthened. The government however, was committed to strengthen links with national, provincial and local governments. Multi-disciplinary teams consisting of provincial and local government were created to respond to a vast array of emergencies. Members of the health department, water and forestry and defence force constituted the working committee. Partnerships between public health facilities and non-governmental-organisations were established and strengthened to enhance and broaden the scope of service delivery (Ministry of Health (MOH), 2003).

2.6 PROVINCIAL HOME-BASED CARE REFERRAL PATHWAY

2.6.1 Description of the protocol

HCBC services are characterized by the delivery of a wide range of services to accommodate the physical, social and emotional need of the patient. Functional independence of the patient is promoted. The service promotes the involvement of the whole family in the rehabilitation process. The desires and viewpoint of the patient are
respected and applied. It is a custom made package to meet the immediate needs of the patient, and continues as long as necessary. The services are provided to all people of all age groups. It pledges commitment to the provision of high quality services and considers the safety of the patient at all times. (NDOH, 2001).

HCBC promotes the Alma Ata declaration of “Health to the people, by the people.” Through the involvement of the family members in the care of their loved ones, new skills are developed and transferred. This causes a ripple effect in the community because communities apply these newly acquired skills and knowledge. Communities also become aware of the causes and patterns of disease and apply prevention strategies. Community ownership ensures sustainability of the services at community level. The provision of care at community-based level minimizes unnecessary hospital admission. The cost burden to institutions is reduced and more beds are available to admit patients suffering with more acute illnesses. Care is delivered in a familiar environment, which is more acceptable to the patient and conducive to the healing process (NDOH, 2001).

The Western Cape Department of Health developed a strategy to improve the quality of health care and simultaneously reduce financial expenditure to affordable limits. The plan was to concentrate on the delivery of primary level services, community based care, health promotion and prevention of disease. It involved the re-direction of patients to the most appropriate level of care. Patient intake will not to be decreased but the plan proposes that eighty nine percent of patients with acute illnesses will be treated at primary level care. Eight percent managed at secondary level and three
percent at tertiary level hospitals. Ninety-nine percent of patients with chronic diseases will be treated at primary and 0.5 % treated at secondary level hospitals. The secondary level hospitals will increase their scope of practice / services by increasing the number of specialist physicians at this level. Specialist physicians from tertiary hospitals will support primary level hospitals through an outreach programme (Western Cape Department of Health (WCDOH), 2003).

The underlying principles of the strategy are: to provide qualitative and efficient services at all levels of care. To ensure the provision of services that is affordable to communities. Health care services must be accessible to communities and therefore situated within an appropriate distance from households. PHC services would be delivered in line with the PHC approach. Interaction and effective communication between all levels of care must be ensured. Patients suffering from chronic diseases were to be discharged from hospitals to alternative units of care within the community (WCDOH, 2003).

District hospitals and PHC facilities originally formed the service delivery platform for primary health care. The new strategic plan broadened the scope and platform for PHC, by integrating the community-based level into the PHC platform. Community based care will be co-ordinated by designated staff from the PHC facilities. It was envisaged that communities would actively engage in the planning, managing and adherence to treatment regimes (WCDOH, 2006).

Non-governmental-organisations (NGOs) have been contracted to deliver home and community based services at community-based level. All NGOs are linked to a PHC
facility. All patients are referred via the relevant PHC facility to the NGO in line with the HCBC referral pathway. Community based workers are recruited and employed by the respective NGOs. Healthcare services are delivered to patients in their home environment or in the community. Training is provided to the community-based workers to ensure that they are functionally competent (WCDOH, 2006).

NGOs are contracted to deliver home or community based care for recovering patients in an appropriate / alternative community based unit of care. These facilities render different types of services depending on the intensity of care or the required length of stay. Such units are step-down facilities, respite centres, Life Long Care centres, community Mental Health centres or home based care. Patients that meet the admission criteria to these units are de-hospitalised and admitted to the low cost centres for further management (WCDOH, 2006).

NGOs delivering services within the community ensure patient adherence to treatment, trace and refer defaulting patients back to CHCs. They also provide support to patients and families. A relapse / re-admissions to hospital are to be prevented due to the financial burden upon institutions. Appropriate follow-up care decreases mortality and morbidity rates for patients suffering from chronic diseases such as diabetes, hypertension, mental illness, Tuberculosis, HIV and AIDS. Health promotion and disease prevention strategies introduced by NGOs reduce the impact of risk factors that contribute to the burden of disease (WCDOH, 2006).

The overall objective is to ensure the provision of appropriate management / treatment to patients at community based level upon discharge from hospital (WCDOH, 2003).
The implementation of infrastructure at community level is aimed at improved service provision for the patient. Appropriate community care plans are developed before patient discharge. The liaison officer facilitates and ensures the availability of HCBC services, equipment, medication and medical supplies. Continued interaction between partners in care ensures that the role of each partner is clarified. Each role player is fully informed regarding further management to avoid duplication / gaps in service delivery. Feedback mechanisms on patient progress are implemented at all levels of care (WCDOH, 2003).

A physician clinically assesses the patient before discharge from hospital. If the patient's condition is stable, the patient is referred for home-based care. The type and intensity of care is then formally communicated to the next level of care. A home assessment is conducted to determine whether the condition at home is favourable for discharge. If conditions at home are unfavourable the patient will then be discharged to an alternative unit of care. In the case of a minor, a mentally or physically incapacitated person, the patient and / or family are given the right to choose the preferred method of care (WCDOH, 2003).

2.6.2 The referral pathway
All home based care patients are referred to the community health centre nearest to the area where the patient lived. Appropriate management at home is essential in the recovery process. A smooth transition between hospital and home is facilitated through the design of roles and functions of the different role players at the different levels of care (WCDOH, 2003).
2.6.3 Providers’ functions at the different levels

_Tertiary Level Care_

Patients are admitted to Tertiary Level hospitals when they are in need of highly specialised health care services. As soon as the patient’s condition is stabilised, the patient is referred to the next appropriate level of care or discharged. A medical officer conducts the final clinical assessment and discharges the patient from hospital. If the patient has not fully recovered and needs on-going care at home, the patient is referred to the Community Healthcare Centre (CHC) to facilitate the provision of
HCBC services. A designated discharge liaison officer completes the discharge referral form and refers the patient to the nearest CHC in the area where the patient lives. The original referral form is given to the patient. The patient / family is instructed to report to the CHC at his / her earliest convenience for follow-up treatment. The discharge liaison officer also faxes a copy of the discharge referral form to the relevant CHC. A copy of the discharge referral form remains in the patient’s file at the Tertiary Hospital (WCDOH, 2003).

**Primary Level Care (Community Health Centres)**

The Western Cape is divided into thirty-two (32) sub-districts. Within each sub-district, a chief professional nurse has been appointed at CHC level to co-ordinate HCBC services. This official receives the paper referrals from the Tertiary Hospital and opens a folder for the patient at the CHC. The patient reports for follow-up care to the relevant CHC and is assessed by a medical officer. The medical officer prescribes the necessary medication, supplies or assistive devices and refers the patient to an NGO for further home management. The sub-district home based care co-coordinator provides on-going support, monitors and evaluates the service delivery of the relevant NGOs (WCDOH, 2003).

**Community Level (Non-governmental-organisations (NGOs))**

The health department contracts NGOs to deliver home and community based care services. NGOs sign a service level agreement in line with the department’s expected outcomes for the delivery of home-based care. The NGO management then appoints a
registered nursing sister and community-based workers to deliver the required home based care services (WCDOH, 2003).

The nursing sister receives a patient’s paper referral from the CHC. A home visit is conducted within the first forty-eight hours after receipt of the referral. The patient is re-assessed to determine the intensity of care that is required. The nursing sister then develops a nursing care plan to ensure that the appropriate care is provided. A community-based worker is then assigned to the patient to execute the care plan (WCDOH, 2003).

Compliance to the care plan is continuously monitored and evaluated by the nursing sister. The progress of the patient is also closely monitored and recorded. Upon full recovery, the patient is discharged. If there is a relapse the patient is referred back to the CHC (WCDOH, 2003).

At community-based level, health and health related services are delivered by NGOs in partnership with health facilities. Health workers, volunteers, community members, traditional healers, family members and lay health workers are all involved in service delivery. The setting is either in the home, in the community, the workplace or in an institution. These include the day-care centres, old aged clubs, crèches, churches, rehabilitation centres, mental health institutions, old aged homes, hospice facilities, step-down facilities, long-term care facilities, children’s homes etc. The services range from primary prevention to secondary and tertiary prevention (WHO, 2004).
Examples of community and home based health care activities

<table>
<thead>
<tr>
<th>Activities</th>
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<tr>
<td><strong>Primary prevention</strong></td>
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<tr>
<td>1. Health education</td>
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<td>2. Health promotion</td>
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<td>3. Disease prevention</td>
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<td>4. Antenatal care</td>
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<td>5. Counselling</td>
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<td>6. Condom promotion</td>
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<td>7. Child Care</td>
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<td>8. Exercise programmes</td>
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<td>9. Elderly clubs</td>
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<td>10. Environmental health campaigns</td>
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<td>11. School health</td>
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<td>12. Development of personal skills</td>
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<td>13. Parenting classes</td>
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<td>14. Women / community empowerment groups</td>
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<td>15. Safe sex campaigns</td>
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<td>16. Information, education and communication e.g. family planning</td>
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<td><strong>Secondary prevention</strong></td>
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<tr>
<td>1. Basic dressings</td>
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<tr>
<td>2. Referral</td>
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<tr>
<td>3. Drug administration</td>
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<td>4. Safe delivery</td>
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<td>5. Newborn care</td>
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<td>6. Screening</td>
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<td>7. Needs assessments</td>
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<tr>
<td>8. Mass / group treatments e.g. de-worming of school / crèche children</td>
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<tr>
<td><strong>Tertiary prevention</strong></td>
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<tr>
<td>1. Rehabilitation</td>
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<td>2. Palliative care</td>
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<td>3. Management of chronic disease e.g. HIV, diabetes</td>
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<td>4. Establish &amp; maintain Support groups</td>
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<td>5. Emergency care</td>
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<td>6. Community based rehabilitation</td>
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<td>7. AIDS care</td>
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Source (WHO, 2004).
2.6.4 Types of patients referred for home based care

The HCBC annual report revealed that the majority of patients referred for home-based care suffered from chronic diseases. These were mainly, HIV & AIDS, cardiovascular diseases such as coronary heart disease and stroke, cancer, diabetes and chronic respiratory illness (WCDOH, 2004/5). “Other diseases” comprised diseases such as: diabetes and other heart diseases.

Cardiovascular diseases

The global deaths from cardiovascular disease amounted to more than sixteen billion people in the year 2002 (WHO, 2007). There are a number of different types of cardiovascular diseases. The CVDs that cause the highest mortality rates are coronary heart disease and stroke. Every year, there were more than seven million deaths due to coronary heart disease. Deaths due to stroke amounted to almost six million people (WHO, 2007). CVDs are the number one cause of death in high, middle and low-income countries worldwide. Eighty percent of deaths occur in the middle-income countries. Approximately 10% in low and middle income, and 18% in higher income countries’ Disability Adjusted Life Years (DALYs) are lost globally due to cardiovascular diseases (WHO, 2007).

The economic impact of cardiovascular diseases globally is astronomical. It is an additional cost burden to the patient and its relatives. The primary caregiver is often forced to take time off work resulting in lost earnings. The recovery of a stroke patient during the acute phase of the illness often requires admission in a hospital with specialist services. The global health care costs related to smoke – related illnesses,
amounted to a loss of fourteen billion rand in 1994. One third of the losses occurred in developing countries. Between forty and fifty percent of health budgets are spent on diabetes related illnesses globally (WHO, 2007).

Tobacco use, high blood pressure, high blood glucose, obesity, physical inactivity are the major preventable contributing factors to cardiovascular diseases. Ageing, ethnicity, gender and hereditary are also considered to be contributing factors to cardiovascular diseases (WHO, 2007).

**Coronary heart disease**

Coronary heart disease occurs when the blood vessels supplying the heart muscle become diseased (WHO, 2007). Major risk factors that contribute to coronary heart disease are physical inactivity, diabetes, unhealthy diets, high blood pressure, high blood cholesterol, tobacco use, age related and genetically engineered. Other related factors to a minor degree are poverty, depression, inflammation and blood clotting disorders (WHO, 2007).

Globally, over sixty percent of coronary heart disease occurs in developing countries. It is estimated that the disease burden would increase from forty seven million DALYs (1990) to eighty two million in 2020 (WHO, 2007). The human brain needs a constant flow of blood in order to function properly. Any obstruction in the blood flow to or from the brain causes damage to the tissues resulting in a stroke. A blood clot that has burst, or the narrowing of blood vessels can cause the obstruction (WHO, 2007).
Heart attack, heart failure and atrial fibrillation, raised blood pressure and tobacco use are the major risks factors for stroke. In many developed countries the incidence of stroke is declining because governments have implemented effective policies to control smoking and high blood pressure. The overall number of strokes continues to rise because of the increase in the ageing population. Other risk factors are high blood cholesterol, unhealthy diets, physical inactivity and diabetes (WHO, 2007).

There are fifteen million stroke sufferers worldwide of which five million have died and another 5 million became severely disabled. In the United Kingdom, the majority of disabilities are caused by strokes. It is projected that the incidence of stroke will rise from thirty eight million DALYs in 1990 to sixty one million DALYs in 2020. The incidence of stroke is uncommon in persons under the age of forty years, but does occur in this age group due to raised blood pressure. The incidence of stroke in young people newly diagnosed between 1986 – 1997 per 100,000 population per year in selected populations were as follows: In Israel there was ten persons between the ages of seventeen and forty nine years. There were nine stroke sufferers between the ages of fifteen and forty four years in Florence, Italy. In Kuwait there were three stroke sufferers under the age of thirty-five years, but the incidence rose to forty-seven between forty and forty nine years of age. Libya had forty-seven stroke sufferers between the ages of fifteen to forty years. In Manhattan, USA the incidence between the ages of twenty and forty four years was as follows: twenty-five blacks, twenty-six Hispanics and ten whites. In South Africa the incidence of stroke amongst blacks between twenty and fifty-four years of age were thirty-three per 100,000 population (WHO, 2007).
The patient could encounter difficulty with speech and be disoriented to time and place in varying degrees. The vision could be affected and vision impairment could occur in one or both eyes. Physical imbalance, dizziness and headaches are the most obvious symptoms of a stroke. In severe cases the patient could lose consciousness and die, depending on the severity of the stroke (WHO, 2007).

**Cancer**

Cancer is a generic term for a group of more than one hundred diseases that affected any part of the body. It is also known as a malignant tumour or neoplasm. It is caused by an abnormal creation of cells that invades any part of the body and could then spread to other organs. The spread of the tumour from one organ / body part to another is referred to as metastasis. The majority of cancer deaths occur when the tumour started spreading to other parts of the body (WHO, 2006).

Out of fifty eight million people that died globally, thirteen percent died of cancer. It is therefore confirmed that cancer is the leading cause of death in the world. Approximately one million people died of stomach cancer. Six hundred and sixty two people died of liver cancer. Six hundred and fifty five of colon cancer and five hundred and two thousand died of breast cancer. Low and middle-income groups are the hardest hit by cancer deaths at more than seventy percent. It is projected that the incidence of cancer will rise to nine million in 2015 and approximately eleven million by 2030 (WHO, 2006).
“Cancer occurs because of changes in the genes responsible for cell growth and repair. It is the result of the interaction between the genetic host factory and external agents which is categorised as physical carcinoma and chemical carcinogens” (WHO, 2006). Cancer develops from one single cell. It could progress from a pre-cancerous lesion to a malignant tumour. The development of cancer could be genetically engineered or it could be caused by external factors. It appears that cancer incidence is more prevalent with age. This could be contributed to the fact that the repair mechanisms are less effective with ageing. It could also be the result of the accumulation of other risk factors over a prolonged life cycle (WHO, 2006).

The incidence of cancer could be reduced through the implementation of effective prevention strategies, early diagnosis and appropriate management. It is estimated that implementing prevention strategies could reduce a third of the cancer burden. Restricting the use of tobacco and alcohol are perceived as the largest preventable cause of cancer. Tobacco causes cancer of the lung, throat, mouth, pancreas, bladder, stomach, liver and kidneys. Long standing chronic infections contributes to the development of malignant tumours and causes one fifth of cancers worldwide. Immunization against infection could assist in controlling the onset of cancer. Minimizing exposure to occupational hazards and sunlight could also contribute to the reduction in the incidence of cancer. Early diagnosis and appropriate treatment is inevitable to reduce the incidence of the cancer burden. Communities should be educated to recognise early warning signs such as lumps, sores, persistent indigestion, persistent coughing and seek timeous medical advice. Patients that might be at risk should be encouraged to have screening tests such as mammograms for breast cancer or cytology tests for cervical cancer (WHO, 2006).
The management of cancer is ultimately to cure the disease in order to prolong life expectancy. Treatment is also aimed at improving the quality of life for the affected patient / family. Breast and colorectal cancers have high cure rates if it is detected early. The main methods of treatment are surgery, chemotherapy and radiotherapy. This treatment regime only commences once a diagnosis had scientifically been confirmed by means of an ultrasound, endoscopy or radiography (WHO, 2006). Palliative care is an important aspect in the management of cancer. A multidisciplinary approach is used for treating the patient to achieve the best outcomes. Palliative care can be introduced right from the onset of diagnosis to enhance the quality of life for the patient. It is three-dimensional because the physical, emotional and social needs of the patient are taken into account. Pain control is an important aspect in palliation. Effective pain management is achieved in more than ninety percent of cases. Palliative care promotes life and regards death as a normal process. Support is extended to the relatives until after the death of a patient (WHO, 2006).

**Asthma**

Asthma is a chronic disease characterized by recurrent attacks of breathlessness and wheezing (WHO, 2007). The lining of the bronchial tubes becomes swollen during an asthma attack. This results in the reduction of the airflow in and out of the lungs (WHO, 2007). The attack could differ from patient to patient in frequency and intensity. It could happen anytime during / and several times a day. It however occurs more frequently during the night. In some cases physical activities could also cause the onset of an asthma attack. A severe asthma attack can lead to the death of an
individual and should therefore be appropriately managed to ensure control of the disease (WHO, 2007).

Three hundred million people were diagnosed and two hundred and fifty five thousand people died of asthma in 2005. It is found to be the most common chronic disease amongst children. Countries are equally affected, but the lower and lower middle-income countries contributed to over eighty percent of asthma deaths (WHO, 2007). Asthma is very often under-diagnosed and therefore lacks timeous intervention and treatment. Asthma restricts the quality of life for an individual if the disease is undetected. The very nature of the disease not only affects the patient but also overburdens the family and their resources (WHO, 2007).

Recurring asthma attacks weaken a person’s physical condition. Physical weakness leads to general lethargy and the person is unable to perform optimally. This could be the reason why some asthma sufferers are unable to report for work or school due to the inability to perform their normal duties at work / school after having an acute asthma attack (WHO, 2007). The cause of asthma is not clearly understood. It could be caused through the inhalation of allergens inside or outside of the home environment. Primary prevention is aimed at reducing exposure to the risk factors that causes the onset of asthma. These risks factors are mostly air pollution, occupational health hazards and tobacco smoke. Effective treatment for lower respiratory infections also reduces the risk of asthma (WHO, 2006).
Diabetes

Diabetes is a chronic disease that is caused by the malfunctioning of the pancreas. The pancreas produces insulin that regulates the blood sugar levels in the body. The symptoms are mostly identical in all three different types of diabetes. Type two diabetes however is less severe at its onset. It often goes undetected and is only diagnosed when the patient already has signs and symptoms of diabetes. The symptoms are mostly vision changes, fatigue, weight loss, constant hunger, thirst and excessive excretion of urine (WHO, 2006). The WHO estimates that approximately 180 million people globally have diabetes. Approximately one million people died from diabetes in 2005. This number excludes deaths due to the complication of diabetes such as stroke or heart disease. The combined number of deaths amounted to approximately 2,9 million people. Approximately eighty percent of deaths due to diabetes occurred in the lower and middle-income countries. Approximately fifty percent of deaths occurred in people younger than seventy years of age. Fifty five percent of patients that died due to diabetes were females (WHO, 2006).

Diabetes gave rise to many common problems such as tingling feeling, pain, weakness or numbness in the hands. If the condition remains untreated / uncontrolled it causes more severe damage. There is an increased risk of heart disease, stroke and kidney failure due to damage to the heart, blood vessels and kidneys. The possibility of limb amputation / s increases if there is insufficient blood flow to the extremities. Blindness was another complication if the patient’s eyesight was not regularly tested (WHO, 2006).
Maintaining optimal health through physical activity and appropriate eating habits are the key preventative measures to reduce the incidence of diabetes. People at risk had their blood glucose tested regularly. Regular foot care screening, monitoring of blood sugar levels and eye testing would enable health care providers with early detection of diabetes. Effective treatment and patient education were all fairly inexpensive interventions to control diabetes (WHO, 2006).

2.7 THE BURDEN OF CHRONIC DISEASES

Globally, chronic diseases are the leading causes of death and disability. It is estimated that approximately sixty percent of all deaths were due to chronic diseases. These were cardiovascular diseases, mainly heart disease and stroke at thirty percent. Cancer at thirteen percent. Chronic respiratory diseases at seven percent. Diabetes at two percent, and other chronic diseases at nine percent (WHO, 2007).

Worldwide the chronic disease epidemic is growing rapidly and unfortunately preventative mechanisms are seriously lacking in the majority of countries. Several misconceptions regarding chronic diseases existed. This resulted in poor or slow response for the prevention of chronic diseases. One such misunderstanding was that chronic diseases mainly affected high-income countries. The reality was that the incidence of chronic diseases is at its second highest level in the low-income countries (35%). The incidence in the lower middle income countries is at its highest at thirty seven percent. The incidence in the high-income countries is at twenty percent and the lowest incidence is found in the upper middle-income countries (8%). Almost fifty
percent of people world-wide under the age of seventy years suffers from a chronic disease (WHO, n.d.).

It was predicted that there would be a dramatic rise in non-communicable diseases (NCD) that would contribute to forty-four percent of deaths in America in the next century. These conditions were: Cardiovascular disease, such as stroke and ischaemic heart disease. Cancer, such as cervical, uterine and breast cancers amongst women. Stomach, lung and prostate cancer (in certain population groups) were the most probable cause of death amongst men. Thirty five million people are suffering from diabetes. Intentional and non-intentional injuries were a major cause of death in adolescents and young adults. The incidence of hypertension contributed between fourteen and forty percent of the disease burden amongst people between the ages of thirty-five to sixty-four. At the time of diagnoses, approximately sixty percent already presented with a microvascular complication. Early detection of the underlying illness could have prevented complications and disabilities such as blindness, amputations and chronic renal failure (The Pan American Health Organisation, 2002).

In the WHO European Region non-communicable diseases are the highest contributing factor to the burden of disease. It accounted for seventy seven percent of the burden of disease. Eighty six percent out of 9.6 million deaths were caused by NCDs. Seventy seven percent from an estimated one hundred and fifty million Disability Adjusted Life Year (DALYs) in the region were caused by NCDs (WHO, 2005).

The burden of NCDs accounted for approximately half of the world population for all age groups, with a ten percent increase since 1990. The incidence in developed
countries is estimated at approximately eighty five percent in adults over the age of fifteen years. In the middle-income countries the disease burden exceeds seventy percent. In the developing countries, fifty percent of the adult disease burden is caused by NCDs. This phenomenon could be attributed to longetivity and changes in the distribution of risk factors (WHO, 2005).

Cardio Vascular Diseases (CVD) causes thirteen percent of the burden of chronic diseases in adults over the age of fifteen years. For the over- sixty age group, ischemic heart disease and stroke are the leading causes of mortality and burden of disease. CVD is amongst the top ten causes of disease burden between the fifteen to fifty nine year olds. Thirty six percent of deaths are attributable to ischemic heart disease and stroke in developed countries. In developing countries cancer contributed to six percent of the disease burden in adults over fifteen years of age. Fourteen percent of the burden of disease in developed countries was attributable to cancer. In 2001, there were over seven million deaths. Seventeen percent was caused by lung cancer, an increase of thirty percent since 1990. Deaths due to stomach cancer amounted to eight hundred and fifty thousand. Liver cancer caused six hundred and nineteen deaths per year. Mortality In adult females were mostly caused by breast cancer (WHO, 2005).

Neuropsychiatry ailments in adults cause nineteen percent of the disease burden. Injuries, often resulting in severe disability in young adults accounted for sixteen percent of the disease burden globally. Injuries and road traffic accidents contribute to more than thirty percent of the disease burden in male adults between the ages of fifteen and forty four years. Areas mainly affected are parts of America, Eastern
Europe, and the Eastern Mediterranean. Road traffic accidents are the third leading cause of disease burden world-wide in that particular age group. The leading cause for the burden of disease in this specific age group is the Human Immune-deficiency Virus (HIV) & Acquired Immuno-Deficiency Syndrome (AIDS) followed by unipolar depression. Globally, in the developing countries of sub-Saharan Africa, southern and Southeast Asia the disease burden of road traffic accidents is increasing (WHO, 2005).
### Ten leading causes of Disease Burden per WHO Region

<table>
<thead>
<tr>
<th>No</th>
<th>High Income</th>
<th>% DALY</th>
<th>No</th>
<th>Europe and Central Asia</th>
<th>% DALY</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Ischemic heart disease</td>
<td>8.3</td>
<td>1</td>
<td>Ischemic heart disease</td>
<td>15.9</td>
</tr>
<tr>
<td>2</td>
<td>Cerebrovascular disease</td>
<td>6.3</td>
<td>2</td>
<td>Cerebrovascular disease</td>
<td>10.8</td>
</tr>
<tr>
<td>3</td>
<td>Unipolar depressive disorders</td>
<td>5.6</td>
<td>3</td>
<td>Unipolar depressive disorders</td>
<td>3.7</td>
</tr>
<tr>
<td>4</td>
<td>Alzheimer &amp; other dementias</td>
<td>5</td>
<td>4</td>
<td>Self inflicted injuries</td>
<td>2.3</td>
</tr>
<tr>
<td>5</td>
<td>Trachea, bronchus, lung cancer</td>
<td>3.6</td>
<td>5</td>
<td>Hearing loss, adult onset</td>
<td>2.2</td>
</tr>
<tr>
<td>6</td>
<td>Hearing loss, adult onset</td>
<td>3.6</td>
<td>6</td>
<td>Chronic obstructive pulmonary disease</td>
<td>2.0</td>
</tr>
<tr>
<td>7</td>
<td>Chronic obstructive pulmonary disease</td>
<td>3.5</td>
<td>7</td>
<td>Trachea, bronchus, lung cancer</td>
<td>2.0</td>
</tr>
<tr>
<td>8</td>
<td>Diabetes mellitus</td>
<td>2.8</td>
<td>8</td>
<td>Osteoarthritis</td>
<td>2.0</td>
</tr>
<tr>
<td>9</td>
<td>Alcohol use disorders</td>
<td>2.8</td>
<td>9</td>
<td>Road traffic accidents</td>
<td>1.9</td>
</tr>
<tr>
<td>10</td>
<td>Osteoarthritis</td>
<td>2.5</td>
<td>10</td>
<td>Poisonings</td>
<td>1.9</td>
</tr>
<tr>
<td></td>
<td>Latin America &amp; Caribbean</td>
<td>% DALY</td>
<td>No</td>
<td>Middle East &amp; North Africa</td>
<td>% DALY</td>
</tr>
<tr>
<td>1</td>
<td>Perinatal conditions</td>
<td>6.0</td>
<td>1</td>
<td>Ischemic heart disease</td>
<td>6.6</td>
</tr>
<tr>
<td>2</td>
<td>Unipolar depressive disorders</td>
<td>5.0</td>
<td>2</td>
<td>Perinatal conditions</td>
<td>6.3</td>
</tr>
<tr>
<td>3</td>
<td>Violence</td>
<td>4.9</td>
<td>3</td>
<td>Road traffic accidents</td>
<td>4.6</td>
</tr>
<tr>
<td>4</td>
<td>Ischemic heart disease</td>
<td>4.2</td>
<td>4</td>
<td>Lower respiratory infections</td>
<td>4.5</td>
</tr>
<tr>
<td>5</td>
<td>Cerebrovascular disease</td>
<td>3.8</td>
<td>5</td>
<td>Diarrhoeal diseases</td>
<td>3.9</td>
</tr>
<tr>
<td>6</td>
<td>Endocrine disorders</td>
<td>3.0</td>
<td>6</td>
<td>Unipolar depressive disorders</td>
<td>3.1</td>
</tr>
<tr>
<td>7</td>
<td>Lower respiratory infections</td>
<td>2.9</td>
<td>7</td>
<td>Congenital anomalies</td>
<td>3.1</td>
</tr>
<tr>
<td>8</td>
<td>Alcohol use disorders</td>
<td>2.8</td>
<td>8</td>
<td>Cerebrovascular disease</td>
<td>3.0</td>
</tr>
<tr>
<td>9</td>
<td>Diabetes mellitus</td>
<td>2.7</td>
<td>9</td>
<td>Vision disorders – age related</td>
<td>2.7</td>
</tr>
<tr>
<td>10</td>
<td>Road traffic accidents</td>
<td>2.6</td>
<td>10</td>
<td>Cataracts</td>
<td>2.3</td>
</tr>
<tr>
<td></td>
<td>South Asia</td>
<td>% DALY</td>
<td>No</td>
<td>East Asia &amp; Pacific</td>
<td>% DALY</td>
</tr>
<tr>
<td>1</td>
<td>Perinatal conditions</td>
<td>9.2</td>
<td>1</td>
<td>Cerebrovascular disease</td>
<td>7.5</td>
</tr>
<tr>
<td>2</td>
<td>Lower respiratory infections</td>
<td>8.4</td>
<td>2</td>
<td>Perinatal conditions</td>
<td>5.4</td>
</tr>
<tr>
<td>3</td>
<td>Ischemic heart disease</td>
<td>6.3</td>
<td>3</td>
<td>Chronic obstructive pulmonary disease</td>
<td>5.0</td>
</tr>
<tr>
<td>4</td>
<td>Diarrhoeal diseases</td>
<td>5.4</td>
<td>4</td>
<td>Ischemic heart disease</td>
<td>4.1</td>
</tr>
<tr>
<td>5</td>
<td>Unipolar depressive</td>
<td>3.6</td>
<td>5</td>
<td>Unipolar depressive</td>
<td>4.1</td>
</tr>
</tbody>
</table>
In South Africa, more than twenty nine percent of deaths are caused by HIV & AIDS. Over sixteen percent of deaths are attributable to cardiovascular disease. Infectious and parasitic diseases contributed to more than ten percent of deaths. Cancer caused approximately seven percent of deaths. More than seven percent died due to intentional injuries and approximately five percent died due to unintentional injuries. The proportion of deaths due to HIV & AIDS and cardiovascular diseases were higher in females than in males. The proportion of deaths due to injury was higher in males than in females (Medical Research Council (MRC), 2003).
Cause of death profile by sex

<table>
<thead>
<tr>
<th>Cause</th>
<th>Male</th>
<th>Female</th>
<th>Persons</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV &amp; AIDS</td>
<td>26%</td>
<td>34%</td>
<td>30%</td>
</tr>
<tr>
<td>Communicable diseases</td>
<td>21%</td>
<td>20%</td>
<td>21%</td>
</tr>
<tr>
<td>Non communicable diseases</td>
<td>36%</td>
<td>40%</td>
<td>37%</td>
</tr>
<tr>
<td>Injuries</td>
<td>17%</td>
<td>6%</td>
<td>12%</td>
</tr>
</tbody>
</table>

Source: (MRC, 2003).

Top ten causes of premature mortality

<table>
<thead>
<tr>
<th>Rank</th>
<th>Cause of death</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>HIV &amp; AIDS</td>
<td>39.0</td>
</tr>
<tr>
<td>2</td>
<td>Homicide / Violence</td>
<td>7.5</td>
</tr>
<tr>
<td>3</td>
<td>Tuberculosis</td>
<td>5.0</td>
</tr>
<tr>
<td>4</td>
<td>Road traffic accidents</td>
<td>4.1</td>
</tr>
<tr>
<td>5</td>
<td>Diarrhoeal diseases</td>
<td>3.8</td>
</tr>
<tr>
<td>6</td>
<td>Lower respiratory infections</td>
<td>3.8</td>
</tr>
<tr>
<td>7</td>
<td>Low birth weight</td>
<td>3.3</td>
</tr>
<tr>
<td>8</td>
<td>Stroke</td>
<td>2.7</td>
</tr>
<tr>
<td>9</td>
<td>Ischeamic heart disease</td>
<td>2.4</td>
</tr>
<tr>
<td>10</td>
<td>Protein –energy malnutrition</td>
<td>1.4</td>
</tr>
</tbody>
</table>

Source: (MRC, 2003).
Disability Adjusted Life Years (DALY)

<table>
<thead>
<tr>
<th>Group</th>
<th>Male</th>
<th>Female</th>
<th>Persons (per 1,000 population)</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV &amp; AIDS</td>
<td>97.1</td>
<td>107.5</td>
<td>102.1</td>
</tr>
<tr>
<td>Maternal, perinatal and nutrition</td>
<td>78.7</td>
<td>62.9</td>
<td>70.5</td>
</tr>
<tr>
<td>Non-communicable diseases</td>
<td>153.3</td>
<td>121.4</td>
<td>136.0</td>
</tr>
<tr>
<td>Injuries</td>
<td>79.4</td>
<td>26.5</td>
<td>52.3</td>
</tr>
<tr>
<td>TOTAL</td>
<td>408.5</td>
<td>318.3</td>
<td>361.0</td>
</tr>
</tbody>
</table>

Source: (MRC, 2003).

Years of Life lost (YLLs)

In the year 2000, lower respiratory infections, Tuberculosis, low birth weight, HIV & AIDS contributed considerably towards the years of life lost in South Africa. The highest contributing factor for NCDs in women was strokes and ischeamic heart disease in males. The top causes of death for women were diabetes mellitus, respiratory conditions and hypertensive heart disease, in males the top causes of death were chronic obstructive pulmonary disease, diabetes mellitus, liver cirrhosis and cancer of the lung. Premature death due to intentional injuries ranked higher than unintentional injuries. However, the opposite in the ranking occurred when there were no fatalities (MRC, 2003).

In order to facilitate the reduction in mortality rates, drastic measures had to be implemented to reduce the rising incidence of HIV & AIDS. The socio-economic growth of the country was under severe threat if the basic needs of the rising number of orphaned children were not addressed. Johnson and Dorrington, 2001 (as cited in MRC, 2003).
2.8 STRATEGY FOR REDUCTION IN THE BURDEN OF DISEASE

Inadequacies are encountered to definitively determine the DALYs because of the lack of sufficient information. These gaps will close and more accurate data obtained as assessments for the burden of disease continues in South Africa. It is however evident that the burden of disease must drastically be decreased. A number of strategies could possibly reduce the disease burden if it was effectively implemented such as: vigorous campaigning to educate communities in the prevention of disease and the promotion of health and healthy lifestyles. To effectively reduce the incidence of malaria, diarrhoeal diseases, respiratory tract infections and low birth weights in children. To Improve cure rates and reduce new infections for tuberculosis. To decrease the incidence of HIV & AIDS through the implementation of effective programmes to reduce HIV infections. In the South African context the aim to achieve optimal health is often challenged by factors such as societal norms, values, cultural aspects, religious beliefs, crime, violence, gender inequalities and lack of basic resources (MRC, 2003).

Globally, the implementation of the primary health care approach to service delivery has had both a negative and positive impact. Conditions such as: Political and economic changes, epidemics and the neglect of primary health care services. Lack of, or insufficient funding for primary health care services has impacted negatively on the global burden of disease. In a large majority of countries however, due to government commitment of the PHC approach many positive results had been achieved (WHO, 2002).
Inter-sectoral collaboration and community participation has been identified as an important element for the successful implementation of the PHC approach. In order to strengthen and develop communities, governments should develop PHC policies in consultation with communities. Inter-sectoral coordination and effective use of resources within communities would limit costs, exclude overlapping, and duplication of services (WHO, 2002).

Seventeen out of twenty countries reported that there was improved equity and access to essential health services. The same number of countries reported improved control of communicable diseases through intervention strategies, such as immunization, control of diarrhoeal diseases, malaria and acute respiratory infections. Sixteen out of twenty countries reported improvement in maternal, child and / or women’s health. A general improvement in health status and life expectancy in fifteen out of twenty countries was achieved because of these positive changes. Ten out of twenty countries reported improvement in sanitation, water supply, hygiene and access to essential medicines (WHO, 2002).

Government departments, the private sector and civil society play an important role to minimise the incidence of chronic diseases. Through the involvement of different sectors including communities, policy makers are kept informed regarding disease trends and population needs. These could be enacted upon through the formulation of policy guidelines (WHO, 2002).

A community based Chronic Disease Self-Management Programme was implemented in thirteen communities and six districts in Shanghai, China. This programme involved patients that were diagnosed with more than one chronic disease. Lay health
workers educated the patient on self-management. A randomised control trial was introduced in 1999, which involved nine hundred and fifty four patients. The programme improved the health status and reduced hospital admissions six months after implementation of the programme (WHO, 2002).

2.9 SUMMARY

In this chapter the significance of an effective referral management system was discussed. This included positive patient outcomes for the continuum of care, due to the implementation of timeous and appropriate discharge plans. Health care service delivery, using the PHC approach was also highlighted. Furthermore, the literature review indicated that the majority of patients in receipt of home based care services suffered from chronic diseases. A global and South African perspective of the burden and a possible strategy to reduce the burden of chronic diseases was discussed.
CHAPTER THREE:
RESEARCH METHODOLOGY

3.1 INTRODUCTION

The aim of the study was to explore and describe the referral pathway of patient discharged from a Tertiary Hospital in Cape Town to home-based care as well as the key stakeholders’ perceived user-friendliness of the referral pathway guidelines developed by the Western Cape Department of Health. The study has a two-pronged approach, i.e. quantitative and qualitative method. The first phase involved the collection of data from discharged patient files for the quantitative method. In the second phase, and for the qualitative method, data was collected from personal interviews as per selection criteria.

3.2 RESEARCH APPROACH AND DESIGN

3.2.1 Approach

A mixed method research approach was used in this study. This is a combination of the quantitative and qualitative methods. Mixed method research analysed variables in a quantified format and capturing the actual perceptions of people during the qualitative phase enriches the data. The quantitative approach views human behaviour as regular and predictable whilst the qualitative approach believes that behaviour is dynamic, situational and contextual. Mixed method research is commonly used when the researcher intends to explore and describe a phenomenon of interest in view of understanding the extent the phenomenon with it context. This approach further combines the nature of reality in a realistic and pragmatic world, in other words searching to understand what is happening now. The mixed method approach allows
the researcher to use several methods of data collection such as tick sheets (Polit et al 2001), closed and open ended questionnaires and individual interviews as well as a reflective diary (Brink & Wood, 1998), to ensure that the researcher minimize bias by recognizing her own and past experiences (Polit et al 2001).

3.2.2 Design

Polit et al (2001), define a research design as the strategic plan or blue print that assists the researcher to answer the research question and simultaneously ensure that all information collected is accurately reflected. In this study a descriptive, explorative, longitudinal design was used as a strategic plan. A descriptive design describes findings whereas an explorative design explores the objectives. Longitudinal studies often use retrospective data that looks back in time (Brink & Wood 1998). In this study quantitative data was collected retrospectively using document analysis of patients from the discharged point up to the home-based care facilities. The intervals were depictive of the time the patient’s discharged referral letter was issued and recorded at the tertiary hospital, the PHC facilities, the Community-based NGO and finally at the patient’s home. A qualitative descriptive exploratory design with individual semi-structured interview was used to collect qualitative data. This design assists the researcher to explore and understand the phenomenon of interest.

3.3 RESEARCH SETTING

The study was conducted at a Tertiary Academic Hospital in the Western Cape Province and the referral facilities from two regions attached to the academic hospital. These referral facilities included the primary health care clinics and the community-based Non-Governmental organizations from the Northern parts of the Cape Town.
Metropole region (urban) and the Boland Overberg region (rural). The combination of the rural and urban was done in an attempt to capture the differences that may be between urban and rural settings in terms of resources and access.

3.4 POPULATION OF THE STUDY

Burns and Grove (2008), defined a study population as the set of elements that the research focuses upon and to which the results obtained should be generalised. The study population for this study constituted of the records of discharged patients from the targeted Tertiary Hospital and referred to home-based or community-based facilities for follow-up care; the designated home-based care discharge liaison officer at the Tertiary Hospital; the sub-district home-based care co-ordinators at PHC facilities; the home-based care managers at the community-based NGOs.

3.5 SAMPLE AND SAMPLING TECHNIQUES

Purposive sampling was used to recruit participants who met the following inclusion criteria:

- Patients that were discharged over a period of one year (prior to the first day of data collection) from the target Tertiary Hospital and referred for follow-up care in the Northern parts of the Cape Town Metropole and Boland Overberg regions of the Western Cape Province.
- Patients with traceable contact details.
- The designated home based care discharge liaison officer at the Tertiary Hospital.
- The sub-district Home Based Care co-ordinators at PHC facilities.
- The Home Based Care managers at the NGO facilities.
- Willingness to participate in the study.

A purposive sampling is non-probability method where the researcher selects participants from the study population who can best describe the phenomenon of interest (Polit & Beck 2006).

The intention of the researcher was to follow the referral pathway for patients that needed follow-up care from the point of discharge at the Tertiary Hospital up to the home-based care facilities. The official records showed that 123 patients were discharged and referred to home-based care at the target hospital during the researcher target period; and 25 staff members were in-charge of the referral process in the two selected research settings. Of the 123 patients identified at the starting point of referral, twenty were referred to regions outside the research target regions, two had their names registered twice in the referral register, and thirty-three had incomplete contact details. All the above 55 patients were excluded from the study and the remaining 68 were included in the final sample. Of the 25 staff members, 5 were not willing to participate in the study and were therefore excluded from the sample. The remaining twenty agreed to participate in the study and were included in the final sample.

3.6 DATA COLLECTION PROCESS

3.6.1 Quantitative data

A checklist was used as tool to guide the collection of quantitative data. Checklists are mostly very straight forward and therefore extremely user friendly. A checklist is understood to be a list of factors that were separately considered in order to perform a
certain task. Using a checklist reduced the risk of omission or exclusion of important information (Scriven, 2005). In this study the checklist included the name, address, admission number, contact details, next of kin, diagnosis, dates of admission, discharge and referral, and the follow-up care.

Data collection started at the Tertiary Hospital and continued through to the PHC facilities and the NGO’s for the same patients that were discharged for home based care services at community-based level. Data was collected from patient files at the different health and NGO facilities. The researcher obtained permission from the appropriate authorities to access the discharged and referral records of patients for the designated period (12 months prior to the date of data collection). The patient names on the database were captured to a data collection sheet. The folders of these were then requested from registry. The checklist was then used against the folder to collect data at the relevant health care and NGO facilities.

3.6.2 Qualitative data
Semi-structured individual interviews were used to collect qualitative data from staff members responsible for patient discharge and referral follow-up care at the different levels of the referral pathway up to home-based care. The researcher developed an interview schedule to guide this process. An interview schedule is a semi-structured list of questions that is posed to a respondent by the interviewer whereby the answers are then recorded (Bowling, 2002). The semi-structured interviews allow the interviewer to probe for answers from the respondent to clarify unclear statements and offer the respondents opportunities to give accurate, but detailed account of their experiences or perceptions (Bowling, 2002).
Interviews were scheduled with staff members according to their availability and willingness to participate in the research. Appointments were scheduled with the interviewees, at their own convenience and at a place where they felt the most comfortable. All the participants chose a private room at the workplace. The interviews lasted between 30 – 45 minutes. All interviews were tape recorded with the consent of the participants. The participants were informed about the aim of the study and the reason for their involvement. The researcher explained that their participation was on a voluntary basis without any personal gain, but that their input was necessary to enhance service delivery. They were then asked if their responses to the questions could be recorded. The interview started after the signing of the consent form (see Ethical considerations).

3.7 VALIDITY AND RELIABILITY OF DATA

3.7.1 Quantitative data

In quantitative approaches, validity referred to whether the instrument measured that which it intended to measure (Polit et al 2001). Reliability in quantitative research related to the stability of a measurement by producing the same result each time that the measurement is used (Babbie & Mouton, 2001). It further referred to as the consistency of results over time, as well as the accuracy thereof in representing the total population.

The researcher consulted the task team that developed the home based care discharge referral tool to assist in developing the research instrument. The task team consisted of doctors, nursing managers and nursing staff from the different levels of care as well as
nursing staff from NGO’s. They evaluated to ascertain whether it was presentable, ethically acceptable, and the contents of the components applicable to the research question (Bless & Higson-Smith, 1995).

Using a checklist facilitated actual documentation of facts and enhanced the possibility to exclude irrelevant data that was not useful for the study. Whenever this specific checklist is used under similar conditions it would give any researcher the same outcome. The checklist was thus considered to be a reliable instrument because of the degree in which it measured the same variables repeatedly, the stability of the checklist and the similarity that was obtained between the measurements over the time period that it was used (Babbie & Mouton, 2001).

In this study the checklist was pre-tested with 10 patients’ files two months before data collection. Information from a patient record was used to ensure that the checklist captured all the relevant information needed. Polit et al (2001) described pre-testing of the designed instrument to be a trial administration to ensure that the instrument was unbiased, reliable and useful for accessing information.

3.7.2 Qualitative data

From a qualitative aspect the researcher ensured that the study reflected credibility, transferability and trustworthiness. Conformability or objectivity referred to the neutrality of the results in terms of whether they were reflective of the participant and not a product of the researcher’s preconceived notion. It is acknowledged that validity could be influenced by the researcher’s own paradigm. A reflective diary was used
during interviews to ensure that responses were the viewpoint of the participants and not of the researcher that was ultimately reflected in the results (Polit & Hungler, 1999).

Credibility referred to how truthful the findings were or how representative they were to the population. Transferability on the other hand referred to the issue whether the results could be applicable to another population with the same inclusion criteria (Babbie & Mouton, 2001).

The scheduled interview was discussed with the supervisor of the participating nursing staff at the different levels of care so that the questions were able to stimulate appropriate responses. It was found that the tool was appropriate and consumer friendly. Mixed research methods or triangulation was used to assist in the validation of the qualitative data collected (Polit & Hungler, 1999). The interview schedule was pre-tested with 5 staff members who were not part of the study. The pre-testing was conducted with the aim of ensuring that the research instrument would achieve the desired outcomes in order to answer the research question.

### 3.8 DATA ANALYSIS

#### 3.8.1 Quantitative data

Data obtained was analysed by means of SPSS (statistical package for the social sciences). The researcher worked closely with the UWC statistical department in order to ensure appropriate data analysis and interpretation thereof. Categorical data were given in frequencies / proportions and continuous values in means and standard error
of the mean. The information from the checklists was then entered on to an excel spreadsheet for analysis. Data was reviewed after every twentieth folder for quality assurance and to exclude any discrepancy in gathering the data (Babbie, 2001, as cited in De Vos, Strydom, Fouche, Delport, 2002).

3.8.2 Qualitative data

Qualitative data was analysed using Atlas TI. The data was transcribed and converted into an Atlas TI filed. Themes, families and groups were identified and presented in a narrative way supported by literature.

3.8.3 Triangulation of data

The information gathered during the quantitative and qualitative methods were compared against each other. The results were used to confirm the outcome, whether it reached the same conclusion of the phenomena under study. A mixed method approach enables the researcher to continuously analyse data and provides greater insight into a situation, and the knowledge to address any contradictions (Richards, L, 2006).

3.9 ETHICAL CONSIDERATIONS

Ethical clearance was obtained from the University of the Western Cape, Senate Higher Degrees before the commencement of the research (see Appendix D). Further permission was obtained from the Head of the Health Department and the Chief Directors at the various sites (see Appendix A). Informed consent was obtained from the participants before the individual interview (see Appendix C).
The participants were informed about the aim of the study and their involvement in the study explained. They were aware that participation was completely voluntary and that they had the right to withdraw at any stage. Participants were assured that their dignity, privacy and confidentiality would be respected throughout the study. The information supplied would be kept strictly confidential and will only be utilized for the purposes of research. They were informed that they might not directly benefit from the results but that it may benefit other people as the results would be made available to the Department of Health and would be published in an academic journal. The information obtained was kept strictly confidential and only utilized for the purposes of this study. All documents and audiotapes were stored in a locked cupboard during the interview process for follow-up purposes and were destroyed after the study.

3.10 SUMMARY

Chapter three described the research methodology followed in answering the research question. It looked at the research approach, the research design, the study population, the sample and sampling techniques, the data collection process, the validity and reliability of data, data analysis, and ethical considerations.
CHAPTER FOUR:
PRESENTATION OF THE RESULTS

4.1 INTRODUCTION
The aim of this study was to explore and describe the referral pathway of patients discharged from a Tertiary hospital to home-based care in the Western Cape. A qualitative descriptive design was used to guide the research. Document analysis and individual interviews were used to generate data. Quantitative and qualitative data were triangulated to produce the final results. The results are presented in this chapter according to the objectives of the study.

4.2 RESULTS FOR OBJECTIVE 1
Patients diagnosed with cancer 66.1% (45), cardio-vascular diseases 11.7% (8), diabetes 1.5% (1), asthma 1.5% (1), tuberculosis 1.5% (1) other chronic diseases 11.7% (8), unrecorded and unknown 6% (4). Of the 68 discharged patients from Tertiary hospital, 72 % (49) collectively reached 8 CHC’s in the Metropole region and 3 in the Boland/Overberg community health care facilities. Collectively at eight NGOs in the Metropole and 3 in the Boland/Overberg, 71% (48) patients reached the community home-based care facilities.
Clinical diagnosis profile of patients discharged to Home-based Care

<table>
<thead>
<tr>
<th>Primary diagnosis</th>
<th>Frequency</th>
<th>Percentage (%)</th>
</tr>
</thead>
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<tr>
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<tr>
<td>Cardio-vascular diseases</td>
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<td>11.7</td>
</tr>
<tr>
<td>Diabetes</td>
<td>1</td>
<td>1.5</td>
</tr>
<tr>
<td>Asthma</td>
<td>1</td>
<td>1.5</td>
</tr>
<tr>
<td>Tuberculosis</td>
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<td>1.5</td>
</tr>
<tr>
<td>Other chronic diseases</td>
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<td>11.7</td>
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<tr>
<td>Unrecorded and Unknown</td>
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</tr>
<tr>
<td>Total</td>
<td>68</td>
<td>100</td>
</tr>
</tbody>
</table>

The following process was to be followed at the tertiary hospital:

- The patient was officially discharged by a medical officer.
- A date for follow-up treatment at designated CHCs was given to the patient.
- The discharge liaison officer completed the HCBC discharge referral form and faxed it to the CHC for follow-up treatment immediately post discharge.
- A copy of the discharge form was left in the patient file.
- Feedback mechanisms between Tertiary and CHC level were implemented to monitor patient progress.

The result of the document analysis showed that of the 68 patients, 61.8% (42) were discharged by the medical officer, 11.8% (8) by nursing sisters, 19.1% (13) did not
have the name of the discharging officer, 2.9% (2) were discharged by the social worker, 1.5% each (1) by stoma therapist, physiotherapist and dietician.

Patients were referred to the CHC closest to their home. To ensure timeous follow-up at PHC level, accurate recording of the referral CHC’s was of utmost importance. There was 89.7% (61) adherence to protocol.

At CHC level the SDHCBC co-ordinators received the discharge referral form faxed from Tertiary level. The patient details and prescribed treatment was then captured in a HCBC admission register. The process then continued as follows:

- Patients to attend the relevant CHC facility at their earliest convenience or as per follow-up date.
- A medical officer to assess the patient and either continued Tertiary level’s instruction or prescribe new treatment regimes as necessary.
- An official referral form forwarded to a designated NGO requesting the required type of HCBC service. A copy of this referral form was kept in the patient file.
- Patients are given TCA dates and attended CHC until full recovery.
- Implement feedback mechanisms between Tertiary and CHC level.

Results show that the number of patients that attended CHC was 38.2 % (26). The number of patients examined by a medical officer was 38.2 % (26). Patients referred back to the NGOs after their CHC visits were 37% (25). Only 28% (19) of patient
files contained copies of referral letters to NGOs. TCA dates were given to 34% (23) patients. No evidence of any progress reports was found in the patient files and 0% (0) feedback was given to Tertiary level. Patients were referred to the CHC closest to their home. To ensure timeous follow-up at PHC level, accurate recording of the referral CHC’s was of utmost importance. There was 89.7% (61) adherence to protocol.

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patients. No evidence of any progress reports was found in the patient files and 0% (0) feedback was given to Tertiary level.

The entry point for the patient was a paper referral from CHC level upon which a file was opened.

- The SDHCBC co-ordinator forwarded an official request for HCBC service delivery to the NGO.

- Within 48 hours after the paper admission, the NGO nursing co-ordinator visited and conducted a physical patient assessment at home. Attendance at CHC and TCA dates were confirmed. Defaulters were requested to attend CHCs at their earliest convenience. The NGO nursing co-ordinator developed a nursing care plan and assigned a care worker to execute the duties under direct / indirect supervision. Each visit, follow-up visits, and the services provided were carefully recorded on a work sheet. These worksheets were also used to monitor and evaluate service delivery.

- Continuous feedback was given to CHC on patient progress until discharge from NGO level.

Referral letters remained in the patient file with other relevant information and treatment regimes. Results show that 56% (38) of patient files contained copies of referral letters from CHCs. NGO follow-up of all referred patients was 71% (48). Results revealed that only 9% (6) feedback reports were given to the respective CHCs.
4.3 RESULTS FOR OBJECTIVE 2

The experiences of health care workers both within the public service as well as in the NGO sector as verbalised during the in-depth interviews are hereby discussed. By using in-depth interviews as a data collection tool, it was assumed that the participants were knowledgeable and could provide valuable information regarding the provision of home-based care services. Successful implementation of any new project depended largely on buy-in and co-operation of all role players.

Responses to the perception of the proposed HCBC discharge referral pathway varied considerably from institution to institution. Participants were not sure because “it appears that it is working otherwise there would be more queries from patients for help at home because no news is good news.”

Other participants mentioned “some wards in the tertiary institutions do not seem to be aware that upon discharge of their patients they have to refer the patient directly to the home based care TA [Technical Assistant – a name given to the SDHCBC co-ordinator] and not to the CHC.”

Other comments received were such as “implementation to district level needs attention” and “when discharging patients to please inform the CHC.” Further more it was also stated that the “CHC is not aware of any discharges or referrals for home based care.” It was also said “referrals are unknown to us. No referrals have been received from the Level 1 hospitals or NGOs. Patients in need of home based care services are reporting for help, support and prescription drugs by themselves” and “according to my knowledge the referral are supposed to work as the above. Unfortunately is does not always work that way.” Including “the referral pathway is not effective. Patients and CHC do not adhere to the prescribed referral pathway.”
Patients are “discovered” by care workers in the field. “Other comments were “patients are not always referred in line with the protocol. The forms are not always completed properly or there is unclear directions regarding the patient’s address etc.”

It was also said “CHCs do not routinely refer patients for home based care. A request for the delivery of home based care services is mostly extended by patients or their relatives to care workers in the field.”

The following recommendation was made by a participant, “I would appreciate a referral letter from ... (Tertiary Hospital) or any other hospital regarding the diagnosis, treatment, follow-up and any action or treatment plan that should be delivered by the clinic or NGO at home”

In contrast to the above one participating CHC was confident that “it is working well. Our doctors in the CHC complete the forms and give it to the person-in-charge who in turn contacts the Sr.-in-charge at the NGO level. Patients are followed up.”

Demographic data regarding health care workers involved in the referral and / or discharge and / or receipt of patients were described. Their knowledge, understanding and perceptions of the proposed HCBC discharge referral pathway were carefully documented.

**Turn-around time**

Nursing staff members at the different levels of care i.e. Tertiary Hospital, CHCs and NGOs were involved in the discharge and referral of patients between hospital and the patient’s home. Some of the participants complained that receipt of the discharge referral forms were delayed for different reasons such as “the referral form does not always reach the CHC in time” and “referral forms are sent from...(Tertiary Hospital)
to the nearest regional office. The regional office sends the referral form to the NGO. Receipt of the referral form from... (Tertiary Hospital) can take up to one week to reach the Regional Office because it goes from pillar to post before it reaches Ms. ... at the regional office who then forwards the referral to the relevant CHC or the referral is sent to ... (NGO) who in turn sends it to the TA “

Others mentioned that “due to ill health, or the fact that the patient might stay on a far-away farm this referral letter is often only received a week or longer after discharge from hospital” and many TAs do not have offices near the provincial hospitals which mean that the referrals from the regional office might first be placed in a file before being sent to the relevant TA, causing more delays.” Delayed responses in providing services were highlighted, such as “sometimes, there is a too long delay to respond to referrals by the home-based care workers.”

NGO staff stated that “if a referral form is faxed directly to the NGO, quicker response and better care can be rendered” and that “at times it takes too long for the referral to reach the NGO which delays follow-up for the patient at home.” It was also mentioned “the referral at times reaches the NGO long after the patient had been discharged from hospital” and “the delay is often at the TA level. It is sometimes very difficult to contact the TA per telephone if the CHC or the patient has a problem.” It was very strongly recommended that “referrals should be sent from ... (Tertiary Hospital) to the NGOs as well” because “this will expedite services to the patient, prevent deterioration of the patient’s condition, facilitate continuation of services to the patient without interruption and accelerate the recovery of the patient.”
Communication

Two participants, when asked about the referral pathway said, “there has been no communication from anyone in this regard.” During the interview with one of the recipients of care the mother said “they [ambulance men] just dumped her here [at home] and left. I did not receive any letters.”

Lack of information

Interviewees expressed their need for sufficient information in order to operate optimally. “Another suggestion is to provide….(Tertiary Hospital) with a database of all the TAs. Referral forms should then be forwarded directly to them. It would also be the responsibility of the TA to update the ... (Tertiary Hospital) database if any changes.”

“It delays treatment by the care workers of the respective NGO responsible for the delivery of home based care services.” It was also mentioned “there is not always sufficient information regarding the patient’s needs or medication.”

Other comments from participants were “incomplete referral forms have only been received from specific wards.”

The participants stated that verification of the patient’s personal details were important to ensure follow-up. “The address of the patient must be verified upon discharge to minimise unnecessary searches to find the patient.”
**Feedback**

There were no set guidelines for giving feedback. Participants reported, “oral feedback only was given.” In other instances “monthly statistics are given.” and “bi-weekly meetings are held and in some areas there was a monthly sub-district Home Based Care Forum Meeting.”

The interviewees raised some concerns regarding the lack of feedback because they had anticipated that, ”feedback from CHCs would be provided regularly on a weekly or monthly basis because ... only get contacted by the patient or their families when they have not received the promised home based care service.”

One participant indicated that receipt of the prescribed care had not been confirmed. “Communication needs to improve because... do not receive any feedback on any of the patients that are referred for home based care and ...sometimes would like to know what happens to the patients.” It was also mentioned that “the timeframe for retrieving the patient information for follow-up care by the SDHBC co-ordinator is a concern because if this information is not collected ...am concerned whether the patient has received any follow-up care or whether it was the proper type of care that was given if they did not have complete instructions to manage the patient”.

Other responses were, “to receive feedback on special queries or requests for home bases care services so that I know whether the patient’s problem / queries had been attended to “and “feedback is not generally given. Only in specific cases when there is a problem e.g. a wound that does not heal or poor progress or when the patient needs to be examined by a doctor.”
Partnerships

Participants highlighted the need for role clarification and the establishment of closer relationships between all the role-players. “Better communication between tertiary, regional and district hospitals will improve services at community level.”

“Home based care workers need to keep closer contact with their patients and the staff at CHC level” and “we experience problems faxing the referral discharge forms especially to the rural areas because of the constant change in fax numbers, phone numbers and HBC district co-ordinators.”

Collaboration

Inter sectoral collaboration was lacking between the role players at Tertiary, CHC and NGO levels. Participants verbalised their frustration by saying “I would appreciate regular updated details of fax and phone numbers as well as names of the relevant staff members who is supposed to receive the referral form at CHC level” and “when discharging patients to please inform the CHC.” “Only aware of referrals to NGOs for the delivery of home based care services from the clinic.” “If a patient gets a referral letter upon discharge from hospital to their local CHC, they must be told to report to the CHC at their earliest convenience.”

Co-ordination

Participants reported, “CHC is not aware of any discharges or referrals for home based care.” A mother caring for her daughter said “I went to the clinic for TB tablets
because she ...(patient) had TB before she went to hospital. The clinic only gave TB tablets but no other help was offered."

Participants also remarked that there was need for improvement in the system.

“The referrals from CHC level must be consolidated.”  “To have a folder system in place for each patient. “ “Good record keeping to monitor progress (solve problems if any).”

**Patient rights**

It was reported that patients’ rights at times were violated because “very often patients are being discharged from hospital without knowing what they are entitled to.”

“Hospital staff must give proper information to the patient whilst they are in hospital.”

“The patient is not well informed upon discharge.”

A mother reported, “I would have been glad if there was someone to help care to my daughter when she was sent home in December 06 because she was very ill and I struggled alone with her. I have looked after her and now I’m used to her condition. She is a bit better but I don’t know for how long it will be.”

**Summary**

The study indicated that 98% of nursing staff interviewed were familiar with the draft policy framework for HCBC. However, although they were aware of the process, compliance was unsatisfactorily low.
There appeared to be a number of reasons for these phenomena of non-compliance such as:

- The delayed response in faxing the discharge referral form to the CHC post discharge could be attributed to the fact that:
  - The nursing manager at Tertiary level was not directly involved with the discharges but was dependant on the ward sisters for the submission of the discharge forms.
  - The delays could have occurred at ward level. Proper co-ordination to ensure that all the discharge referral forms sent from the respective wards to the office of the nursing manager was lacking.

- Missing / lost files influenced patient outcomes because important information was lost and prescriptions / instructions could not be executed.

- The defaulter rate for CHC attendance was extremely high (66%). Unfortunately the reasons could not be determined during the study because 99% of the defaulters had already died at the time. Judging from interviewees’ responses at NGO level who maintain close contact with patients and their families, there could be contributing factors such as:
  - Lack of financial resources due to unemployment.
  - Ill health of the patient.
  - Lack of transport and / or inaccessibility of CHCs.

- Interviewees mentioned that there was not enough communication between the various role-players.
• Interview participants claimed that the decision regarding implementation of the referral policy framework was not an inclusive, consultative process.

• The lack of feedback from the different levels of care. Interviews conducted with the participants confirmed this observation. There is therefore an urgent need to promote feedback from the upper levels to the lower levels and vis-à-vis.

• NGO service delivery was restricted to 70% due to delays caused at health facility level.
CHAPTER FIVE:
DISCUSSION, LIMITATIONS, RECOMMENDATIONS

5.1 INTRODUCTION

In this chapter the researcher endeavours to discuss the results of the study as objectively as possible. The purpose of the study was to explore the referral pathway for patients in need of nursing care at home, after they had been discharged from the Tertiary Hospital. The referral pathway for patients through the health care system included the admission, treatment, discharge and outpatient activity at Tertiary, CHC and NGO levels. The discussion and conclusions of the findings will be put into perspective and the implications to the health system outlined.

5.2 DISCUSSION

5.2.1 Objective 1

Provider compliance was measured by using a standardised checklist. The compliance checklist showed that adherence to the guideline recommendations had in some cases been fully complied with and in other cases to a lesser degree. According to Sternberg (2001), compliance means to agree with a request that was extended by someone else. The goal standard was determined at 80%. A goal standard is a mechanism whereby the level of performance is measured to determine compliance to a proposed guideline (NEPC, 2007).
**Tertiary level**

According to the records, only 68% of patients had been discharged by a medical officer. Referral facilities were recorded in 89.7% of cases but further observation at CHC level however showed that ten facilities were incorrectly recorded. The turn-around time for faxing the HCBC discharge referral form was unacceptable. No obvious reason for the delays was found. Deducting from the interviews it was reported from the NGOs that in some cases by the time they received the referral and conducted a home visit the patient had already died. There were no discharge referral forms in the patients’ file because the HCBC district co-ordinators collected these forms from the Tertiary hospital. Discharge referral forms from a particular department at Tertiary level were faxed directly to the NGOs. They bypassed the proposed HCBC discharge referral guideline and used their own system. Staff was uninformed regarding patient outcomes at CHC level. This evidence strongly correlated with the views expressed by the interviewees whereby the only feedback they ever received was from the patient. Feedback is an integral part of any system in order to monitor and evaluate its effectiveness. Some form of feedback is therefore crucial to determine whether a strategy is effective in order to achieve a desired outcome (Nickols, 2000). On average the goal standard had not been attained at this level.

**CHC facilities**

Discrepancy was identified between the Tertiary hospitals HCBC discharge register and CHC admission registers. The number of discharges and admissions between
these two care levels did not correlate. These differences were identified in five out of the eleven CHCs that implemented HCBC registers.

Follow-up visits to CHC at 33.8% were also subject to correction because 25% of those whom have attended had new files. According to Maslow’s hierarchy of needs (Abraham Maslow (1943, 1954, 1970)) as cited in Sternberg (2001), people will first ensure that their most basic needs are met before they would proceed to meet other needs. It could therefore not be determined with certainty if they had attended CHC for HCBC related treatment or not. Similarly the argument for the 38.2% examined by a Medical officer, 27.9% referral letters to NGOs would be the same because of missing information in 25% of the files.

Adherence to the guideline was poor and below the goal standard at CHC level.

**Non-Governmental Institutions**

Registers and patient files were neatly kept and up to date. Seventy one percent was in receipt of HCBC services. Fifty six % of files contained referral letters from CHC. During the data collection process, it had been discovered that an additional 246 patients had been discharged for HCBC services within the same time period. Their names however, did not reflect in the Tertiary Hospital’s discharge register. Feedback given to CHCs was insufficient at 8.8%. Nickols, (2000), states that feedback can only be useful if it is continuous, appropriate and timeously provided.
The NGO sector was more compliant to protocol than Tertiary or CHC level. They have however not been able to reach the goal standard. The reason for the provider non-compliance could be not be determined during the observational phase of the study. Further research has to be undertaken to determine the factual reasons for non-adherence to the protocol.

5.2.2 Objective 2

Information that was generated from interviews provided data from peoples’ account i.e. “what they said and how they said it”. The information collected from the interview data did not reflect actual behavioural patterns in their natural environment (Green and Thorogood 2009). However, the information that was obtained from the interviews remained an invaluable resource because interviewees provided input as they understood it from their perspective. Outcomes from the interviews produced emerging themes which were then categorized (Hamilton & Dinat, 2006).

Communication

Communication is an important aspect to ensure continuity of care. It provides a platform whereby mis –understanding / mis-interpretations are minimized / excluded. Communication is a two-way transfer / exchange of information and ideas between people. Effective communication means that the sender’s message / information is fully understood by the recipient /s of the message (Hugman, 2009). In systemic communication there is a risk of mis-interpretation as the message is transferred through the different levels of care (Hamilton & Dinat, 2006).
Analysing the interview data it was clear that there had not been enough communication between the partners in care. Two interviewees stated that they were not aware of the policy framework on HCBC. This could be attributed to the fact that the HCBC processes extended over three levels of care. Due to the off/on duty roster there could have been missed opportunities to share the process with all the staff members. The resistant-to-change attitude could also be considered as a reason for their ignorance regarding this new proposed HCBC referral process.

Miscommunication was the reason why a patient did not access the necessary home based care services. The patient’s mother gave an account of the hardship that she bore whilst her daughter was extremely ill and unable to help herself. This unfortunate incident could have been prevented if the sender and recipient of the message have clearly defined and understood the instructions.

Staff at Tertiary level also found it problematic to communicate effectively with the districts due to staff changes and no update on contact details. Partners did not ensure all the role players were appropriately informed of the changes that occurred. An understanding of their inter-dependence would have prevented suchlike incidences. Relationship-building, acknowledgement and respect for each other could have been enhanced through effective communication.

**Lack of information**

Geographical factors, faulty systems design, staff attitudes and physical barriers were the possible reasons for blocking access to a “seamless” continuum of care. These
dynamics caused the transfer of information across all sectors to “fall between the
cracks”.

Safe keeping of patient information and accurate record keeping is a legal requirement
(NHA, 2004).

Original folders had been misplaced and replaced with new ones, losing valuable
information regarding the patient’s previous treatment regimes / tests and test results
and follow-up treatments. Irresponsible behavioural patterns of staff by omitting
important patient information when completing records.

NGOs in general have been noted for their altruistic behaviour. They responded to any
call for help even though it could be detrimental to them because the correct channels
had not been used (Sternberg, 2001). It had been noted that according to information
found at NGO level, that the admissions to NGOs far outweighed the discharges from
Tertiary level for the same time period.

Mis-information at times led to case overload at NGO level because they received and
accepted referrals outside the referral protocol. Had the patients been appropriately
referred, help could have been enlisted from other NGOs operating in the same area. It
was reported that in some cases patients had died by the time the NGO conducted their
first visit. The lack of adequate / incorrect / mis-information had at times contributed
to the non-delivery of services to patients.

*Feedback*
Feedback was the vehicle through which patient progress was communicated to all the role players involved in the patient’s care plan. “Feedback is an essential part of a relationship…it’s critical for the survival of any relationship” (Lybi, 2004). Feedback is also important to keep all the members of the team informed. It should be both positive and constructive to prevent any discomfort to the recipient when constructive feedback is given (Evans, 2005). Nickols, (2000), states that feedback can only be useful if it is continuous, appropriate and timeously provided.

Inadequate feedback had been forwarded and received between the partners which accounted for the dissatisfaction and frustration at the different levels of care. Partners felt deprived and ignored because they did not receive any patient progress reports from their counterparts. The statistical analysis confirmed the statements made by the interviewees. The lack of feedback was identified as one of the elements hampering effective functioning of the proposed HCBC discharge referral pathway.

**Partnerships**

It had been noted that change and the maintenance of change in the clinical environment had been difficult. Interview data indicated that staff at grassroots (NGO) levels was at the receiving end of ill-defined partnerships from their colleagues at institutional levels.

A partnership is the association of likeminded people working together towards a common goal (American Heritage Dictionary, 2007).
The equity theory, Walster, Walster & Bersced, 1978 (as cited in Sternberg 2001), plays an important role between partners whereby each member feels that they are treated and respected on equal terms.

Staff at one specific department at the Tertiary hospital displayed their lack of trust in the staff at CHC level. They bypassed the proposed referral system and referred their patients directly to the NGO. Staff at Tertiary level also complained that they were not kept informed of patient progress. The only feedback on the programme results became known if a patient’s condition deteriorated at home and had to be re-admitted.

Statistical analysis had confirmed that there were no feedback reports from CHC to Tertiary level. At CHC level staff complained that they were not always informed appropriately and timeously from Tertiary level. Once again these statements have been confirmed through the statistical analysis of the study data. CHC staff also complained about their counterparts at NGO level and vis-a-vis.

The results of the study demonstrated that the weakness in consolidating a firm relationship had influenced the outcome of a successful partnership between the partners in care.

**Collaboration**

The proposed policy framework for the HCBC discharge referral pathway had been developed with the intention of providing better and continuity of care to patients. The partnership spanned across different levels of care and created a complex situation. Although partners were committed in working together they first and foremost had their own personal departmental goals to achieve.
(Hamilton & Dinat, 2006), defines collaboration as a structured, recursive process where two or more people work together toward a common goal that is creative in nature by sharing knowledge, learning and building consensus. Collaboration does not need leadership and can even bring better results through decentralization and egalitarianism. Teams that work collaboratively can obtain greater resources, recognition and reward when facing competition for finite resources. Structured methods of collaboration encourage introspection of behaviour and communication. These methods specifically aim to increase the success of teams as they engage in collaborative problem solving.

Data obtained from the interviews show that some form of collaboration existed. It was however a cause of frustration to the partners at all levels of care due to its inadequacy. Non compliance as revealed in the content analysis was directly related to the lack of intersectoral collaboration.

**Co-ordination**

The HCBC guideline was amongst others developed to facilitate a coordinated, sustainable approach to the delivery of HCBC services across the different levels of care.

Current trends in health care delivery promote the networking of professionals across different levels of the care spectrum, developing and implementing unified patient management protocols. Effective co-ordination of health care services prevents
duplication of services, gaps in service delivery, unnecessary admission to acute care facilities and assessments that contradict each other (Arnold & Boggs, 2011).

Reports from the interviewees corroborated with the results of the empirical data. Partners in care were ill-informed. There appeared to be system inefficiencies. Although HCBC discharge referral guidelines were in place, in-effective co-ordination between the role players caused a breakdown in service delivery.

**Patient rights**

Awareness raising programmes in hospitals, newspapers and on television had made patients more aware of what is ethically and morally correct regarding patient care.

People are much more knowledgeable and confident. At times they also forcefully demand treatment and value for money. Von Bultzingslowen, Eliasson, Sarvimaki, Mattson & Hjortdah, 2006 (as cited in Arnold & Boggs, 2011).

Although staff at NGO level felt that the patients’ rights were violated It could not with certainty be concluded on the evidence of one patient that was interviewed. However, in telephone conversations with the relatives of the twenty four deceased patients as reported in chapter 4, families had verbalised their disappointment in the health system. Their complaints were issues pertaining to their diagnosis / treatment plans and even follow-up dates. It was also noted that parents / spouses / relatives at times had to assume the necessary caring function in the absence of properly communicated treatment / follow-up plans.
5.3 RECOMMENDATIONS

- A dedicated HCBC liaison officer be assigned for the sole purpose of completing the discharge referral forms at ward level, co-ordinate discharge, ensure appropriate follow-up and receive progress reports of all discharged patients.
- Feedback mechanisms must be established and written progress reports provided between all levels of care.
- Overall monitoring and supervision of the HCBC discharge and admission processes at all levels of care.
- HCBC admission and discharge registers to contain relevant and accurate patient data. i.e. full name, folder number, address and contact details of the patient.
- Medical officers remain responsible for patient discharge.
- The verbal agreement of forty-eight hours between hospital discharge and follow-up care at home should be formally documented.
- Collaborative partnerships should be strengthened between all role-players and all levels of care.
- All relevant role-players from all sectors should be involved in finalizing the policy to ensure buy-in and acceptance of / adherence to the guidelines.
- Regular information sharing platforms should be created to increase awareness.
- Information brochures, continuous education and in-service-training sessions to keep hospital staff informed and to orientate all new staff members to the process.
- Record keeping and the filing systems should be improved.
- An electronic system is implemented to preserve patient information and test results.
- All staff members should respect the Bathopele principles, work ethics and patients’ rights charter.
- Record keeping and archiving of patient information must be improved.
- The NGO sector should maintain their autonomy but respected as fully-fledged partners in the provision of health care.

5.4 LIMITATIONS OF THE STUDY

The scope of the study was limited to the northern parts of the Metropole and in one rural area, even though it only excluded 17 patients from the West Coast Winelands and three patients from South Cape Karoo Regions respectively. The findings of this research were based on data that was obtained from 68 patients. These findings can therefore not be generalised for the entire Metropole region or for the Western Cape Province.

5.5 CONCLUSION

The study aimed to explore the proposed home based care discharge referral pathway for patients eligible for discharge from hospital to home in the Western Cape. If one considers the global challenge with regard to an increased demand for the provision of health care services, then South Africa, which is regarded as a developing country rates amongst those countries whereby the demand outweighs the ability to deliver adequate
health services to its peoples. Early discharge from hospital resulted in re-admissions due inappropriate or lack of basic nursing care at home.

The development of policy guidelines for a HCBC discharge referral system was crucial to ensure continuous care for the patient from hospital to grassroots level. Provision of care to these patients’ involved cross-functional teams and therefore the roles and responsibilities of each role player had to be clearly defined. The findings of the study support the researcher’s initial perception that there was insufficient follow-up of patients between hospital and home due to systemic and human inadequacies.

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RE: PERMISSION TO CONDUCT RESEARCH IN TYGERBERG HOSPITAL, BOLAND / OVERBERG REGION AND THE METRO DISTRICT HEALTH SERVICES

I have enrolled as a Masters Degree student at the University of the Western Cape with the intention to do research on the Home / Community Based Care (H/CBC) discharge referral pathway for patients that have been discharged from Tertiary Level Care for continuum of care at Community Based Level in the Western Cape Province.

The aim of the study is to determine whether patients that have been discharged from Tygerberg Hospital have been referred appropriately, and have received the required home based care services at grassroots level.

Due to the nature of the study, I need to access the abovementioned health facilities to conduct my research. I am also keenly interested to do a comparative study between urban versus rural referral pathways, hence my request to include one of our rural areas in the study.

I therefore, hereby request your permission to approach the Medical Superintendent, Dr. T. Carter at Tygerberg Hospital, and the Directors at the Metro, Dr. Bitalo and Dr. Krige at Boland / Overberg Region in order to conduct the study in the relevant health care facilities.

Trusting that my request will meet with your favourable approval.

Thanking you in anticipation.

Sincerely

---------------------------------------------------------
L.L. SCHEEPERS
Dear Dr. Carter,

RE: PERMISSION TO CONDUCT RESEARCH IN TYGERBERG HOSPITAL

I have enrolled as a Masters Degree student at the University of the Western Cape with the intention to do research on the Home / Community Based Care (H/CBC) discharge referral pathway for patients that have been discharged from Tertiary Level Care for continuum of care at Community Based Level in the Western Cape Province.

The aim of the study is to determine whether patients that have been discharged from Tygerberg Hospital have been referred appropriately, and have received the required home based care services at grassroots level.

Due to the nature of the study, I need to access information from patient files as well as interview staff that have been involved with the discharge of patients from Tygerberg hospital for continued health and health related care at Primary level.

I therefore, hereby humbly request your permission to access the necessary patient files for the period mentioned above, as well as the opportunity to interview the relevant staff members.

Trusting that my request will meet with your favourable approval.

Thanking you in anticipation.

Sincerely

……………………………………………………………..

L.L. SCHEEPERS
Dear Dr. Krige,

RE: PERMISSION TO CONDUCT RESEARCH IN THE REGIONAL HOSPITAL AND PRIMARY HEALTH CARE FACILITIES WITHIN THE BOLAND / OVERBERG REGION

I have enrolled as a Masters Degree student at the University of the Western Cape with the intention to do research on the Home / Community Based Care (H/CBC) discharge referral pathway for patients that have been discharged from Tertiary Level Care for continuum of care at Community Based Level in the Western Cape Province.

The aim of the study is to determine whether patients that have been discharged from Tygerberg Hospital have been referred appropriately, and have received the required home based care services at grassroots level.

Due to the nature of the study, I need to access information from patient files as well as interview staff that have been involved with the discharge of patients from the relevant Regional hospital for continued health and health related care at Primary level.

I therefore, hereby humbly request your permission to access the necessary patient files for the period mentioned above, as well as the opportunity to interview the relevant staff members at the Regional hospital, Primary Health Care facilities and NPO sector.

Trusting that my request will meet with your favourable approval.

Thanking you in anticipation.

Sincerely

……………………………………………………………..

L.L. SCHEEPERS
Dear Dr. Bitalo,

RE: PERMISSION TO CONDUCT RESEARCH IN THE PRIMARY HEALTH CARE FACILITIES

I have enrolled as a Masters Degree student at the University of the Western Cape with the intention to do research on the Home / Community Based Care (H/CBC) discharge referral pathway for patients that have been discharged from Tertiary Level Care for continuum of care at Community Based Level in the Western Cape Province.

The aim of the study is to determine whether patients that have been discharged from Tygerberg Hospital have been referred appropriately, and have received the required home based care services at grassroots level.

Due to the nature of the study, I need to access information from patient files as well as interview staff that have been involved with the discharge of patients from Tygerberg hospital for continued health and health related care at Primary level.

I therefore, hereby humbly request your permission to access the necessary patient files for the period mentioned above, as well as the opportunity to interview the relevant staff members at the Primary Health Care facilities and NPO sector.

Trusting that my request will meet with your favourable approval.

Thanking you in anticipation.

Sincerely

L.L. SCHEEPERS
The Chief Medical Officer
Dr. ………………………
……………………… District

Dear …………………

RE: PERMISSION TO CONDUCT RESEARCH IN THE PRIMARY HEALTH CARE FACILITIES

I have enrolled as a Masters Degree student at the University of the Western Cape with the intention to do research on the Home / Community Based Care (H/CBC) discharge referral pathway for patients that have been discharged from Tertiary Level Care for continuum of care at Community Based Level in the Western Cape Province.

The aim of the study is to determine whether patients that have been discharged from Tygerberg Hospital have been referred appropriately, and have received the required home based care services at grassroots level.

Due to the nature of the study, I need to access information from patient files as well as interview staff that have been involved with the discharge of patients from Tygerberg hospital for continued health and health related care at Primary level.

I therefore, hereby humbly request your permission to access the necessary patient files for the period mentioned above, as well as the opportunity to interview the staff members at the relevant Primary Health Care facilities and NPO sector. If the study necessitates personal interviews with relevant patients, I would like to hereby also request your permission to interview the patient / caregiver.

Trusting that my request will meet with your favourable approval.

Thanking you in anticipation.

Sincerely

…………………………………………………………..

L.L. SCHEEPERS
<table>
<thead>
<tr>
<th>2. STAFF INTERVIEW: TERTIARY LEVEL</th>
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<tbody>
<tr>
<td>Are you familiar with the HBC discharge protocol</td>
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<tr>
<td>Yes</td>
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<td>………………………………………………………………………………………………………………………………………………………………………………</td>
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<tr>
<td>What is your perception of the discharge referral pathway?</td>
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<tr>
<td>Do you have any suggestions for improvement on the discharge referral pathway?</td>
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### 3. STAFF QUESTIONNAIRE: CHC LEVEL

<table>
<thead>
<tr>
<th>Question</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are you familiar with the HBC discharge protocol</td>
<td>Yes/No</td>
</tr>
<tr>
<td>What is your perception of the discharge referral pathway?</td>
<td></td>
</tr>
<tr>
<td>Do you have any suggestions for improvement on the discharge referral pathway?</td>
<td></td>
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</table>
4. **STAFF QUESTIONNAIRE (NPO SECTOR)**

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are you familiar with the HBC discharge protocol?</td>
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<tr>
<td>Are patients referred in line with the protocol?</td>
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<tr>
<td>Do you give feedback to CHC with regard to the patient’s progress?</td>
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<tr>
<td>What is your perception of the discharge referral pathway?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you have any suggestions to improve the referral pathway?</td>
<td></td>
<td></td>
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