

**FACILITATING CARE: THE EXPERIENCES OF
INFORMAL CARERS DURING THE TRANSITION OF
ELDERLY DEPENDANTS FROM HOSPITAL TO HOME
- A GROUNDED THEORY STUDY**

JUNE D. JEGGELS

The logo of the University of the Western Cape, featuring a classical building with columns and a pediment, with the text 'UNIVERSITY of the WESTERN CAPE' below it.

**Thesis submitted in the fulfillment of the requirements for the degree of
Philosophiae Doctor in the School of Nursing, Faculty of Community and
Health Science, University of the Western Cape**

**Supervisor: Prof. R M B Mpofu
Co-supervisor: Prof D A Meerkotter**

October 2006

FACILITATING CARE: THE EXPERIENCES OF INFORMAL CARERS DURING
THE TRANSITION OF ELDERLY DEPENDANTS FROM HOSPITAL TO HOME
– A GROUNDED THEORY STUDY

June D Jeggels

School of Nursing, Faculty of Community and Health Science,
University of the Western Cape



South Africa
Informal carers
Family carers
Unpaid carers
Hospital discharge
Home-based care
Community-based rehabilitation
Elderly care
Qualitative research
Grounded theory

ABSTRACT

Major changes have occurred in South Africa over the past twelve years. Following the first democratic elections in 1994, a government representing all the people in South Africa replaced the apartheid government. The delivery of health care changed significantly. Community Health Centres (CHCs) became the main service delivery sites within districts. The new government promoted primary health care as the preferred model for the delivery of care within the CHCs. Tertiary hospitals served as referral centres for the delivery of acute care services.

Due to socio-economic changes in the country, the care of dependants, particularly children and the aged, became problematic to families where most of the adult members have to work to secure an income. Within this context, families often experience challenges when an elderly member, who might have contributed to the income of the family, or assisted with the care of dependants, is hospitalised. These challenges are compounded, if the aged is discharged back to the family for home care, especially if the person requires assistance with self-care activities and rehabilitation.

The Government has acknowledged the need for home-based workers in the district health system and has earmarked funds for the training of these workers, but has not, as yet, deployed adequate numbers of these workers into the system. This means that the primary care of the elderly dependants remains the responsibility of informal carers.

A focused literature search indicates that informal carers are ill prepared for their task, that there is a need to include these carers in the discharge planning of the dependants and that the carers need to be supported within their families and communities.

The aim of this study was to explore the experiences of informal carers during the transition of their elderly dependants from hospital to home, within the home and across different social groupings in the metropolitan area of Cape Town, South Africa. In addition, the involvement of informal carers in the rehabilitation of the elderly was explored.

A qualitative approach was followed to describe the experiences of informal carers within their unique contexts. Two tertiary hospitals in the Cape Town metropolitan area were targeted. Hospital staff used specific criteria to identify informal carers prior to the discharge of the elderly dependant from the hospital. The sampling of participants was purposive and data analysis closely followed data collection. The research instruments used were, amongst others, demographic questionnaires, interviews, fieldwork notes and written memos.

Questionnaires were used to collect demographic data from the informal carers and the elderly dependants, followed by interviews with the informal carers. The interviews, using open-ended questions, were scheduled as follows: prior to the discharge, within the first week of the discharge and one month later at the homes of the dependants. During the second and third contact visits, direct observation was used to collect additional information.

The data was transcribed verbatim and stored in a computer assisted data analysis programme (N. VIVO). The coding procedure introduced by Strauss and Corbin (1990, 1998) was used and memos written to keep track of the data analysis process. The N. VIVO programme facilitated the coding of transcripts, the retrieval of data and the linking of annotations and memos to the text.

Thematic analysis and constant comparison were used to develop substantive theory based on empirical evidence. The guidelines of Strauss and Corbin (1990, 1998) formed the basis for the development of the grounded theory. The research outcomes showed that informal home-based carers were *facilitating care* during the transition of the elderly from hospital to home by revealing the link between *facilitating care*, the basic social process, and other categories associated with informal health care. These categories include: the *prior relationship* between the carer and the elderly, the traumatic *incident*, the need for *role fitting*, *maintenance-* and *repair care*, as well as, the consequences of facilitating care, i.e. *connected* or *disconnected* care.

The main research outcomes were discussed in relation to current literature on the research topic; the conceptual framework; the debate on the position of informal carers in community based rehabilitation and their inclusion in the role-out of primary health care in the Western Cape, South Africa.

The outcomes of this study could undoubtedly be used to: inform health professionals and hospital managers about the needs of informal carers regarding discharge planning; inform district or community service providers about the accessibility of support services in their areas, as well as, inform policy decision-makers about the involvement of informal carers in home-based health care and rehabilitation services within districts. The information may also be used to develop guidelines for informal carers and to inform the development of education and training programmes for home-based health workers and health professionals in this country.

DECLARATION

I declare that *Facilitating care: the experiences of informal carers during the transition of elderly dependants from hospital to home - a Grounded Theory Study* is my own work, that it has not been submitted before for any degree or examination in any other university, and that all the sources I have used or quoted have been indicated and acknowledged as complete references.

June Deanna Jeggels

October 2006

Signed:.....



The financial assistance of the National Research Foundation (NRF) towards this research is hereby acknowledged. Conclusions arrived are those of the author and are not necessarily to be attributed to the National Research Foundation.

ACKNOWLEDGEMENTS

I wish to express my sincere gratitude to:

- ❑ My supervisor, Prof R Mpfu for her patience, support and guidance and for encouraging me to complete the research journey.
- ❑ My co-supervisor, Prof D Meerkotter for his positive feedback and attention to technical detail.
- ❑ My mentor, Dr M Coetzee for her guidance during the data analysis phase of the grounded theory research study
- ❑ My colleagues and friends, Enid Fortuin and Lorraine Britten for their assistance during the data collection phase of the study.
- ❑ The medical superintendents and staff of Tygerberg and Groote Schuur hospitals for their assistance with the selection of research participants.
- ❑ The informal carers and their families who participated in the study and shared their experiences with me. Their contribution made this research study possible and is highly appreciated.
- ❑ The National Research Foundation (NRF) for their financial support.
- ❑ My colleagues in the School of Nursing who had to step into my shoes when I was granted special leave to attend to various aspects of the research process.
- ❑ My family for encouraging and supporting me when I encountered obstacles along the way and shared my joy when the end of the journey was in sight.

TABLE OF CONTENTS

KEYWORDS:	ii
ABSTRACT	iii
DECLARATION.....	v
ACKNOWLEDGEMENTS.....	vi
CHAPTER 1: CONTEXTUALIZING THE RESEARCH STUDY.....	1
1.1. INTRODUCTION	1
1.2. BACKGROUND TO THE STUDY	2
1.2.1. CONTEXTUAL BACKGROUND	2
1.2.2. THEORETICAL BACKGROUND.....	8
1.3. RESEARCH QUESTION AND SIGNIFICANCE OF THE STUDY	10
1.3.1 RESEARCH QUESTION.	10
1.3.2. THE SIGNIFICANCE OF THE PROPOSED RESEARCH.....	11
1.4. MOTIVATION FOR THE STUDY	12
1.5. RESEARCH AIM AND OBJECTIVES.....	13
1.6. RATIONALE FOR STUDY	14
1.7. RESEARCH METHODOLOGY.	16
1.8. CHAPTER OUTLINE.....	17
1.9. CONCLUSION	18
CHAPTER 2: LITERATURE REVIEW.....	20
2.1. INTRODUCTION	20
2.2. INFORMAL HOME-BASED CARING.....	20
2.2.1. INFORMAL CARE DEFINED.....	20
2.2.2. INFORMAL CARE IN DEVELOPED COUNTRIES	22
2.2.2. INFORMAL CARE IN DEVELOPING COUNTRIES	24
2.3. REHABILITATION AND CBR.....	27
2.4. CONCEPTUAL FRAMEWORK.....	29
2.4.1. GENERIC THEORIES.....	31
2.4.2. NURSING THEORIES	31
2.4.3. REHABILITATION THEORIES.....	32
2.5. CONCLUSION	33
CHAPTER 3: RESEARCH METHODOLOGY	34
3.1. INTRODUCTION	34
3.2. SOCIAL RESEARCH PARADIGMS.....	34
3.2.1. RESEARCH PARADIGMS.....	34
3.2.2. QUALITATIVE RESEARCH.....	38
3.2.3. GROUNDED THEORY RESEARCH – THE ORIGIN	39
3.2.4. GROUNDED THEORY RESEARCH – THE METHOD	41
3.2.5. GROUNDED THEORY RESEARCH – THE METHOD OF CHOICE	42
3.3. PHILOSOPHICAL UNDERPINNING, RIGOR AND ETHICS	44
3.3.1. PHILOSOPHICAL UNDERPINNING	44
3.3.2. RIGOR IN GROUNDED THEORY RESEARCH.	45
3.3.3. ETHICAL COMPORTEMNT.....	47
3.4. RESEARCH DESIGN.....	51
3.4.1. SELECTION OF RESEARCH SAMPLE	51
3.4.2. RESEARCH INSTRUMENTS.....	54
3.4.3. DATA COLLECTION	60
3.4.4. DATA ANALYSIS	64
3.5. CONCLUSION	74

CHAPTER 4: RESEARCH OUTCOMES	75
4.1. INTRODUCTION	75
4.2. THE VOICE OF THE RESEARCHER.....	75
4.2.1. A PERSONAL REFLECTION	75
4.2.2. A PROFESSIONAL REFLECTION.....	78
4.3. THE CONTEXT OF CARE	80
4.3.1. A CLOSER LOOK AT CONTEXT	80
4.3.2. THE CONDITIONAL MATRIX	83
4.4. FACILITATING CARE – THE MODEL.....	84
4.4.1. PRIOR RELATIONSHIP.....	85
4.4.2. THE INCIDENT.....	88
4.4.3. ROLE FITTING	92
4.4.4. MAINTENANCE CARE	101
4.4.5. REPAIR CARE	110
4.4.6. CONNECTEDNESS	120
4.5. CONCLUSION	128
CHAPTER 5: REFLECTION ON RESEARCH OUTCOMES	129
5.1. INTRODUCTION	129
5.2. APPROPRIATENESS OF THE METHODOLOGY.....	129
5.3. AIMS AND OBJECTIVES	131
5.4. FACILITATING CARE – A GROUNDED THEORY.....	132
5.4.1. FACILITATING CARE – BASIC SOCIAL PROCESS.....	133
5.4.2. A CLOSER LOOK AT PROCESS	134
5.4.3. CATEGORIES	136
5.5. IMPLICATIONS OF THE RESEARCH OUTCOMES.....	144
5.5.1. IMPLICATIONS FOR MYSELF.....	144
5.5.2. IMPLICATIONS FOR THE CARER	145
5.5.3. IMPLICATIONS FOR EDUCATION AND TRAINING	146
5.5.4. IMPLICATIONS FOR HEALTH AND SOCIAL WELFARE SERVICES	147
5.6. CONCLUSION	148
CHAPTER 6: CONCLUSIONS AND RECOMMENDATIONS	149
6.1. INTRODUCTION	149
6.2. THE RESEARCH JOURNEY	149
6.3. CHALLENGES AND RECOMMENDATIONS.....	152
6.4. LIMITATIONS OF THE RESEARCH STUDY.....	155
6.5. CONCLUSION	156
REFERENCES.....	157
APPENDIX 1: DEMOGRAPHIC DATA QUESTIONNAIRE: CARER.....	168
APPENDIX 2: DEMOGRAPHIC DATA QUESTIONNAIRE: DEPENDANT	169
APPENDIX 3: INTERVIEW GUIDES.....	170
APPENDIX 4: SAMPLE CRITERIA	171
APPENDIX 5: CONCEPT INFORMATION AND CONSENT DOCUMENT	172
APPENDIX 6: CONSENT FROM TRAINING HOSPITAL	174
APPENDIX 7: CONDITIONAL MATRIX	175
APPENDIX 8: EXAMPLES OF TRANSCRIPTS.....	176
APPENDIX 9: EXAMPLE OF CODE REPORT	205

FIGURE 1.1: SOUTH AFRICAN PROVINCES.....	4
FIGURE 2.1: CONCEPTUAL FRAMEWORK.....	30
FIGURE 3.1: RESEARCH PARADIGMS.....	35
FIGURE 3.2: RESEACH PHASES AND TIMELINES.....	59
FIGURE 3.3: CHARACTERISTICS OF INFORMAL CARERS.....	64
FIGURE 3.4: EXAMPLE OF OPEN CODING.....	70
FIGURE 3.5: STRAUSS AND CORBIN’S PARADIGM MODEL.....	72
FIGURE 4.1: FACILITATING CARE – THE MODEL.....	85
FIGURE 4.2: PROPERTIES OF THE INCIDENT VS. DIMENSIONS OF FACILITATING CARE	89
FIGURE 4.3.1 ACTION AND INTERACTION STRATEGIES – ROLE FITTING.....	92
FIGURE 4.3.2 ACTION AND INTERACTION STRATEGIES – MAINTENANCE CARE.....	102
FIGURE 4.3.3 ACTION AND INTERACTION STRATEGIES – REPAIR CARE.....	111
FIGURE 4.4. CONSEQUENCES OF FACILITATING CARE – CONNECTEDNESS.....	121
FIGURE 5.1: FACILITATING CARE – A CLOSER LOOK AT PROCESS.....	135



CHAPTER 1: CONTEXTUALIZING THE RESEARCH STUDY

1.1. INTRODUCTION

This study explored the experiences of informal home-based carers of elderly persons during the transition from hospital to home. The experiences of these carers reflected the context of care and their inclusion in the rehabilitation of the elderly.

Smith (1999: 10) suggests that people need to become re-integrated into their communities, following acute illness or injury. The early re-integration of patients into the community involves effective discharge planning and efficient co-ordination between the multidisciplinary health team, the patients and their carers. The World Health Organization defines the strategy that facilitates the social re-integration of people with impairments as community-based rehabilitation (WHO, 1976). In South Africa, the Integrated National Disability Strategy (INDS) proposed that community-based rehabilitation (CBR) form the basis of the national rehabilitation strategy (Office of the Deputy President, 1997).

The exploration of the experiences of informal home-based carers provided important baseline information since a bottom-up approach to the provision of rehabilitation services is proposed at national level.

In this chapter the background to the study is described. The research problem is clarified and the purpose and significance of the study explained. The research question is formulated and an overview is given of the aims and objectives of the study. This is followed by a brief description of the research methodology used in the study and an outline of the rest of the chapters of the thesis.

This chapter is divided into the following sections under the headings:

- Background to the study
- The research question and significance of the study
- Motivation for the study
- Research aim and objectives
- The rationale for the study (purpose)
- Research methodology
- Chapter outline

1.2. BACKGROUND TO THE STUDY

1.2.1. CONTEXTUAL BACKGROUND

This research study was done in Cape Town, South Africa, the southern-most tip of Africa and home to a diverse mix of people. The participants were ordinary people who, within the context of a developing country, provided care to elderly dependants.

1.2.1.1 South Africa and its people

South Africa is a developing country situated in sub-Saharan Africa. The country falls within the subtropical belt ensuring warm, dry weather all year round. With wide expanses of ocean on three sides of the country, moderate temperatures prevail. The region in which this research study was conducted however, has a typical Mediterranean climate with long wet winters and moderate summers.

The Census done in South Africa in October of 2001 (Statistics SA, 2003), reflected the following: there were 44 819 778 people in the country, of which 79% classified themselves as African; 9,6% White; 8,9% Coloured and 2,5% as Indian / Asian. The South African Constitution (Act 108 of 1996) recognizes eleven (11) official languages, i.e. Afrikaans, English, isiNdebele, isiXhosa, isiZulu, Sepedi, Sesotho, Setswana, siSwati, Tshivenda and Sitsonga. Mother-tongue languages generally distinguish social groupings that share common cultural beliefs.

People aged 65 years or older, represented 4,9% of the total population, namely 2,2 million people (Statistics SA, 2003). It is expected that the population will continue to age for at least the next ten to fifteen years, despite the shortened average life expectancy resulting from the impact of HIV/AIDS (Joubert, Reddy & Bryan, 2002). It is unfortunate that the health care needs of older persons are currently being overshadowed by the emphasis on child, adolescent, reproductive and maternal health care (Ferreira & Charlton, 1996).

In South Africa, the elderly may choose to live with the extended family or in a home for the aged. A vast majority of elderly persons (98,5%) are living in housing units with others, or on their own (Joubert, 2005). The homes for the aged are either state-subsidized or privately funded institutions. A profile of the state subsidized institutions show that more than 80% of residents are from the minority (white) groupings in the country (Perold & Muller, 2000: 91). Perold and Muller (2000: 87) stated that home care and other support services for families of the elderly were grossly under-developed and in most areas in South Africa these services are not available. Despite a growing pressure for old age homes to reflect the race composition of South Africa, the historically disadvantaged majority group has to care for their elders in their homes (Aged Persons Amendment Act, 1998:6).

In terms of the Constitution, the country is divided into nine (9) provinces, i.e. the Western Cape, Eastern Cape, KwaZulu-Natal, Northern Cape, Free State, North West, Gauteng, Mpumalanga and Limpopo (Figure 1.1).



Figure 1.1: South African Provinces

Each of these provinces has their own Legislature, Premier and executive councils to manage amongst others: their finances, health services and educational services. While the legislative capital of the country is located in Gauteng, the executive capital is in the Western Cape.

1.2.1.2. The Department of Health

The national department of health is responsible for the co-ordination of healthcare services within the country. Primary, secondary and tertiary levels of health care are provided in each of the nine provinces within South Africa (Department of Health, 1997). Research has shown that formal health services are inadequate and do not provide satisfactory care to those in need of care (Njongwe, 2003; Uys & Hensher, 2002). The reasons for the inadequacies include: overcrowding, long waiting times and limited service hours (Modiba, Gilson & Schneider, 2002), lack of support systems and inadequate government funding (Njongwe, 2003).

Primary care services represent the first level of health care and focus on the promotion of health and prevention of disease. These services i.e. immunizations, family planning and the treatment of minor ailments, are delivered at rural clinics and community health centers in urban areas. Patients who are diagnosed with acute health problems are referred from the primary care level facilities to secondary hospitals. Secondary hospitals provide a variety of health care services, i.e. medical, surgical and paediatrics and only those patients who present with complex health problems would be referred for specialized care to tertiary (academic) hospitals.

On discharge from provincial hospitals, the routine is that patients are sent back to the primary referring facility, or sent home to be followed-up at the nearest primary health care centre. Many non-governmental organizations (NGOs) also contribute to the health care of the people of the country by providing supportive services at primary care level. Trained home-based workers employed by NGOs assist with, amongst others; care of the elderly, people living with HIV/AIDS and AIDS orphans. Informal carers have, however, not been recognized as participants at primary care level.

For those individuals who have health insurance, their first point of call would be a general practitioner (GP) or the emergency room of a private hospital. These individuals would then be admitted to private clinics or hospitals and on discharge be referred back to their GPs. Unfortunately, private health care falls beyond the financial capacity of the average South African and only 20% of the population make regular use of private health care services (Cornell, Goudge, McIntyre & Mbatsha, 2001)

1.2.1.3. The Western Cape Province

The capital of the Western Cape Province is Cape Town. The province has a population of 4 524 335 (Statistics South Africa, 2003) and their preferred

languages are Afrikaans 55,3%, isiXhosa 23,7% and English 19,3%. The Western Cape has the highest adult literacy level in the country with only 5,7% of the adults not having had any schooling. The official unemployment figure for the province is 20,6%, somewhat lower than the national average of 28,2%. The Western Cape is rich in agriculture and fisheries and one of the best grape-growing and wine-producing regions in the world. Unfortunately, the wealth is not shared by all the citizens of the province as affluent suburbs border on sprawling informal settlements.

1.2.1.4. Health services in the Western Cape

Prior to 1994, health services were fragmented at community and local district levels and the focus of health care was directed towards curative services. The Department of Health set out, in collaboration with all the interest groups in the health sector, to transform the prevailing system (Draft Provincial Health Plan of the Western Cape, 1995). Areas with a Community Health Centre (CHC), being the leading health facility within the districts, were identified. The services rendered at these CHCs include, amongst others, community nursing and home-care services.

Information about community- and home-based services has been inadequately documented. It appears as if the Department of Health acknowledged the need for home-based workers and subsidized their training, but until recently most of these workers were employed by NGOs. By 1995, an estimated 337 community-based health workers (CHWs) had been trained by non-governmental organizations (NGOs) to assist in areas where the health services were inadequate (Draft Provincial Health plan, 1995). However,

The sustainability of NGOs employing CHWs remains an ongoing dilemma. The Health Branch cannot afford to employ CHWs on the establishment of the province at this stage (Provincial Government of the Western Cape, 2000:6)

By 2005, 910 home-based carers attended to 8,615 patients within the province (Uys, 2006). This implies that over a period of ten years, an additional 600 home-based workers were deployed by non-profit organizations (NPOs), at an average of 60 per year. In the Health Budget Speech (Uys, 2006) it was suggested that guidance be offered to NPOs, and the coordination of services within NPOs be improved to address the health challenges within the province. It appears as if an inadequate number of home-based carers have been trained to attend to the needs within communities, thus creating a gap in the provision of home-based health care services. A gap that is currently been filled by informal home-based carers.

1.2.1.5. Disease profile in Western Cape

At provincial level a review of the health status of the people was done to serve as a guide for the planning of health care services. Premature deaths occurred in the 25 to 65 year age group as a result of ischaemic heart disease, chronic obstructive airway disease, cerebro-vascular accidents and tuberculosis (Draft Provincial Health Plan, 1995). The most common conditions suffered by the elderly in the Western Province were the exacerbation of the above-mentioned chronic diseases. These chronically ill older persons would therefore require home-based care when they are not being cared for in a health institution.

1.2.1.6. Impact of the HIV/AIDS pandemic

There is a perception that the majority of informal home-based carers in South Africa are women. With the HIV/AIDS epidemic spreading rapidly there is noticeable rise in the incidence of women with HIV/AIDS-related diseases. Annual surveys conducted by the Department of Health at antenatal clinics, show an increase in the prevalence of HIV-infections in the Western Cape, from 1.25% in 1994 to 5.2% in 1998 (Provincial Government of the Western Cape, 2000: 3). The national prevalence of HIV infections of young people aged 15-24 was 20.3% in 2005 (Statistics South Africa, 2005). One can assume therefore, that

women carers may become sufferers of this disease and may subsequently require health care themselves. If there is an increase in the death rate due to HIV/AIDS, fewer women will be available to serve as carers.

Statistics show that home-based care and other support services to families of the elderly are inadequate in most areas in South Africa (Perold & Muller, 2000: 87). It shows that communicable and non-communicable diseases are causing chronic symptoms in the elderly. It also shows an inadequate number of home-based workers in the Western Cape (Uys, 2006; Draft Provincial Health plan, 1995) and that the HIV/AIDS pandemic could impact the number of potential carers in the province (Provincial Government of the Western Cape, 2000). In many households, in this province, an elderly family member will at some stage require informal home-based care.

1.2.2. THEORETICAL BACKGROUND

This study is based on the theoretical premise that informal carers are not included in formal rehabilitation programmes. They are, however, expected to provide care and participate in the rehabilitation of the elderly.

1.2.2.1. Care

The word *care* is commonly used to specify the attention, support, and protection given by one person in society to another. Mc Cance, Mc Kenna and Boore (1997: 247) state that it is difficult to define the concept of caring. Following an in-depth concept analysis they identified the key elements of caring as, serious attention, concern, providing for and getting to know the patient.

Different societies, communities and individuals attach various meanings to the word, depending on the cultures and contexts in which it is used. These range from a term of endearment to the provision of all the basic needs of an individual. The latter may include activities like, obtaining and preparing food, providing

personal and home hygiene, maintaining ambulence and preventing any kind of injury. Orem (1991) refers to assistance with the abovementioned activities as dependent care and the WHO (2002a: 3), refers to it as dependency. An in-depth discussion of the concept care will be done in the context of informal care in Chapter Two.

1.2.2.2 Rehabilitation

Rehabilitation is considered an important aspect of all health care programmes. Smith (1999: 2) analyzed various definitions of rehabilitation and identified threads that exist across these definitions. He considered rehabilitation to be client centred, holistic and intended to foster independence, empower, reduce disability and to educate.

Rehabilitation is a multi-faceted process, which assists people with disabilities to optimize the use of their physical, emotional, mental and social abilities. Institution-based rehabilitation is very costly and provides in the needs of a relatively small percentage of people with disabilities (Mitchell, 1999: 459). The alternative is to promote rehabilitation within communities. Kendall, Buys & Larner (2000: 435) suggests that rehabilitation needs a professional identity to emerge as discipline and until this happens, rehabilitation will either follow the restorative medical model or remain an add-on to health related professions. Health care professionals are sensitized to the basic principles underlying the rehabilitation process within their subject specific fields. Various rehabilitation theories have been developed and facilitators of learning have a choice to select the most appropriate theory to include in their academic programmes. In some of the programmes the carer is mentioned but it is unclear to what extent informal carers are involved in the rehabilitation process. This research study has shed some light on their inclusion in the care and rehabilitation of the elderly in their communities. Carers' experiences in this regard are discussed in Chapter Four and Chapter Five.

1.2.2 3. Rehabilitation vs. caring

The definitions of caring and rehabilitation imply that caring per se, does not always include rehabilitation, for example terminal or palliative care. Rehabilitation, however, always includes care which means that following a cerebro-vascular accident (stroke) the elderly would require care as defined, but also a conscious attempt to improve the capacity of their functioning.

1.2.2.4. Informal home-based carers

The contribution to the welfare of the people of the country by informal carers generally goes unrecognized and these individuals (mainly women) are often exploited by their family members and regarded as having no needs of their own. They have yet to be acknowledged as important members of the health care team (Department of Health, 2001). These carers are expected to care for the elderly while unwittingly providing rehabilitation services within communities. Various aspects of informal home-based care are explored in an extensive literature review in Chapter Two.

1.3. RESEARCH QUESTION AND SIGNIFICANCE OF THE STUDY

1.3.1 RESEARCH QUESTION.

According to Strauss and Corbin (1990: 39) a research question is directive and helps the researcher to stay focused throughout the research project. It points to the interaction to be investigated, the site, the people involved and the potential participants. The following question directed this research study:

How do informal home-based carers of elderly dependants experience the transition of such dependants from hospital to home, at home and within different social groupings in Cape Town, South Africa?

1.3.2. THE SIGNIFICANCE OF THE PROPOSED RESEARCH

Firstly, the research aims to make a specific theoretical contribution to literature describing the experiences of the informal carers within a specific context. In this study the experiences of carers are explored during the transition of the elderly from hospital to their homes and within the home setting.

Secondly, the empirical research outcomes and grounded theory may be used to develop information packages for informal carers. The need for information has been the focus of many research studies (Robinson, Francis, James, Tindle, Greenwell & Rodgers, 2005; Smith, Lawrence, Kerr, Langhorne & Lees, 2004; Morris & Thomas, 2002; Mant, Carter, Wade & Winner, 1998; Kerr & Smith, 2001; Ndaba-Mbata & Seloilwe, 2000). Stewart, Marley and Horowitz (1999: 1077) suggest that new carers are very receptive to information during the period of care-giving.

Thirdly, it is hoped that the study will inform health professionals and hospital managers about the needs of the carer when the patient is discharged from the hospital. Tyson and Turner (2000: 381) found considerable dissatisfaction with the poor service offered during hospital discharge and follow-up for people who suffered strokes. Providing carers with information may positively impact on the quality of informal home-based care offered.

Fourthly the research outcomes may inform policy decision-makers about the involvement of informal carers in home-based health care and rehabilitation services. It appears as if these carers are providing care and rehabilitation services to the elderly without being adequately connected to the formal health care service structures.

Fifthly, it is my opinion that nursing research should focus on improving the quality of the lives of providers of health care (informal carers) and the recipients of that care (the elderly dependants in this case).

Finally, the importance of the research lies in an exploration of a topic of which there is limited local literature available; a topic which will give a voice to carers who selflessly carry on with the job of caring.

1.4. MOTIVATION FOR THE STUDY

My interest in this topic stems from my roles and experiences as a teacher, nurse, informal carer and woman in South Africa. These experiences will be described in more detail in Chapter Four, as it constitutes the context of the study, enhances theoretical sensitivity and impacts on the research outcomes.

The provision of primary health care to the citizens of South Africa necessitated the restructuring of health care related academic programmes. Primary Health Care courses were presented as modules at Institutions of Higher Learning. At the University of the Western Cape, the Faculty of Community and Health Sciences developed inter-disciplinary shared courses to include students from the Departments of Nursing, Physiotherapy, Occupational therapy, Dietetics, Natural Medicine, Dentistry and Social work. Departments in other faculties aligned their curricula with the Mission of the University, which states that learners should be prepared to serve their respective communities.

The Department of Nursing reviewed their under-graduate program to ensure that students were exposed to primary health care in both theory and practice. The clinical placements of under-graduate nursing students included not only curative but also primary health care settings. During clinical tutorials the students expressed their concern with regard to the lack of support for informal carers in the community.

I became aware of this lack of support, when I met a caregiver whose husband was bedridden following a cerebro-vascular accident. He was an obese man, in a comatosed state with a naso-gastric tube and urinary catheter in-situ. A neighbour assisted the wife with the daily bed-baths and her adult children

provided support after work. She was also able to consult the district nurse from a nearby primary health care facility during office hours. She stated that she was given minimal information about care-giving practices prior to her husband's discharge from the hospital. It was apparent that she spent most of the day tending to the needs of her husband and even though she said that she was coping, she appeared to be tired. She regarded the provision of total patient care as her spousal responsibility and was not given any respite.

Being the only nurse in an extended family, I spent three months providing home-based care to elderly members of my family. This experience enabled me to empathize with carers who are thrust into a position for which they were ill prepared. A detailed account of my personal experience as an informal carer is described in Chapter Four.

I am of the opinion that it is generally assumed in this country:

- that women instinctively know how to care for elderly dependants
- that women will take care of older relatives following hospitalization
- that women will be able to cope with the task of care-giving as well as other domestic responsibilities and
- that women will continue with the care-giving task indefinitely.

The study has clarified these assumptions about South African women as informal carers of elderly dependants (see Chapter Four).

1.5. RESEARCH AIM AND OBJECTIVES

The research study focused on the experiences of informal carers during the transition of their elderly dependants from hospital to home. Smith (1999: 10) refers to this process of transition or re-integration as the successful return of individuals to their communities. Mitchell (1999: 461) states that one of the principles of CBR is that rehabilitation occurs within communities and ideally, within the homes of the dependants. He also regards the informal carer as the primary provider of community-based rehabilitation.

The aim of this study was to explore the experiences of the informal home-based carers of elderly dependants in the Metropolitan area of Cape Town, South Africa. Linked to the exploration was the development of grounded theory on informal home-based care. The *objectives* of the study were:

- To describe the experiences of informal home-based carers prior to discharge of the elderly dependants (preparatory phase) as well as their experiences during the week following discharge (initial caring phase) and a month after home-based care has been given (established caring phase)
- To describe informal carer's experiences with regard to the rehabilitation of the elderly
- To describe the challenges faced by informal carers at the various phases during the care-giving process
- To establish the type of support required by informal carers.

1.6. RATIONALE FOR STUDY

The reasons for exploring how informal home-based carers of elderly dependants experience the transition of such dependants from hospital to home, at home and within different social groupings in Cape Town, South Africa, are linked to the significance of the study. The rationale for the study include, amongst others:

- o To engage in personal and professional development. An important professional attribute of a nurse is one of advocacy, i.e. to speak on behalf of others. This research study allowed me to relate the stories of carers who may otherwise not have had the opportunity to share their experiences with others.
- o To join the academic debate about informal carers and their experiences, needs, challenges and burdens and to add to local literature on the topic.
- o To engage in grounded theory research which is a challenge to novice researchers.

- To explore the experiences of informal carers in the provision of care and rehabilitation services in the province. Ideally the informal home-based carer should be:
 - involved in the discharge planning of the dependant
 - adequately prepared for the care-giving process
 - appropriately referred between the various levels of health service providers
 - able to overcome the challenges associated with caring for an elderly dependant in the home
 - adequately supported by the family and community
 - adequately supported by governmental (CHC staff) as well as non-governmental organizations (home-based workers)

As human-beings we know that the ideal rarely exists. It is therefore imperative that we consult with informal carers to gain a better understanding of their realities. This information could be of value to a number of role-players involved with the care and rehabilitation of individuals within communities, i.e.

- Departments of Health could ease the strain on formal health care services by recognizing and adequately preparing informal carers within the district health system.
- Managers of health care services could provide a continuum of care by involving informal carers in discharge planning.
- Educators of health care workers could sensitize professionals about the value of providing informal carers with knowledge and skills.
- Professionals could provide support to informal carers by sharing information and skills prior to the discharge of the dependant.
- Home-based care workers could train and support informal carers within their communities.
- Family and neighbours and friends could support the carer physically, emotionally, financially and in terms of respite care.

1.7. RESEARCH METHODOLOGY.

A qualitative research study was done using the grounded theory method to develop a substantive theory on informal caring. The method used, reflects Strauss and Corbin's version (1990, 1998) of grounded theory that deviates from the classic method described by Glaser and Strauss (1967). Based on the philosophical underpinning of symbolic interactionism, (Strauss & Corbin, 1990, 1998; Glaser & Strauss, 1967) grounded theory presented a social research method best suited for the exploration of social interaction. A detailed discussion of the qualitative research methodology including the grounded theory method is presented in Chapter Three.

The main characteristics of grounded theory were adhered to, namely, theoretical sensitivity gained by personal and professional experience as well as a preliminary literature review. The sampling of participants was purposive and data analysis closely followed data collection. Two tertiary hospitals were targeted to ensure the recruitment of carers from both the northern and southern suburbs of Cape Town. Data collection included the use of demographic questionnaires, open-ended interview schedules and the informal observation of participants. The data was transcribed verbatim and stored in a computer assisted data analysis programme (N. VIVO). The coding procedure introduced by Strauss and Corbin (1990, 1998) was used and memos written to keep track of the data analysis process. The N. VIVO programme facilitated the coding of transcripts, the retrieval of data and the linking of annotations and memos to the text.

However, at the conceptual level I chose to engage with the data in the traditional way by developing conceptual categories and linking those categories independent of computer assistance. Once again Strauss and Corbin (1990, 1998) provided guidelines to verify the emerging theory. The issue of rigor and ethical comportment is discussed in Chapter Three.

1.8. CHAPTER OUTLINE

Chapter 1: INTRODUCTION

In this chapter the reader is introduced to the concepts of care, informal care and rehabilitation. A contextual and theoretical background is given, highlighting the gaps in the provision of care and rehabilitation to the elderly, following their discharge from tertiary hospitals in Cape Town, South Africa. The motivation and specific reasons for embarking on an exploratory study is discussed. This is followed by a description of the research aims and objectives and a brief overview of the research methodology. An outline of the rest of the thesis is given.

Chapter 2: LITERATURE REVIEW

The study is located within the current academic debates on informal caring and community-based rehabilitation. The key concepts are clarified and a conceptual research framework developed for this study. The literature review was done in two phases. The first phase was aimed at developing theoretical sensitivity to the topic and was done prior to data collection. The second phase was done during data collection / analysis and was aimed at enhancing rigor with regard to the emerging theory.

Chapter 3: RESEARCH METHODOLOGY

Qualitative research methods were discussed in general and the grounded theory method in particular. Specific reasons for choosing this research methodology were provided. The philosophical underpinnings of the grounded theory method as well as issues of rigor and ethics were described. This was followed by a detailed discussion of the research design, i.e. sampling, research instruments, data collection and data analysis protocols. Data analysis was facilitated by the use of a computer assisted qualitative data analysis programme (N VIVO).

Chapter 4. RESEARCH OUTCOMES

The main research outcomes were presented in this Chapter. A detailed description of my previous experiences as an informal carer and nurse educator provided evidence of theoretical sensitivity. A brief overview of the demographic data was followed by a narrative description of the context of care.

The main thrust of the chapter was devoted to the categories that emerged from the data. These categories were linked in a storyline memo and the core category (basic social process) identified.

Chapter 5. DISCUSSION OF RESEARCH OUTCOMES

The main research outcomes were discussed in relation to current literature on the research topic; the conceptual framework; the debate on the position of informal carers in community based rehabilitation and their inclusion in the role-out of primary health care in the Western Cape, South Africa.

Chapter 6. CONCLUSIONS AND RECOMMENDATIONS

The relevance of the results was discussed with regard to practice implications. This included a description of the implications of the research outcomes for informal home-based carers, the elderly, educators and service providers. Recommendations were leveled at government departments, non-governmental organizations, community and faith-based organizations and the public at large.

1.9. CONCLUSION

In Chapter One, an orientated was given to locate the research study in the metropolitan area of Cape Town, South Africa. This was followed by a brief description of the diverse people of a country in the midst of change. Change with regard to a new political dispensation, the impact of HIV/AIDS on health profile of the citizens and the need for community-based rehabilitation within the new district health care system in the country. The aim and objectives of the

research study was described including, the research question, methodology, rationale and significance of the study. Finally an overview of the chapters was given.

In the next chapter a focused literature review exploring the key concepts of the study is presented. It should be noted that the conceptual framework was not used to drive the research process but rather to sensitize myself to the phenomenon of informal caring.



CHAPTER 2: LITERATURE REVIEW

2.1. INTRODUCTION

The initial literature search was aimed at exploring literature on various aspects of informal home-based care. This was followed by a search to locate informal home-based care within the CBR paradigm. The concept of CBR and the ongoing debates about the effectiveness of the strategy was explored. A conceptual framework was developed using generic, nursing and rehabilitation models and theories.

The literature search was one of the strategies used to enhance theoretical sensitivity. Theoretical sensitivity refers to the attributes of having insight, being able to understand and being capable to distinguish between relevant and irrelevant information (Strauss & Corbin, 1990: 42). The main review of literature was done to support the emerging theory.

This chapter is divided into the following sections under the headings:

- ❑ Informal home-based caring
- ❑ Rehabilitation and CBR
- ❑ Conceptual framework

2.2. INFORMAL HOME-BASED CARING.

2.2.1. INFORMAL CARE DEFINED

In research reports, the term informal home-based carer is used interchangeably with informal carer, family carer, caregiver or carer (Robinson, *et al.* 2005; Arksey, 2002; Kerr & Smith, 2001; McGarry & Arthur, 2001). In this study, the informal home-based carer refers to the person who provides care to an elderly person who is dependent in at least two activities of daily living. The informal home-based carer may or may not be related to the elderly and the care follows

hospital discharge to a home setting. In this research report the informal home-based carer will be referred to as the carer.

The concept informal carer lacks a clear analytical definition. According to Twigg, Atkin, & Perring (1990) it centres on the performance of tasks of a supportive nature, but implies elements of social or familial relationships. Twigg, *et al.* (1990) admit that it is difficult to distinguish between ordinary patterns of care and those related to dependency. There is, however, a perception by the carer and the broader society, that the carer takes some responsibility for attending to the needs of the dependant individual. This indicates a closer relationship between the dependant and the carer, than between dependant and close friends or neighbours (McGarry & Arthur, 2001; Mignor, 2000; Grunfield, Gossop, Mc Dowell & Danbrook 1997).

Procter, Wilcockson, Pearson & Allgar (2001) and Grunfield, *et al.* (1997) allege that family members who accept the role of informal carers are motivated by a moral commitment to the patient while Mignor (2000) found that many caregivers accepted the responsibility of care-giving because of a belief that it was their duty.

The WHO (2002d: 19) defined informal care as *care given by relatives and friends to disabled individuals*. Pijl (2003: 27) quotes two definitions of informal care used in Northern and Western European countries. In the United Kingdom informal carers are defined as:

people who look after a relative or friend who need support because of age, physical or learning disability, or illness, including mental illness,
and in the Netherlands, as:

persons who provide care, not in the context of a care profession, to someone who needs care in their direct circle of friends.

Pijl (2003: 27) claims that the term informal or family carer does not adequately describe the relationship between the carer and the recipient of care, or the

scope of carer's responsibilities. Even though the term *informal carer* is used to distinguish between these carers and the formal or professional health care providers, *informal*, may not be the most appropriate word to describe the scope of the care that they offer. In Joubert's study (2002) carers admit to spending up to ten hours per day on caring tasks. The term *family carer*, inevitably excludes neighbours, volunteers and friends, who, on occasion take on major caregiving responsibilities.

2.2.2. INFORMAL CARE IN DEVELOPED COUNTRIES

Researchers in developed countries acknowledge that family caregivers have become important members of the health care team (Bull, Maruyama & Luo, 1995; Houts, 1994; Naylor, 1990). Houts (1994) suggests that caregivers needed clear guidance from the health professionals in all respects of home-based care. Bull, *et al.* (1995) found that if carers were not included in the discharge planning of elders, the risk of readmission to the institution increased.

Smith, Lawrence, Kerr, Langhorne and Lees (2004: 235) found that carers lacked the knowledge and skills to care for stroke survivors within their homes in Scotland. They also found that carers were inadequately prepared for the caring role and recommended a public health campaign to educate and inform carers about stroke care. The experiences of carers were explored one year after the stroke occurred. This followed an earlier study by Kerr and Smith (2001: 428) in which they suggested that carers of stroke victims did not receive adequate preparation prior to hospital discharge. The physical and emotional toll on carers was great and the support services for carers were inadequate.

In a qualitative study on informal caring late in life McGarry and Arthur (2001:182) explored the needs of 14 older carers. They suggested that these carers have unique needs related to; the structure and demands of the caring relationship, support from informal and formal services and the constancy of caring. They recommended that nurses should play a key role in identifying older

carers and develop strategies to support them particularly during crises situations.

Robinson, *et al.* (2005: 563) proposed an intervention in a study on caring for carers ($n=14$) of people with stroke. They identified *loss of control* as the core category in a grounded theory study conducted six months after the stroke. Their intervention strategy focused on addressing the carers' loss of control, self-care, emotional and support issues. Carers' recommended that such intervention courses be offered prior to the hospital discharge.

Various studies focused on the needs of the carers, amongst others; information, educational, support and psychosocial needs of informal carers (Robinson, *et al.* 2005; Smith, *et al.* 2004; Morris & Thomas, 2002; Kerr & Smith, 2001; Mant, Carter, Wade & Winner, 1998; Wiles, Pain, Buckland & McLellan, 1998). In an article on informal carers and information, Morris and Thomas (2002: 183) proposed that the following topics be researched: understanding the information needs of carers in variable situations, ways of addressing carers needs, how carers "fit into" health care systems and how information sharing with carers could be improved.

While the needs of carers are being recognized in healthcare policy documents in the United Kingdom, informal carers of cancer patients have expressed significant unmet needs (Soothill, Morris, Harman, Francis, Thomas & McIlmurray, 2001: 464). Items of unmet needs clustered around, managing daily life, managing emotions and social identity. These carers also regarded the maintenance of good relationship with healthcare professionals and receiving honest information as important.

In a study done in Australia, O'Connell, Baker and Prosser (2003: 28) found that despite the initial uncertainty expressed by potential carers in acute hospital and community settings, limited information was given to them about their new role.

They suggested a multi-faceted approach, i.e. developing educational material, encouraging carers to maintain records of caregiving and providing support during the transition from the hospital to the community setting.

In an earlier study done in England, Wiles, *et al.* (1998: 794) explored the information needs of carers at three points post-stroke, i.e. during hospitalization, one month post-discharge and 2-12 months post discharge. They showed that the information needs of carers were not met and recommended that carers be provided with information packages and that information be individualized as far as possible.

In a qualitative study on the health and social needs of Asian informal carers, conducted in South Wales, Merrell, Kinsella, Murphy, Philpin and Ali (2005: 549), found that carers were not aware of the health and social services available to them and that the involvement from nursing and social services was inadequate. Their conclusion was that limited knowledge and skills of carers and the lack of support from formal health care services were unmet needs shared by carers.

Despite the acknowledgement of the value of informal or family carers in developed countries, researchers still show that carers experience a range of unmet needs. These include the need for information, skills development, emotional and social support and access to community resources. However the literature also shows that a number of intervention strategies have been offered to the informal carers to ease their burden of care (Robinson, *et al.* 2005; Mant, *et al.* 1998).

2.2.2. INFORMAL CARE IN DEVELOPING COUNTRIES

The paucity of local literature shows that research on informal care has not received much attention in South Africa. Joubert published the first demographic report on informal carers in 2005. A multi-stage stratified area cluster probability sample of 2704 persons was drawn from a nationally representative household

survey. Joubert (2005: vii) found that 27% of the adult population provided informal care to a range of dependent persons; that women were more likely to provide informal care and that the most extensive demand for informal care was in the provinces of Kwazulu-Natal, Gauteng, Limpopo and Mpumalanga.

In an earlier study, commissioned by the NGO, Age-in-Action, Joubert, Reddy, & Bryan (2002) found that the health conditions that lead to the need for informal care-giving in South Africa were physical disabilities, urinary incontinence and stroke; that one-quarter of the care recipients were bedridden; and that three-quarters could not make use of transport on their own.

The other local empirical studies focused on the informal care offered to people living with AIDS (Orner, 2006; Akintola, 2004). Orner's (2006) study explored the psycho-social needs of carers of PWA (people living with AIDS) in the Western Cape. The main outcomes indicate a lack of professional support and inadequate access to financial and material resources. However, the carers were satisfied with the support provided by home-based workers in their areas. Akintola, (2004) did a gendered analysis on the burden of care on family caregivers and volunteers of PWA in Kwazulu-Natal and found that caregiving undermined the well-being of families; that there is a need to recognize the effect that care-giving has on women and that home-based care should not be seen as the solution to the complex demand for care in this country.

Ndaba-Mbata & Seliolwe (2000: 218), in a qualitative study on home-based care of the terminally ill in Botswana, found that family carers lacked the knowledge and skills to provide appropriate care. The research outcomes, as expressed by informal carers within differing contexts of care in African studies, resemble those expressed by carers of stroke survivors in developed countries.

In South Africa, home-based services were traditionally provided by non-governmental service organizations for the elderly and terminally ill. These

organizations include Age in Action, the Cancer Association of South Africa, Hospice and Palliative Care Association of South Africa and other community- and faith-based organizations. The restructuring of home-based services, which started in the early 1990's, has been inadequately documented. The Department of Health's National Guidelines on Home-based Care / Community-based Care, issued in 2001, defines home-based care 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 dignified death

The guideline's objectives included amongst others, ensuring a functional referral system, shifting the emphasis of care to the community and empowering carers through appropriate targeted education and training at home (Department of Health, 2001: 8). Since the objectives of the Department of Health's National guidelines on home-based care coincide with the research objectives of this study, the experiences of participants regarding the appropriateness of the education and training are described in Chapter Four.

The national government provides financial support, namely an older persons grant, to women over the age of sixty and men over the age of sixty-five (Social Assistance Act, 2004). A person is also eligible for a grant-in-aid, if that person is in a physical or mental condition that requires attendance by another person. Unfortunately, informal carers do not qualify for any financial assistance from the government and many of them are not able to accept full-time employment. Joubert (2005: 108) found that generally, low income, informal employment and unemployment were associated with a higher prevalence of informal caregiving. It was, however, not conclusive from the study whether people were carers because of unemployment or whether they were unemployed because of the extent of the caring tasks.

In South Africa a District nurse attached to a Primary Health care facility traditionally assisted the informal carers with the performance of their tasks. However, with the retrenchment of staff and reorganization of the health care system, nurses are, in most instances, not able to attend to the needs of these carers. Hence, the need for the appropriate deployment of home-based workers, who, according to the National guidelines, would provide targeted education and training to the carers within the home setting (Department of Health, 2001: 8).

The research outcomes of the studies published during the time that I was collecting and analyzing research data were primarily used to validate the emerging theory of my study. The specific links between the literature and emerging theory are described in Chapter Five.

2.3. REHABILITATION AND CBR.

One of the research objectives is to describe informal carers experiences with regard to the rehabilitation of the elderly. Locally, the involvement of carers in the rehabilitation of patients following hospital discharge has not been documented. Ten years ago the government proposed that community-based rehabilitation (CBR) form the basis of the national rehabilitation strategy (Office of the Deputy President, 1997). It is important to determine whether carers' experiences attest to this. The government recognized the need for home-based care as part of a CBR strategy, but is unable to train enough home-based care workers to serve the citizens of the country (Uys, 2006).

In 1976 the WHO recommended that the CBR strategy be implemented to serve the rehabilitation needs of people in developing countries (WHO, 1976). The primary tenet of CBR is to provide primary care and rehabilitation assistance to people within their own communities. It is a service strategy aimed at involving the community in the rehabilitation of its members. Mitchell (1999: 523) states that the most effective method of implementing this service strategy is to ensure that an integrated national, provincial and district CBR policy is in place.

According to Mitchell (1999: 524) the following conditions will facilitate the implementation of CBR, i.e. community leaders and organizations that support the programme, the availability of a cadre of community workers and referral services that provide basic appliances and equipment.

The ideal would be that at national level all the Ministries involved in rehabilitation, would co-ordinate the overall planning of a CBR programme. These Ministries include, amongst others, the Ministries of Health, Social Development, Housing, Public Roads and Education. It was also suggested by Mitchell (1999: 526) that specialized services be located at specific centers within districts, e.g. rehabilitation services for people with amputations or people living with stroke. Such service centers would avoid duplication in terms of equipment and the training of staff.

Ideally, the implementation of CBR is monitored at provincial level. An important monitoring task is to train and supervise rehabilitation or home-based workers. Currently, the provincial government, NGOs and various other service providers in the Western Cape are training home-based carers. It is not clear whether the basic training of home-based carers at such diverse sites, include the development of specialized rehabilitation skills.

At district or community level, the assumption is that policy should direct the allocation of resources, technology and materials. Mitchell (1999: 526) states, within a CBR programme the district is the key point in the delivery of rehabilitation services. My research study was located at this level, as a characteristic feature of CBR is the involvement of the family and community in the rehabilitation of its members.

Some of the most recent research studies on CBR looked at viable methods of evaluating CBR programmes (Sharma, 2004) and ethical issues regarding CBR initiatives in developing countries (Turmusani, Vreede & Wirz, 2002). Sharma

explored various research methods, provided examples of where the methods were used, and recommended that a combination of qualitative and quantitative methods would be the most appropriate way to evaluate the programmes. Some of the examples quoted in Sharma's article are presented in brief. In a collective case study of ten evaluation efforts of CBR programmes, Wirz and Thomas (in Sharma, 2004: 328) found that there were few indicators to measure the effectiveness of the programmes. Kuipers, Kendall and Hancock (in Sharma, 2004: 330) discovered that by using participatory, rural appraisal in a CBR project, decision-making skills of community members were improved.

Turmusani, *et al.* (2002: 559) after reviewing recent research literature on CBR initiatives in developing countries, state that CBR has been under scrutiny regarding its cost effectiveness and appropriateness for rehabilitation programmes in these countries. The reasons for programmes failing included, non-participation by communities and the perception that CBR is an outreach project initiated by external funders. Another critique was that the initiators of these CBR programmes do not take the local cultural practices of communities into consideration. An example quoted was the failure of a CBR programme transposed from Norway to Botswana (Turmusani, *et al.* 2002: 561).

The type of support received by informal carers from family members, the community and the formal health care professionals, is described in Chapter Four.

2.4. CONCEPTUAL FRAMEWORK

The conceptual framework incorporated concepts of theories from various disciplines, amongst others, generic theories, nursing theories and theories on rehabilitation. These concepts refer to the needs and actions of a person (informal home-based carer) in relation to another person (elderly dependant) within a changing environment (transition from hospital to home). The framework

was created to show these relationships and to illustrate the transition from hospital to home (Fig 2.1).

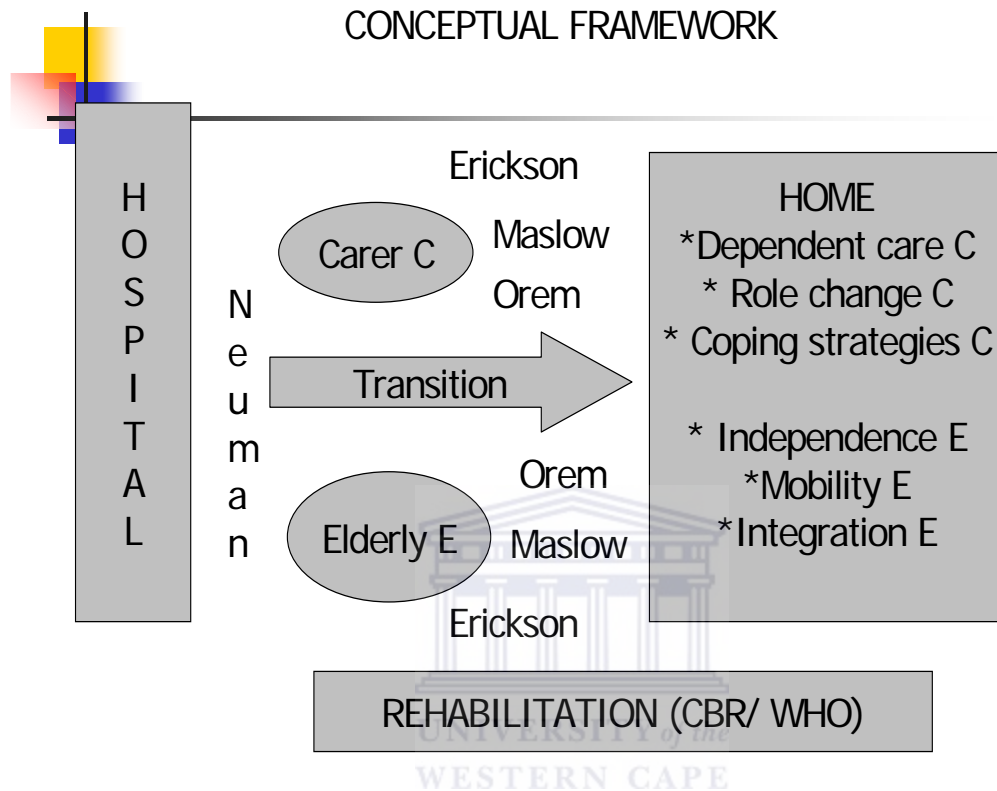


Figure 2.1: Conceptual Framework created for the study

The following theories and models was included in the framework:

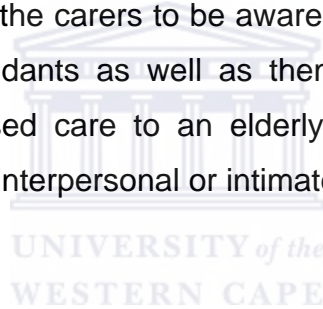
- Maslow's hierarchy of needs
- Ericksons theory on social growth and development
- Neuman's systems model
- Orem's theory on self-care and dependant-care
- The WHO's model on societal functioning
- Community-based rehabilitation model

2.4.1. GENERIC THEORIES

The research is aimed at exploring experiences of individuals in a caring relationship. The demographic data sketched who the participants were but their human needs were reflected within Maslow's hierarchy of needs (in Fontaine & Fletcher, 1995). The study determined how the caring process impacted the basic and meta-needs of the informal carer.

In Erickson's theory on social growth and development he states that every person passes through eight developmental stages and that each stage has specific tasks that a person must accomplish (in Fontaine & Fletcher, 1995). Elderly dependants would be in a stage of maturity where they would display an acceptance of life and death.

It would be in the interest of the carers to be aware of the psycho-social stage of development of their dependants as well as themselves. A young adult who provides informal home-based care to an elderly dependant may experience difficulty in developing other interpersonal or intimate relationships.



2.4.2. NURSING THEORIES

Neuman's health care systems model (in George, 2002: 339) gives a multi-dimensional view of individuals, groups (families) and communities in constant interaction with the environment. A major focus of this model is the assessment of environmental stressors. Shyu (2000: 621) found that *role tuning* emerged as a major concept in a study of the needs of family caregivers. *Role tuning* refers to the interpersonal stressors related to role expectations between the carer and dependant. One of the objectives of this research study is to explore the challenges faced by carers during the care-giving process.

In Orem's, dependent-care theory she states that the physical, psychological, interpersonal and social aspects of health are inseparable in the individual (Orem, 1985). Orem suggests that adults take care of themselves and that a

socially dependent person, the elderly, need varying degrees of assistance. It means that adults have to assist elderly dependants with self-care activities. These activities include basic needs, developmental needs and needs related to disease or impairment.

The following highlights the need for an adaptation of Orem's model with regard to informal home-based care of elderly dependants in this country. Orem (1985) states that healthy adults are in a state of total self-care. In South Africa there is a rapid decline in the number of healthy adults as a result of chronic disease (Draft Provincial Health Plan, 1995) and young adults dying of HIV/AIDS related disease. Socio-economic factors such as homelessness, joblessness and crime further impact on the health of the adult population (Provincial Government of the Western Cape, 2000).

As a result of the above-mentioned factors, adults may not be able to care for their elderly dependants. In some instances, following the death of both parents, the head of the household may be a child who has the added responsibility of caring for an elderly dependant.

For the purposes of this study any appropriately trained health worker may provide the assistance required by the elderly dependant. It is however, outside the scope of this study to investigate the roles of health workers other than the informal home-based carer.

2.4.3. REHABILITATION THEORIES

The WHO (1980) proposed a handicap-based model, based on the assessment of six dimensions of societal function. Concepts from this model will allow me to peg the difficulties the elderly dependant may experience with regard to societal functioning. The six dimensions include: physical independence, mobility, occupation, social re-integration, orientation and economic self-sufficiency. The

informal carer is expected to assist the dependant in attaining the optimum level of function within society.

The Community-based Rehabilitation model refers to a service strategy based on diversity and flexibility and aimed at involving the community in the rehabilitation of its members (Hartley, 2001). This model will allow me to establish the level of involvement of the community in the rehabilitation process. CBR as a service strategy was discussed in this chapter (see 2.3).

2.5. CONCLUSION

The literature presented in this chapter was reviewed throughout the duration of the research study. I used the initial literature search to sensitize myself to some of the concepts included in the research question. However, the founders of the grounded theory method cautioned against an extensive literature search prior to conducting the study as it may distract the emergence of substantive theory (Strauss and Corbin, 1990, 1998).

The literature was primarily used as research data to enhance the credibility of the research outcomes. Current research findings were compared to the basic social process as well as the emerging categories in Chapters Four and Five.

CHAPTER 3: RESEARCH METHODOLOGY

3.1. INTRODUCTION

In this chapter the literature review on the research methodology is presented. The qualitative research methodology is discussed in general with a particular focus on the grounded theory method. The theoretical underpinnings of the grounded theory method and concerns of trustworthiness and the ethical implications of the method are described. The research design is described including the research instruments, sampling criteria and techniques, data collection and data analysis.

The chapter has thus been divided into three sections under the headings:

- Research paradigms
- Philosophical underpinning and trustworthiness
- The research design

3.2. SOCIAL RESEARCH PARADIGMS

In this section an overview is given of the main approaches to social science research. The research approach best suited for my study was an interpretive approach and the methodology, the grounded theory method.

3.2.1. RESEARCH PARADIGMS

A paradigm is defined as a basic set of beliefs that guide action (Denzin & Lincoln, 1998:185). Paradigms are human constructions and include three basic elements, i.e. ontology, epistemology and methodology. Ontology refers to the nature of social reality, that is, how humans view the world. Denzin and Lincoln (1998: 185) question, whether humans see the world as a stable place driven by laws (positivist view) or as a fluid place, constituted of multiple social realities (interpretive view). They explain that epistemology gives an indication about the relationship between researcher and the researched. Positivists see this

relationship as objective and one that is based on the precise observations of how things really work. While interpretives, hold the subjective view that during any investigation there is an interaction between the researcher and the researched. Methodology refers to how the researchers would go about doing the research. The methodologies chosen by positivist researchers are experimental and manipulative and aimed at the verification of hypotheses. Interpretive methodologies are dialectical and aimed at the reconstruction of previously held constructions (Denzin & Lincoln, 1998:185).

Neuman (2003: 91) and Guba and Lincoln (in Denzin & Lincoln 1998: 203), provide prospective researchers with useful summaries depicting the major approaches (paradigms) to social research (Figure 3.1).

	Positivism	Interpretive social science	Critical social science
Reason for research	To discover natural laws so people can predict events	To understand and describe meaningful social action	To smash myths and empower people to change society
Nature of human beings	Self interested and rational individuals (Analytical)	Social beings who create meaning in their worlds (Constructivism)	Creative adaptive people with un-realized potential (Critical Theory)
Nature of social reality / How do we know the world <i>Ontology</i>	Stable pre-existing patterns Realism	Fluid definitions of a situation created by human interaction Relativism	Conflict filled and governed by hidden structures Historical realism
Good evidence / Relationship between researcher & researched <i>Epistemology</i>	Based on precise observations that can be repeated - Objectivist	Embedded in the context of fluid social interaction -Subjectivist	Informed by theory that unveils illusions – Transactional / Subjectivist
How to go about doing the research <i>Methodology</i>	Experimental, Manipulative & verification	Hermeneutical / Dialogical	Dialogical / dialectical

Figure 3.1: Research Paradigms adapted from Neuman, (2003) and Guba and Lincoln (in Denzin & Lincoln, 1998)

From this summary it is clear that the choice of methodology would be based on the purpose of the research and the researcher's view of the nature of human beings and social reality.

Positivism is the approach that is widely used by natural scientists doing quantitative research. *Positivism* in social sciences was first used by a Frenchman, Comte (1798 –1857) the founder of Sociology as a field of study. Researchers who adopt a *positivist* approach deduce hypotheses from a general theory (in the form of causal statements or predictions) gather data and use statistical means to test the theory 's predictions (Neuman, 2003: 90).

Positivism sees social science as an

organized method for combining deductive logic with precise empirical behaviour in order to discover and confirm a set of probabilistic causal laws that can be used to predict general patterns of human activity.
(Neuman, 2003:71)

Neuman's definition points to the clinical observation of human behaviour that is predictable and guided by laws of cause and effect. Such an approach would not have served the purpose of my research study that was exploratory in nature and aimed to describe human behaviour within a specific context. According to McCann and Clark (2003: 23) the classical grounded theory method described by Glaser and Strauss (1967) took more of a positivistic stance than that of Strauss and Corbin (1990, 1998).

Interpretive social scientists criticize positivists for not dealing with the meanings that real people attach to experiences; for not acknowledging that people have the capacity to think and reason and for ignoring that peoples' experiences are shaped by social context (Neuman, 2003:76)

Interpretive social science research, a second methodological approach to social science research can be traced to Max Weber (1864 – 1920) a German sociologist who argued that social science needed to study *meaningful social action*, or social action with a purpose. Interpretive social science is associated with the philosophy of symbolic interactionism that embraces the concept of meaningful interaction. Qualitative researchers doing, amongst others: phenomenological or grounded theory research, use the interpretive approach to social science research (Neuman, 2003). Neuman defines the interpretive approach as:

the systematic analysis of socially meaningful action through the direct detailed observation of people in natural settings in order to arrive at understandings and interpretations of how people create and maintain their social worlds (2003: 76)

The interpretive paradigm is based on the premise that human beings create meaning in their worlds and that the meaning is constructed as a result of interaction with others. The qualitative methods of observation and dialogue were used to obtain research data in my study, which implied a subjectivist relationship between participants and myself.

The critical social scientists criticize positivists as being narrow, and non-humanistic while they regard interpretive social scientists as being too subjective and relativist (Neuman, 2003: 81).

Critical social science, a third methodological approach to social science research support the interpretative approach to a degree, but differs on some fundamental issues. Its roots can be traced back to Karl Marx (1818 –1883) and Sigmund Freud (1856 – 1939) and is associated with conflict theory. The critical

social scientists are action orientated and aim to change the world by exposing discrimination and inequity. Neuman defines critical social science as:

a critical process of inquiry that goes beyond the surface illusions to uncover the real structures in the material world in order to help people change the conditions and build a better world for themselves (2003: 81).

Community or political organizations use the critical social science approach to question social structures, uncover underlying social dynamics and propose transformation.

Feminist and postmodern research approaches are relatively new and share the views of critical social science paradigms in their criticism of positivist and interpretive approaches.

3.2.2. QUALITATIVE RESEARCH

From the above discussion of research paradigms, the approach that best suited my research study was an interpretive one. The interpretive paradigm assumes amongst others:

- that the world is fluid in nature and the result of multiple social realities
- that during any investigation there is an interaction between the researcher and the researched and
- that scientific inquiry is aimed at the reconstruction of previously held constructions.

The positivistic paradigm, best suited for quantitative research studies differ fundamentally from that of an interpretive paradigm used in qualitative studies. Many qualitative researchers have described these differences (Patton, 2002; Denzin & Lincoln, 1998; Guba & Lincoln, 1985). The differences include the flexibility of the research design, which means that in the case of qualitative

studies, the design unfolds as the fieldwork proceeds. This implies that the sample size is determined by research outcomes.

Qualitative research is done in the field and not in controlled experimental settings. However, Patton (2002: 42) cautions that the distinction is not as simple as being in the field or being in a laboratory since a range of approaches fall along a continuum with open fieldwork on one end and controlled laboratory work on the other end. In qualitative research the context in which the research is done is described in detail and constitutes important research data. Different standards of rigor, trustworthiness and ethical behavior apply to qualitative and quantitative research studies.

While the interpretive paradigm aims to discover meaning and promote an understanding of that which is being investigated, the emphasis within the different qualitative approaches vary. In phenomenological approaches the emphasis is on language while in the grounded theory method the emphasis is on context (Lowenberg, 1993: 57).

Patton (2002: 40) identifies various themes for qualitative enquiry, which include, naturalistic enquiry, purposive theoretical sampling, direct personal experience and engagement, empathetic neutrality, context sensitivity and triangulated enquiry. These themes served as a checklist to evaluate the appropriateness of the research method used in this study, and is described in Chapter Five (5.2).

3.2.3. GROUNDED THEORY RESEARCH – THE ORIGIN

Glaser and Strauss developed the grounded theory method in 1967. The theoretical orientation they held was that theories should be grounded in field data to reflect the actions, interactions and social processes of people. They stated that grounded theory is derived from data and then illustrated by characteristic examples of data and that the usefulness of such a theory lies in,

amongst others, how it was generated, its clarity, density, scope, integration and fit (Glaser & Strauss, 1967: 5).

Glaser and Strauss, both sociologists, but from different schools of thought, brought different perspectives to their publication *The discovery of Grounded theory* in 1967. In their book they presented qualitative researchers with an alternative approach to theory generation. A theory that would fit empirical situations and would be understood by academics and lay-people alike. Glaser & Strauss described grounded theory research as, *an initial, systematic discovery of the theory from the data of social research* (1967: 3).

In 1990 Strauss, joined forces with a nurse researcher, Corbin and wrote *Basics of Qualitative research*, aimed to provide prospective researchers with practical methodological guidelines. Some of the analytical tools suggested by them drew criticism from followers of what Ansell (1997a: 122), referred to as classic grounded theory researchers. Glaser leveled much of the critique to Strauss and Corbin's *Basics of Qualitative Research*, in his publication *Basics of grounded theory analysis* (1992). Glaser criticized Strauss and Corbin for proposing the paradigm model to establish links between categories, as a model could impact the emergence of grounded theory. A second critique was leveled at the use of the conditional matrix as an analytical tool. Classic grounded theory is underpinned by symbolic interactionism, which looks at the individual in society. Strauss and Corbin (1990: 175) suggested that the conditional matrix allows the researcher to capture all the conditions and consequences that may impact the social interaction under investigation. The social interaction is explored beyond the individual in society to the macro-social issues that may influence the basic social process. In the application of the grounded theory method, some of the conditions and consequences are related to issues beyond the individual in society, e.g. national politics, religion and culture. The conditional matrix is described in Chapter Four (4.3.2.).

McCann and Clark (2003: 23) describe epistemological and methodological differences between Glaser's (1967) and Strauss and Corbin's (1990, 1998) approaches to grounded theory. According to McCann and Clark, Glaser followed a more positivistic epistemology than Strauss and Corbin. Glaser also viewed the researcher's role as independent to that of the researched, whereas Strauss and Corbin suggested an active and dialectic interaction between the researcher and the researched. McCann and Clark further describe the methodological difference of, Glaser's unassisted emergence of theory during data analysis, to the analytical rules and procedures proposed by Strauss and Corbin.

This academic debate reinforced my decision to choose the approach described by Strauss and Corbin (1990, 1998) and not to mix research methods.

3.2.4. GROUNDED THEORY RESEARCH – THE METHOD

Grounded theory research focuses on the generation of theory with the emphasis on inductive strategies of theory development. Inductive analysis involves the generation of categories and themes from research data. Findings emerge through the researcher's interaction with the data. Sampling, data collection and analysis occur simultaneously (Patton, 2002: 453). In contrast, by using deductive analysis the researcher uses an existing framework to analyze data.

Creswell (1998: 56) suggest that rigorous enquiry, systematic procedures and specific methods underlie the generation of grounded theory. He emphasizes that the theory should relate to the phenomenon (informal caring) being studied in its unique context, clarify the concepts or categories that emerge during the analysis of data and indicate the relationship between the concepts.

Annells (1997b: 176) describe the essential elements in any grounded theory study as amongst others, constant comparative data analysis, theoretical

sampling and sensitivity, theoretical saturation and the identification of a core category. She traced these elements to the original work of Glaser and Strauss (1967) and Strauss and Corbin (1990).

The value of grounded theory lies in its contribution to areas in which little research has been done (Chenitz & Swanson, 1986: 7). Much research has been published on the experiences, needs and interventions to support informal carers. However, a gap existed in literature regarding the involvement of informal carers in the rehabilitation of their dependants. Grounded theory therefore was a suitable method to use for my exploratory research study.

Stern, (1994) cautions that grounded theory should only be undertaken if a suitable mentor is able to guide the novice researcher. Fortunately for me, a researcher who had recently completed a grounded theory study in nursing science, herself having been mentored by an experienced grounded theorist, was identified. Monthly mentoring meetings were scheduled with her during the data analysis phase of the research study. The mentoring entailed a discussion of the process of data analysis in grounded theory research, verification of the coding process, linking of emerging categories and developing a story-line memo.

3.2.5. GROUNDED THEORY RESEARCH – THE METHOD OF CHOICE

Upon reflection I was very excited when I first read about the grounded theory method whilst exploring an appropriate research approach for postgraduate studies back in 1994. The grounded theory study that I have done at masters level entailed amongst others, purposive sampling, constant comparative data analysis but stopped short of theory generation. During the preparatory reading for my doctoral studies in 2001, I discovered that grounded theory presents the researcher with more of a challenge than an exploratory, descriptive qualitative study would. It challenged the researcher to move beyond the thematic analysis of qualitative research data, to a level of theory generation.

I have a fascination with the study of the individual in society. At under-graduate level I was the only nursing student in my group who chose to major in sociology instead of psychology. I was always interested in the effect of social circumstance in the causation of disease and the subsequent management of health problems. I wondered about the impact of prior experience on the burden of care in an informal caring situation. At post-graduate level my interest shifted to cognitive education. I wanted to explore how students think, reason and solve problems and how students experienced the same clinical situation and made different clinical judgements based on academic, clinical and other lived experiences. The grounded theory method matched my academic interest about the experiences of the individual in society and academic awareness of the value of inductive thinking processes.

I identified with the nurse researchers who expressed the value of theory generation of grounded theory research (Kendall, 1999; Annel, 1997b; Strauss & Corbin, 1990, 1998). I could also appreciate the analytical tools provided by Strauss and Corbin (1990) to facilitate the implementation of the method. The only real constraint I experienced at the time was the availability of mentors in grounded theory research.

The grounded theory method provided the most appropriate way *to explore the experiences of informal home-based carers ... across different social groupings*. It allowed for the exploration of a research area in which little research has been done (Chenitz & Swanson, 1986: 7). The grounded theory method uses an interpretive social research approach, which is generally used in exploratory social research.

The clear philosophical underpinning and methodological guidelines proposed by the founders and followers of the grounded theory method provided much needed structure to a novice researcher. I did, however, have a few false starts

but having had to re-do much of the coding and conceptual analysis I had unwittingly strengthened my understanding of the research process.

Studies about caregivers, informal carers and family carers have used grounded theory as a research method (Robinson, *et al.* 2005; Shyu, 2000). To join the academic discussion about the experiences of these groups I decided to use similar methods of enquiry.

3.3. PHILOSOPHICAL UNDERPINNING, RIGOR AND ETHICS

3.3.1. PHILOSOPHICAL UNDERPINNING

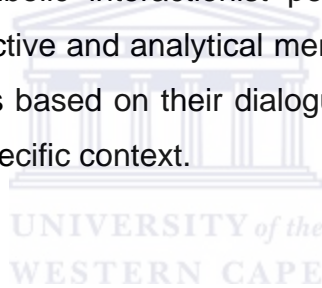
Symbolic interactionism is the philosophical underpinning of grounded theory research. Symbolic interactionism is both a theory about human behaviour and an approach to the investigation of human conduct and group behaviour (Annells, 1996: 381).

George Herbert Mead, a social psychologist, postulated that it is in social interaction, that the individual achieves a sense of self. It is the capacity of seeing the self from the perspective of others that allows the individual to hold the concept of self (Mead, 1934). It is through interaction with others that one develops a sense of one's roles in society. Herbert Blumer, a scholar of Mead, elaborated on symbolic interactionism by identifying three basic premises to the philosophy. The first is that human beings act toward things on the basis of what the things mean to them. These things may be objects, symbols or the actions of other human beings. The second is that the meaning of such things is derived from social interaction with others. The last is that, following such an encounter, the person uses an interpretive process to modify the meaning of the things (Blumer, 1969: 2). In short, the key concepts of the philosophy of symbolic interactionism are; that the self is unique to human beings, that meaning is created by experience and that human behaviour is a result of an interpretive process.

The symbolic interactionist perspective therefore has certain implications for the grounded theory researchers, as they have to:

- investigate human interaction and describe the interaction within a natural setting to illustrate the meaning held by participants within the setting.
- aim to understand the behaviour of participants from the perspective of the participant. This implied that the researcher inevitably become both participant and observer in the world of the participant.
- be able to interpret the interaction of the participants and translate it into a meaningful research report (Chenitz & Swanson, 1986: 6)

The application of the symbolic interactionist perspective was demonstrated throughout my study in reflective and analytical memos. The interpretation of the participants' interactions was based on their dialogue and the direct observation of their behaviour within a specific context.



3.3.2. RIGOR IN GROUNDED THEORY RESEARCH.

The founders of the grounded theory method used different terminology to describe rigor in the application of the methodology. Glaser focused on the emerging theory and identified four criteria for evaluating theory (1978, 1992). These included: fit – the categories should relate to the data; work – the theory should have an explanatory power; relevance – the researcher allows the theory to emerge from the data without imposing preconceived ideas on the data; modifiability – the theory should be adaptable to changing social circumstance.

Strauss and Corbin (1990, 1998) did not identify specific canons for grounded theory research. Instead they referred to existing standards as advocated by other qualitative researchers. They did however outline criteria for evaluating the research process and criteria for evaluating the empirical grounding of the study.

They suggest that to evaluate the research process, researchers have to specify amongst others; how the original sample was selected, how theoretical sampling was done, what major categories emerged, how these categories were linked and how the core category (basic social process) was selected. To evaluate the empirical grounding of the study, researchers have to indicate how the concepts (generated via coding) are grounded in the data, how the concepts are related, how the dimensions of the concepts have been explored and whether the findings are significant and have explanatory power (Strauss & Corbin, 1990: 249). These criteria are used to self assess the research process and grounding of the research study in Chapter Five.

Chiovitti and Piran (2003: 430) suggest that grounded theory researchers employ practical procedures to enhance standards of rigor in their research. They define rigor as the credibility, auditability and fittingness of the research study. Credibility relates to the trustworthiness of the study; auditability to the ability of another researcher to follow the research process of the primary researcher and fittingness or transferability to the likelihood that the research findings will have meaning to others in the same situation. A brief description of the methods will be presented but a detailed account of how the procedures were realized during the study will be done in Chapter Five.

3.3.2.1. Credibility

According to Chiovitti and Piran (2003: 430) the credibility of the study is enhanced by letting the participants guide the research process and by using the actual words of the participants in the theory. Anecdotes from interview transcripts are used to substantiate the research outcomes. In addition, participants' statements serve as cues for purposive sampling.

It is also important to clarify the participants' as well as the researcher's own views, opinions and understanding of certain events. These perceptions and opinions could be presented as memos or notes. To further enhance the

credibility of the study, the researcher could indicate where and how literature was used throughout the research process.

During the data analysis phase, the original digital recordings as well as interview transcripts should be available for the purposes of verification by research mentors and supervisors. More than one source of evidence, i.e. questionnaires, interviews and field notes was used during my research study. Triangulation added to rigor and improved the credibility of the data and an independent grounded theory mentor verified the data analysis process.

3.3.2.2. Auditability

To account for auditability of the research study, the researcher should specify how and why certain decisions were made, for example, the selection of research participants. The researcher should also make an effort to present a clear audit trail throughout the analysis process. This can be achieved by transparent analytical and conceptual reasoning, identification of codes, grouping of codes into categories and in linking emerging categories to the basic social process (Chiovitti & Piran, 2003: 430). In essence, it is important to present the reader with a detailed decision trail.

3.3.2.3. Fittingness

To enhance fittingness in grounded theory research, it is important to identify the level of theory generated. A research study should aim at developing substantive theory that evolves from the study of the phenomenon, such as informal caring, within a specific situational context (Strauss and Corbin, 1990: 174). To further enhance fittingness, the literature should be related to each of the categories that emerge in the theory (Chiovitti & Piran, 2003: 430).

3.3.3. ETHICAL COMPORIMENT

Researchers have an ethical obligation to describe the experiences of the participants in the most faithful way possible (Munhall & Boyd, 1993: 403). This statement and the three ethical principles described by Brink (1996: 39), i.e.

respect for persons, beneficence and justice, present researchers with clear guidelines to conduct and report the research study in an ethically sound way. It is, however, important to reflect on how this is achieved throughout the different phases in the research process.

3.3.3.1 Planning Phase

During the planning phase the proposal was presented and approved by the ethics committee of the University of the Western Cape. The research plan included details about, amongst others, the identification of research sites and samples, informed consent, ethical conduct during data collection, data storage and data analysis as well as an indication of how data would be disseminated. I even had to clarify the planned management of ethical dilemmas, e.g. the therapeutic imperative versus the research imperative. The ethics committee presented me with an ethics clearance letter that I used to gain entry to the two health facilities. I applied for and was given permission by the Medical Superintendents of the hospitals to conduct research within their health care facilities (Appendix: 6). I was also permitted to meet with the Head Nurses of the hospitals to explain the nature of the planned research. I presented the research proposal to nursing teams at both facilities and was introduced to individual registered nurses with whom I had to collaborate during the participant sampling phase. This was a time consuming but necessary process to ensure ethical entry to the research sites. Further challenges during this phase are described in 3.5.1.

3.3.3.2. The Recruitment Phase

The planning phase was followed by the recruitment of participants. Once a participant, who complied with all the sample criteria, was identified, I met with the elderly patient in the hospital and asked permission to contact the potential carer. Most of the time, I scheduled to meet the carer at their convenience. Occasionally, where the potential carer had not been identified at that stage I met with the closest relative who visited the elderly patient. During these meetings I explained the aim and objectives of the research study as summarized in the letter of consent (Appendix: 5). Once the carers were identified, they were briefed

about the purpose of the research study and invited to ask questions for the purpose of clarity.

After informing them about their rights, participants were asked to sign the letter of consent. Occasionally the carers requested permission to discuss their participation with other family members prior to signing. I then made telephonic contact to ascertain their response. Participation was voluntary and uncoerced and only one carer refused to participate in the research study because she was, *not interested in any type of research study*. A number of potential participants were excluded because their elderly relatives were admitted to a step-down facility in Cape Town.

(Munhall & Boyd, 1993) suggested that informed process consent be obtained from participants. This means that consent was re-negotiated in some of the cases. This happened in cases where the role of primary carer changed from, the elderly's granddaughter to the elderly's daughter. On two occasions, where the elderly suffered moderate strokes and were cognitively impaired, the family gave consent.

3.3.3.3. The Data Collection, Capturing and Analysis Phase

During the data collection phase some of the carers voiced their concern about the possibility of me sharing sensitive information with the elderly person. I had to, on more than one occasion, re-assure carers and explain the confidentiality clause in the consent form. In addition, I explained the issue of anonymity and the freedom to withdraw from the research process during contacts with participants. During the fieldwork phase, it was also important to strike a balance between not imposing on and being too detached from the participants. When I met with the participants in their homes I made a conscious attempt to gain their trust. Fortunately, fifteen years of clinical nursing experience provided me with the skills to foster a relationship of mutual trust and respect with participants from all walks of life.

What I found trying was the participants' need for professional counseling. This refers to the ethical dilemma that Munhall and Boyd (1993: 403) alluded to, i.e. the need for professional intervention. I did intervene on a specific occasion where the participant did not attend a follow-up appointment because of a lack of funds. This discovery happened during the third and final contact with the carer. I chose to intervene by scheduling an outpatient appointment and arranging contract transport to collect the elderly and carer, from their residential address. The decision to intervene was based on an ethical obligation to the well being of the elderly person. Even though there was no monetary gain for participating in the study, I scheduled some dedicated time at the end of the final contact to offer professional advice.

I asked the participants' permission to digitally record the interviews and used their names during these recordings. During the transcription of the interviews the names were replaced by a single letter, e.g. Mrs. Hendricks would be transcribed in text, as Mrs. H.

Data was transferred from digital tape recordings onto a personal computer and participants were allocated numbers (Resp: 09) during the data capturing process. A master list that provided the link between the names of the participants and participant numbers was stored in a secure location.

3.3.3.4. The Reporting Phase

It is important to maintain anonymity during the reporting phase. Referring to participants as (Resp: 05) or (Resp: 14) brought an impersonal perspective to the research outcomes. However, the remoteness of the data faded when their stories were related and the context of care sketched. References to race and gender were only done when it impacted on the interpretation of the research outcomes.

Participants were informed that the outcomes would be reported in, e.g. research publications and conference presentations. An annual presentation of the status of the research process to colleagues allowed for immediate constructive feedback and for the clarification of, for example, provisional research findings. These seminars, as well as evaluation sessions with research experts from the National Research Foundation, accounted for the worthiness of the project (Miles & Huberman, 1994).

3.4. RESEARCH DESIGN

3.4.1. SELECTION OF RESEARCH SAMPLE

The aim of this study was to explore the experiences of informal carers during the transition of their elderly dependants from hospital to home, within the home and across different social groupings. In addition, I wished to explore the involvement of the carers in the rehabilitation process. During the sampling process the main criteria for inclusion was that the carer provided care to an elderly person following their discharge from a formal health facility, such as a tertiary hospital.

A small sample size of eighteen participants (informal carers) was selected. Brink (2000: 142) suggested that the trend was to select 20 – 30 subjects for a qualitative study since too many subjects could complicate the data analysis process. Burns and Grove (2001: 376) stated that the researcher, using insights gained from the initial data collection might seek subjects with particular characteristics.

The carers of elderly dependants, discharged from tertiary hospitals were targeted to fully explore the following issues, which formed the basis of the open-ended interview questions used during the data collection process:

- at what stage did the informal carer become involved in the caring / rehabilitation process?

- were informal carers involved with the discharge planning of the elderly?
- what type of training and support was available to the informal carer prior to assuming the role and responsibilities of rehabilitating the elderly?
- to what extent were trained home-based carers involved in the rehabilitation of the elderly?
- what recourse was available to informal carer in the event of problems concerning aspects of care and rehabilitation?
- did informal carers see their role solely as carers or did they have insight into their responsibility regarding the rehabilitation of the elderly?

I was of the opinion that if an exclusively community-based sample was used, the exploration of the phenomenon of informal caring may have been incomplete regarding, e.g. the choosing of carers, their participation in the discharge planning of the elderly and their preparation to care. Hoeman (1996: 118) stated that it is important to establish whether the carer participated in the hospital discharge planning of the dependant as it may impact the caregiving in the home.

The Western Cape Province has two academic referral hospitals located within the metropolitan area of Cape Town. One hospital, Tygerberg hospital, serves mainly the northern suburbs while the other, Groote Schuur hospital, serves the southern suburbs. The metropolitan region of Cape Town was targeted to explore home-based care as a CBR strategy in an urban setting (Kendall, *et al.* 2000: 435). These are the biggest hospitals in the Western Cape Province and the major referral hospitals in the Cape Town metropolitan area. I decided to target both tertiary facilities within the region to explore whether the discharge planning and referral systems used by the hospitals were similar.

Data was collected from informal carers before their elderly dependants were discharged from either of the two hospitals. After the discharge from hospital the research was conducted within the homes of the families of informal home-based carers. This provided the researcher with an insider's perspective to gain an understanding of social actions within a specific context. Babbie and Mouton

(2001: 272) suggested that one needed to understand the context and how it conferred meaning to events before one can claim to understand the events.

The initial plan was to involve registered nurses in the respective hospitals to identify potential participants. The following sample criteria were shared with them (Appendix: 4), i.e. participants resided within the specific area served by the hospital/s (urban area), be South African citizens and willing to participate in the study. Informal home-based carers were the primary caregivers, at least eighteen years old and able to speak English, Afrikaans or Xhosa. Elderly dependants were sixty-five years or older, dependent in at least two activities of daily living (Katz, Ford, Moskowitz, Jackson & Jaffe, 1963: 915) and hospitalized at the time of sampling. The dependants had to be discharged to a private dwelling and not to a nursing home, frail-care centre, hospice or hospital.

The head nurses suggested that certain wards be targeted and that specific registered nurses be given the brief to co-ordinate the hospital sampling. I would then have telephonic contact with these nurses on alternate days to establish whether potential participants were identified. This arrangement would guarantee that no potential participants would be lost should the elderly be discharged before the anticipated date of discharge. I visited the wards and familiarized myself with ward routine, referral and discharge procedures and in the process established a relationship with the registered nurses. I also posted the sample criteria on the notice boards in the offices of the designated registered nurses.

I called the wards on alternate days and over a period of fourteen days did not secure a single potential participant. I visited the wards twice weekly and was informed that unfortunately they were too preoccupied with their routine tasks, forgot to mention a specific potential participant or that potential candidates were discharged before the anticipated discharge date.

I renegotiated the sampling process with the Medical Superintendent of facility 1, who suggested that I speak to the Information Technology (IT) staff of the facility to try and come up with an alternative strategy. The IT staff provided me twice weekly with a spreadsheet of all patients in the hospital. I then scanned hundreds of names to identify the elderly patients living within the Cape Town metropolitan area. On average I drew up a shortlist of thirty elderly patients, over the age of 65 and had to visit every one of them in the hospital to establish whether they fitted the sample criteria.

I subsequently had to contact the potential carer and if no contact number was listed had to try and meet with them during hospital visiting hours. This process was extremely time consuming. Unfortunately, some of the participants who conformed to the sample criteria refused to participate or planned to move out of the Cape Town metropolitan area to a family member who offered to provide informal care. Those who were sampled from the lists of hospital admissions suffered mainly from cerebro-vascular accidents or had had elective lower limb amputations.

Since data analysis closely followed data collection the sampling criteria were modified to include primarily, novice informal carers and exclude the elderly who suffered mental illness or terminal diseases. The decision to modify sampling criteria is known as theoretical sampling. Purposive theoretical sampling was also done to include informal carers from all racial groupings in the Cape Town metropolitan areas (see census data in Chapter One). Since the admissions in the northern suburbs were mainly representative of the coloured race group participants from the other groupings were intentionally sought.

3.4.2. RESEARCH INSTRUMENTS

The research instruments used were, amongst others, demographic questionnaires, interviews, direct observation captured in fieldwork notes and written memos.

3.4.2.1. Demographic questionnaire

The demographic questionnaires (Appendix: 1 & 2) were used to collect information about the informal home-based carers as well as the elderly dependants. The reasons for capturing demographic data in a qualitative study are different from that of a quantitative study. In the latter case statistical inferences based on demographic data constitute important research outcomes. In a qualitative study the demographic information guides purposive sampling. Demographic data is not used to guarantee a representative sample or make generalizations about research outcomes but rather reflect the varied sample of individuals who share common social experiences. In addition it provides contextual information about the carers' age, gender, employment status and relationship to the elderly.

I was able to monitor, amongst others, to what extent participants from all social groupings were sampled and whether different age groups and genders were included in the sample. Questions about the relationship between the carer and elderly provided important data and were scored as daughter or partner or mother-in law or neighbour. The nature of the relationships was observed during the scheduled interviews and captured in the field notes.

3.4.2.2. Interviews

The main instrument used to collect data was an interview schedule comprising of ten open-ended questions (Appendix: 3). The questions were constructed to allow the interviewer the opportunity to probe should the participant's responses be inadequate. The interviews lasted from one to one-and-a-half hours and were recorded with a digital recorder and downloaded onto a personal computer using transcription software (N. VIVO).

The advantage of an interview schedule is that it allows for the best use of time and provides some structure when interviewing a number of different people. Participants are encouraged through probing, to provide as much detail as possible. During these narrative responses important data emerge. It does, however, require some skill to allow participants enough scope for in-depth responses without becoming sidetracked.

The reason for choosing an interview schedule as the main data collection instrument was the flexibility that it offers the interviewer. Face-to-face interviews also allows for the observation of non-verbal responses to interview questions.

Taped voice recordings and transcripts (Appendix: 8) provide detailed and publicly accessible representations of the social interaction. The digital recording ensured that a good quality of voice data inclusive of intonation, pauses and other sound effects were captured. Digitally recorded data contribute to the reliability of the data collection process since the raw data was stored on compact disc and is available for the purpose of verification.

3.4.2.3. Field notes of direct observation

It is required that qualitative researchers get close to the people being studied, that they capture a detailed and accurate account of what was happening in the field and that they present the data to reflect accurate descriptions of the setting and verbatim responses from participants (Patton, 2002: 48).

Field notes were recorded immediately following the interviews to describe the setting and the interaction between the carer and the elderly. These notes were important to depict the context in which the informal caring was given. The notes provided an opportunity to capture changes in the context of caring over a period of time. On two occasions the primary carer changed from being the grand-

daughter during week one (1) to the daughter during week four (4). In some instances the carers' mood changed considerably over the same period of time.

The following information was recorded: the suburb, size of the house, occupants of the dwelling, the room in which the caring occurred, details about the carers and elderly (not captured on the demographic data sheet), apparent relationship between the carer and elderly, any significant others who were or were not involved with the caring.

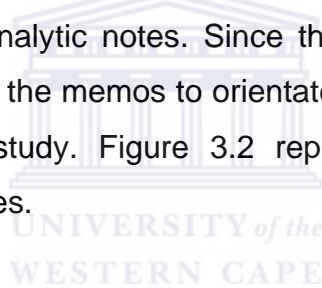
3.4.2.4. Memo writing

Besides the field notes I also wrote memos to capture amongst others, reflective notes, code notes and analytical notes. It is important to record the reasons for choosing specific categories and making specific judgments to facilitate the audit process of peer reviewers (Burns & Grove, 2001: 529). It is also important for the researcher to self-reflect. Reflection is one way of becoming aware of biases, which may influence the interpretation of data (Burns & Grove, 2001: 531). The biases in this study were based on my personal experiences as an informal carer. Reflective notes provided additional information with regard to, e.g. the perceived degree of active caring and rehabilitation provided by the designated primary carer.

Code notes were written to keep track of the coding process. These notes included amongst others, decisions about the initial open coding process, decisions to re-do the coding and decisions to group certain codes during the axial coding process. Initially I found it difficult to assign names to codes. I consulted literature for guidance and found the writings of Munhall (2001), Strauss and Corbin (1990, 1998), Chenitz and Swanson (1986) and Glaser and Strauss (1967), useful as they provided examples of the coding process from a range of grounded theory studies.

Analytical notes were used to illustrate my thinking and reasoning during the process of data analysis. I started writing notes about data analysis after completing the second interview. At the time I had a sense that I should not be including experienced carers and that I may find it difficult to access participants from all social groupings. I identified the need for purposive sampling during the first phase of data collection. Analytical notes provided a way of monitoring data analysis in relation to data collection and excerpts from these notes are included in the research report. I think that these notes were valuable in the verification of the data analysis process.

Memo-writing was one of the strategies used to allow the readers to judge the different aspects of the research process. Many of the links between the different categories and between the categories and the basic social process were captured in reflective and analytic notes. Since the research study spanned a number of years, I also used the memos to orientate myself to the status and the progress of the research study. Figure 3.2 represents an overview of the research phases and timelines.



PHASE	PROCESS	ACTIVITY	TIME LINES
Research design	Review literature	Proposal writing Consultation with qualitative research expert	July 2001- July 2002
Data collection – Phase 1	Planning access	Meeting with staff from facility 1 Setting up lines of communication Reviewing access to potential participants Setting up data management and storing	Aug 2002 – Dec 2002
Data collection – Phase 2	Initial data collection	Collecting data in facility 1 Interviewing participants Writing field notes Writing reflective notes Transcribing data	Jan 2003 – March 2003
Data analysis – Phase 1	Initial data analysis	Open coding (Node / Tree coding –N Vivo) Writing code notes and analytical notes Identifying initial categories Doing theoretical sampling	April 2003 – June 2003
Data collection – Phase 3	Focused data collection	Proceeding with data collection in Facility 1 Meeting with staff at facility 2 Interviewing participants Writing field notes Writing reflective notes Transcribing data	Aug 2003 – Sept 2003
Data collection – Phase 4 / Data analysis – Phase 2	Focused data collection Focused data analysis	Collecting data in facility 2 Concurrent data analysis Tree coding and Axial coding Identifying emerging categories	Oct 2004 – March 2004 Jan 2004 – July 2004
Data analysis – Phase 3	Focused data analysis cont.	Axial and Selective coding Theoretical sensitivity Present paper on data analysis Consulting mentor - grounded theory	Aug 2004 – Dec 2004
Role reversal	Elective surgery	Researcher undergoes major surgery – Research on hold. Experiences dependent role for 2 months	Jan 2005 – June 2005
Data analysis – Phase 4	Final data analysis	Verifying emergent theory Present paper on preliminary findings	July 2005 – Dec 2005
Closure	Reporting on findings	Writing research report Literature comparison Present paper on findings	Jan 2006 – Oct 2006

Figure 3.2: Research Phases and Timelines

3.4.3. DATA COLLECTION

Data collection included demographic data questionnaires, face-to-face interviews using open-ended questions, field-notes describing the context of care as well as informal observations of the relationship between the carer and the elderly as well as reflective and analytic memos.

Data collection started at Facility 1 during the second semester of 2002. A total of eight participants were interviewed. The second phase of data collection started in the second semester of 2003 because there was a delay in obtaining permission to access Facility 2. A total of ten participants from Facility 2 were interviewed.

From the lessons learned in Facility 1 the sampling process was slightly easier in Facility 2. A registered nurse who assumed the role of rehabilitation liaison person facilitated the sampling process. She identified specific wards to which potential participants would be admitted. She was also the person who made contact with the potential carers and assisted them with decisions with regard to the rehabilitation of the elderly. Once again purposive sampling ensured that participants from other race groups, other than the coloured group be included in the sample.

The first interviews were scheduled to occur prior to the discharge of the elderly from the hospital. Occasionally first interviews occurred on the day of, or the day after the discharge of the elderly. Various reasons for this included: the premature discharge of the patient, failure of the participant to keep to an appointment or failure of the participant to visit the elderly in the hospital.

Appointments with the potential informal carers were scheduled and a suitable venue was booked in the ward. The venues had comfortable chairs and were removed from the noise of ward activities. Informed consent was obtained from participants, demographic data was collected and permission obtained to digitally

record the interview. This pre-interview process lasted between fifteen to twenty minutes per participant. Initially I omitted from negotiating for the additional fifteen minutes to explain the research study and obtain consent. On one occasion the interview was cut short when the carer realized that she had to leave to “catch a bus”.

Carers were then asked about the incident that led to the elderly dependant’s admission to the hospital. This question was used to encourage them to start telling a story instead of waiting to answer questions. The technique worked well but initially too much of, what I regarded as insignificant detail, was offered. However, when this detail was analyzed, I discovered that the carers were describing their prior relationship with the elderly. This prior relationship was explored further and found to be an intervening condition in the basic social process that emerged from the study.

During the second and third interviews, the participants were asked to describe in their own words, the routine followed on a daily basis. Once again it was expected that the participants would get into a story telling mode, however, on some of these occasions the expected responses were not elicited. During such occasions significantly more probing had to be done. Participants had to be coached regarding the activities that occur during the course of a normal day. I had the distinct impression that their days were rarely normal.

Occasionally the first interview was scheduled at the carers home because some of the primary carers did not visit the patient in the hospital but relied on telephonic information from health service providers (doctors and nurses). A participant (Resp: 7) stated that it would have cost her R20.00 to travel to the hospital instead of the minimal cost of a local phone-call. It means that she followed telephonic instructions on how to care for her elderly father.

The appointment for the second interview was made prior to the elderly's discharge from hospital. This interview provided the most valuable information as the informal carers shared information unreservedly. They waited in anticipation to reflect on the challenges, which they have had to cope with. The only constraint during these interviews was the interference from the rest of the family, small children, family pets and even the elderly dependants. This happened despite attempts to negotiate for a suitable venue. Some of the homes were so small that most activities occurred in the living room.

The appointments for the third interview were more difficult to secure. One participant cancelled for a valid reason, i.e. a death in the family, but subsequent attempts to secure an appointment failed.

Two participants placed their elderly dependants in homes for the aged within the first month following the primary interview. As a rule, admissions to these facilities are done according to a waiting list, but, because the participants had inside connections they were able to jump the line on the waiting lists. A carer informed me that if the elderly suffered serious illness, such a patient would receive preferential selection on a waiting list.

The field visits were not without incident. Two participants were particularly concerned about my safety and the safety of my car. The African carer lived in a low-socio economic suburb and the Coloured carer, in a gangster-riddled township.

Potential participants were excluded from the data collection process for, amongst others, the following reasons: when the elderly dependant died; when the elderly persons were admitted to step down facilities, e.g. Booths Memorial Hospital; when the family chose not to participate in the research project and when the elderly dependants participated in intensive rehabilitation programmes, e.g. coronary, stroke or amputation rehabilitation programmes. A discerning

discovery was that to qualify for the amputation rehabilitation programme, the elderly had to have a single lower limb amputation. Those with bilateral lower limb amputations were excluded from such a rehabilitation programme.

The interview data was transcribed verbatim. A student assistant (Masters level) verified the English transcriptions as true reflections of the original recorded interviews. Interviews conducted in Afrikaans were translated into English. An Afrikaans- speaking registered nurse (Doctoral level) verified the translations as a true reflection of the original recorded interviews.

Transcribed documents, field notes, reflective and data analysis memos were stored on computer discs and downloaded into the N.VIVO data analysis programme.

3.4.3.1. Computer assisted qualitative data analysis (N.VIVO)

Reflective and analytical memos constituted an audit trail that allows the reader to keep track of the research process and adds to the rigor of the methodology. The N. VIVO data analysis programme facilitated the linking of memos to the transcribed data. It also allowed one to insert annotations and memos to specific sections of the data. Memos showed the movement from data collection to data analysis and from descriptive analysis to theoretical analysis. The properties and dimensions of categories were identified and data that did not fit into emerging categories were identified and explored further. The value of memo writing became clear during the data analysis process.

The computerized data analysis programme also allowed for the generation of transcript and code reports (Appendix 8 & 9). These reports were valuable when I was engaged in cross case analysis. A report of a specific code could be generated that showed its prevalence in all the coded material (Appendix: 9).

3.4.4. DATA ANALYSIS

The characteristics of the informal home-based carers and elderly included in this study are presented in the following table (Figure: 3.3).

Identifier	Age	Race / Gender	Relationship to elderly	Employment	Elderly's age	Elderly's gender	Elderly's diagnosis
Resp 01	45	C F	Grand daughter	Unemployed	90	Female	Hip fracture
Resp 02	32	C F	Grand daughter	Full time	88	Female	Femur fracture
Resp 03	38	W F	Daughter	Full time	67	Female	Femur fracture
Resp 04	49	C F	Daughter	Unemployed	79	Female	Stroke
Resp 05	65	C M	Partner	Pensioner	66	Female	Bilateral lower limb amputations
Resp 06	50	W M	Son	Full time	80	Male	Stroke
Resp 07	58	A F	Daughter	Unemployed	86	Male	Hypo calcaemic convulsions
Resp 08	32	C F	Niece	Unemployed	65	Male	Stroke
Resp 09	40	C M	Son	Unemployed	69	Female	Lower limb Amputation
Resp 10	64	C F	Wife	Pensioner	71	Male	Stroke
Resp 11	38	C F	Daughter	Unemployed	65	Female	Stroke
Resp 12	56	C F	Sister	Voluntary worker	65	Female	Lower limb amputation
Resp 13	75	C F	Wife	Pensioner	75	Male	Stroke
Resp 14	35	C F	Son	Full time	67	Female	Bilateral lower limb amputations
Resp 15	56	C F	Daughter	Unemployed	79	Female	Stroke
Resp 16	54	C F	Daughter-in-law	Part-time	82	Male	Stroke
Resp 17	52	A F	Daughter	Self employed	79	Male	Stroke
Resp 18	42	C F	Daughter	Part-time	67	Female	Lower limb amputation

Figure 3.3: Characteristics of Informal Carers

No statistical analysis of the carer or elderly's demographic data was done since the data was primarily collected to ensure that the participants fitted the initial sampling criteria and to facilitate the purposive sampling of participants. Some discussion about the demographic data is included in Chapter Four.

Other issues that needed attention during data analysis included an awareness of personal experience and context sensitivity. Before any of the scientific steps to data analysis was undertaken, it was important that I reflected on my own experiences. Patton (2002: 64) suggests that *the perspective the researcher brings to a qualitative study is part of the context of the findings* and that self-awareness could be considered an asset in the data analysis process.

An accurate description of the context increases the transferability of a qualitative research study. In this study the carers, the elderly, the traumatic incidents and the settings may have impacted the experiences of the informal home-based carers in their attempt to provide care and facilitate recovery of their dependants. The reader is introduced to the carers, the elderly and the setting in which the caring occurred, so that the experiences shared by these informal home-based carers will reflect their realities. The context of care is described in detail in Chapter Four.

Following the collection, capturing and storing of the data the next important research process, i.e. data analysis started. I had to familiarize myself with the data in order to grasp *what was going on* with the data. Initially I focused on the carers experiences to try and identify similarities and explore the differences in their experiences.

I realized, after analyzing the first five participant's data that the conceptual framework, primarily created to provide conceptual sensitivity, was influencing the data analysis process. Chenitz and Swanson (1986:43) cautions the grounded theory researcher against the tendency towards theory testing rather

than theory discovery. Research that test existing theories use variables within the theory to verify specific social phenomena. Grounded theory is based on the discovery model of theory development, which account for or explain social phenomena.

After consulting literature on the use of grounded theory and examples of the application of the data analysis process, the second attempt at analysis was more successful. The writings of Patton, 2002; Creswell, 1998; Strauss and Corbin, 1998; and Miles and Huberman, 1994, proved useful in providing practical guidance to novice researchers.

I was also aware of the interplay between data collection, data reduction and data display (Miles & Huberman, 1994: 10). This means that qualitative data analysis cannot be seen as a linear process, but rather, one that loops from analysis back to data collection. The delay in obtaining access to Facility 2 afforded me time to analyze the data collected at Facility 1, prior to proceeding with the second phase of data collection. During this phase, the analysis centered on, asking questions about the data and making comparisons to try and understand *what is going on* with the carer.

Creswell (1998) and Strauss and Corbin (1990, 1998) suggest a standard, systematic format of data analysis in grounded theory research, i.e. open coding, axial coding and selective coding.

3.4.4.1. Open coding

Open coding means breaking down the data into smaller segments. It also involves labeling these segments (concepts), examining and comparing them and then grouping them under a more abstract concept (category). Categories are further analyzed by exploring their properties and dimensions (Strauss and Corbin 1998: 101).

The analytical tools which facilitate the process of open coding are *questioning* and *constant comparative* analysis. Concepts are examined by asking questions about them, e.g. when does it occur; why does it happen; what are the effects of it occurring. *Questions* may also be asked across cases, e.g. does it happen to all the carers, how does it affect different carers and to what degree are they affected? *Questioning*, allowed me to link categories, examine my biases and move from descriptive analysis to conceptual analysis.

It is also important to employ the *constant comparative* method of data analysis. This method allowed me to take the data collected and constantly compare it to existing categories. I then linked the data to emerging categories and compared the data at property and dimensional level (Strauss & Corbin, 1998: 85). At this level, I did not compare individual cases but compared the categories. I was not interested in how many cases displayed this particular category but how it presented itself under varying conditions (Strauss & Corbin, 1998: 95).

While engaged in the process of data analysis I was sensitive to the data as well as my own biases with regard to the data and particularly wary of statements like, carers *always* do this or they *never* attend to that ...

During the initial open coding of interview transcripts, before using the computer assisted data analysis software, the categories that emerged from the data related to choosing to care, preparing to care, helping with care activities, challenges relating to caring, i.e. accessing assistive devices and state pensions and the need for respite care.

I also became aware that in many instances the caring became a shared responsibility. This happened in particular where the primary carer was male. The assumption that females primarily accepted the role of carer was proved incorrect during the early phase of the data collection process. Despite having daughters, two elderly ladies were cared for by their sons.

Having had the experience of informal caring, I knew how it felt to be assigned to this role. The carer may choose to care or be chosen by others to provide informal home-based care to an elderly person. During the data collection phase, I purposively included both options, to ascertain whether choosing or being chosen, impacted on the care and rehabilitation offered to the elderly dependant. I also became acutely aware of my strong opinions with regard to the *choosing to care* ...and captured these feelings in reflective notes.

The initial coding was followed by a more structured attempt to use computer software to assist with the process. After immersing myself in the data by reading and re-reading all the relevant documentation about a specific case I started open coding, using the N. VIVO programme. I consciously had to focus on the informal carers and their experiences and found the seemingly unstructured nature of open coding difficult at first. The code segments varied in length from a few words to a paragraph.

The N.VIVO software facilitated the process of open coding and tree coding. A line-by-line tree coding system was used and the software allowed for the retrieval of codes as well as the linking of codes in and across cases. The challenge was to name the categories that would accurately describe the perceptions, opinions or experiences of the carers. I found the similarities across cases interesting but also became aware of the variety of responses to the same interview questions. Field notes and memos were linked to documents and in-document annotations were created. The computer-assisted data analysis programme was useful during the open coding phase of data analysis. However, when conceptual linking of concepts and categories was done, I preferred to use traditional methods of data analysis and the computer-assisted programme was abandoned.

Glaser (in Melia 1996) described the process of segmenting the data as distracting. I agree to a certain extent, namely, that if too many small segments of data are explored, one may lose the sense of *what is really going on* in the data. I found that by constantly reflecting on the *experiences of the carers* in a *particular context* facilitated the process of open coding.

My research mentor assisted with verification of the process of data analysis. She expressed concern about assigning in-vivo codes to the feelings expressed by the participants. I had to account for these in-vivo codes by demonstrating how the code-category links were made, e.g. linking *everything was topsy-turvy* and *things were a bit hectic* to the category *dis-connected care*. I primarily assigned in-vivo codes to describe the emotions of the carers so that their emotional experiences could be captured verbatim.

The following serves as examples of open coding:

Initial codes (6 of 113 codes)

Carer chooses to care	Carer chosen
Carer experienced	Carer novice
Carer shares caring	Carer prepares for caring

These codes were grouped along with others into the category:

Role fitting (1 of 6 categories)

Categories (e.g. *Role fitting*) were explored in terms their properties, e.g. the goal and purpose of the category. Furthermore the processes within a category are discussed in terms of time-lines, e.g. when does it occur and does it change over a period of time.

Strauss and Corbin (1998: 101) further suggest that the dimensions of the category (*Role fitting*) be explored, i.e. the variation within the properties of the specific category, i.e. Carer prepares - carer unprepared

Carer experienced - carer novice

The following diagram represents this process:

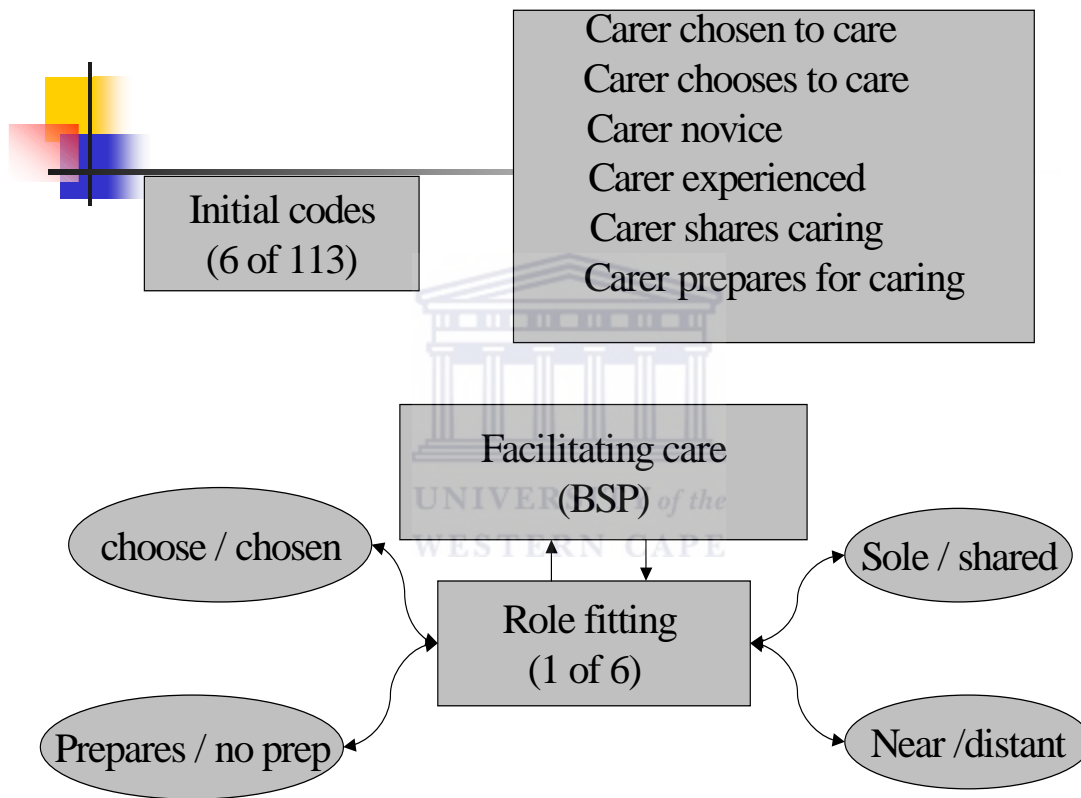


Figure 3.4: Example of Open Coding

3.4.4.2. Axial Coding

The next stage of data analysis involved suggesting relationships amongst categories, i.e. axial coding. Creswell (1998: 57) and Strauss and Corbin (1998: 123) state that the data is now re-assembled in a conceptual way. Codes (nodes in the N.VIVO programme) were grouped together to form sub-categories. Sub-categories and categories were conceptualized in a lengthy constant comparison exercise. Sub-categories were linked to categories and eventually a basic social process emerged. The aim of axial coding is to identify a core category or basic social process – a central idea, event or happening in terms of the *paradigm model* (Strauss & Corbin, 1990: 110).

The *paradigm model* is an analytical tool used to facilitate the exploration of the core category or basic social process. Initially I found the paradigm model distracting, however, by using this model at a later phase during the analysis process, the core category namely, *facilitating care* emerged. It is by *facilitating care* that informal home-based carers make sense of their world as they provide care and assist in the recovery of their elderly dependants. When carers are faced with the prospect of caring for elderly dependants, there are a number of conditions that will impact on this basic social process.

Strauss and Corbin (1990) suggest that causal, contextual and intervening conditions may influence the basic social process – BSP. They further suggest that the action and interaction strategies used by participants engaged in the BSP may lead to specific consequences.

The following diagram shows the relationship between the paradigm model and the categories that emerged from the data.



Strauss and Corbin's paradigm model (1990) Adapted

Identify a basic social process (facilitating care)

Explore / Questions data to find:

- Causal conditions (incident)
- Contextual conditions (carer / elderly / home)
- Intervening conditions (prior relationships)
 - Action / interaction strategies
(role fitting / maintenance & repair care)
 - Consequences of strategies
(connected / disconnected care)



UNIVERSITY of the
WESTERN CAPE

Figure 3.5: Paradigm Model adapted from Strauss and Corbin (1990)

3.4.4.4. Selective coding

Finally in selective coding the researcher identifies a “storyline” and writes a story that integrates the categories in the axial coding model (Creswell, 1998: 57). Strauss and Corbin (1998: 150) refer to a story line memo. Glaser and Strauss (1967:114) refer to this inductive process, as one where the analyst is:

... forced to bring out underlying uniformities and diversities, and to use more abstract concepts to account for differences in the data.

Glaser and Strauss (1967: 31) suggest that grounded theory could be presented as a theoretical discussion of the conceptual categories and their properties, but that it should ring true with great credibility, feel theoretically complete and be simple to apply.

This story-line memo reads as follows: Informal carers are *facilitating care* during the transition of the elderly from hospital to home.

I think what happens is that ... an elderly person who has been in a relationship with others suddenly is involved in an *incident* and is admitted to hospital. It causes much distress and uncertainty within the family when the elderly dependants are discharged, because a carer has to be selected. Sometimes the designated carer would be one with whom the elderly have had an established *prior relationship*. At other times the elderly will decide who they would prefer to care for them.

These carers have to *fit* the role of care facilitator into their existing roles. They think about the prospect of caring and *prepare for caring* with regard to the room, finance, emotional support, food, washing, dressing, shopping. They sometimes *share* the responsibility for specific caring tasks with others. Occasionally, carers do not prepare but decide that the circumstance will dictate the type of care required.

Carers would generally focus on providing *maintenance* care to the elderly, i.e. care to maintain body and soul. They discover that they need people to assist with the caring, they lack information and skills and that the caring requires them to access resources.

They draw on intuition and previous *experience*. They elicit *support* from family members, neighbours and other members of the community. Carers discover that the elderly may also require specialized *repair care* to ensure the recovery of

some basic functions, for example, they may need special exercises and special diets.

Carers become aware that caring takes its toll. They are faced with physical, emotional and social *challenges*. They become tired and frustrated at the lack of *support*. Occasionally family members will offer *respite* for short periods of time. However support is *disconnected* and do not meet the needs of the carer at the time. In some cases the health services do not provide optimal support and they have to rely on the community to assist with informal home-based care.

3.5. CONCLUSION

In this chapter an extensive search was undertaken to identify the most suitable research methodology for the study. The various approaches to scientific enquiry were explored and eventually the research question and aim of the study pointed to the most appropriate method. The grounded theory method appeared to fit myself, the researcher very well as it afforded me the opportunity to get close to the carers in the field. The method also allowed the carers, i.e. the participants, to drive the research process and share their experiences with the potential users of the research findings, i.e. the research audience.

In this chapter I found it particularly difficult to explain the data collection and data analysis process without intruding on the research outcomes. With grounded theory research, these lines become blurred and one can only trust that the logical flow between investigating and reporting is maintained.

In the next chapter the main research outcomes are discussed.

CHAPTER 4: RESEARCH OUTCOMES

4.1. INTRODUCTION

The research methodology was described in the previous chapter. In my opinion, one of the challenges of grounded theory research is to present the research findings in a way that will afford academics, professionals and lay persons equal access to the outcomes. Another is to make the interplay between the context, personal and professional experience and emerging categories transparent.

In this chapter the research outcomes are presented under the headings:

- The voice of the researcher
- The social context of care
- Facilitating care – the model

4.2. THE VOICE OF THE RESEARCHER

The authenticity of grounded theory outcomes demands that researchers remain aware of their own personal norms, values and beliefs; that they share their own experiences and express their biases and that their voice is present in the interpretation of research outcomes. The awareness of personal and professional experiences is viewed as important sensitizing strategies to develop theory that is conceptually dense, integrated and grounded (Strauss & Corbin, 1990: 42). In this section, I wish to introduce myself to the reader in order to place my reflective and analytical notes in context.

4.2.1. A PERSONAL REFLECTION

I am a lecturer in the Department of Nursing, at the University of the Western Cape. In 1994 while on sabbatical leave to complete my masters thesis, I was informed that an elderly aunt was diagnosed with cancer and referred to Cape Town for further investigations. Being the only nurse in the family, and residing in

Cape Town, I offered that her spouse could stay with me for the duration of her hospitalization.

I continued with my studies, but I had to re-arrange my schedule around hospital visiting times. I also had to prepare additional meals and attend to numerous phone calls. I could cope with this, but then my aunt had exploratory surgery and was informed that the cancer was inoperable. She insisted that her niece (myself) could take care of her and was discharged with sutures-in-situ and in a very weak condition. On discharge, I mentioned to the nurse that my aunt appeared to be very pale. She commented that it would be expected seeing that she was a very sick woman.

The caring began. I had to prepare the room, change the menu's, do bed baths, assist with dressing, meals and ambulation. The visitors streamed in. No one assisted because "the nurse knows how to do things best"... even make a cup of tea or prepare dinner. My aunt was a model patient but the family exhausted me. They all wanted to speak to me ... to get "insider information".

I removed her sutures at home and decided to assess her haemoglobin (Hb) level, as I was still concerned with her being so pale. The Hb. level was very low and I personally referred her back to the discharging physician. She was re-admitted and was given a blood transfusion. At the time I was very grateful to have been an experienced nurse because I could imagine how an informal carer would have struggled to assist someone who was so anaemic. For the next four weeks I had to put my studies aside as I was simply too exhausted to think inductively.

After my aunt regained her strength her family took her home to Port Elizabeth and I could resume my studies. Exactly two weeks later I was informed that another aunt took ill and was admitted to a hospital in the Eastern Cape for cardiac bypass surgery. Once again the nurse was summonsed to assist with, in

this instance, rehabilitation care. So I packed up my data and had to find house sitters because I knew that it could be an extended stay.

On arrival in Port Elizabeth I was taken directly to the hospital and introduced to the staff as the nurse who was suitably qualified to take care of a sixty-nine year old patient, a week after major surgery. When I saw my aunt, I became very concerned as she was restrained and labeled a difficult patient. She was restless and the medical motivation for an early discharge was to get her back to familiar surroundings.

I had one day in which to prepare for her discharge. I had to prepare the room to accommodate a second bed for myself, as she needed constant supervision. The “familiar surroundings” did not allay her anxiety and confusion. She appeared to be disorientated and restless. I administered her medication, amongst others, a mild sedative. She, however, fought against the effects of the sedative and insisted on visiting the toilet at least six times during the night. She was receiving medication for a possible bladder infection and did not display any other signs or symptoms of a urinary tract infection (except for frequency). Some-times she would just walk to the toilet (assisted by myself) and turn back without even sitting down on the toilet seat. These nightly “treks” exhausted me. After three nights I consulted with the physician who simply prescribed more potent drugs. This worsened the situation as my aunt was now less steady and simply needed more support during her nightly escapades. I decided to stop the sedatives completely ... and, the trips to the toilet became fewer.

However, while I singled out the fact that I barely slept for ten days, (the most challenging experience) the daily chores continued. This included washing and dressing my aunt, mobilizing her, preparing meals, cleaning house, doing the washing, attending to visitors and phone calls, with my uncle requiring support as well. I remember thinking to myself ... Why doesn't anybody offer to HELP!!!

I still marvel at the fact that I completed the thesis by the end of that year. My aunt was satisfactorily rehabilitated and started resuming some of her responsibilities. I convinced my uncle to employ someone to assist her with household chores.

Subsequent to those home-based care experiences many vacations centred on offering respite to informal carers of family or friends. When a friend asked me to visit her in-laws (in 2000) the elderly gentleman who had suffered a stroke with the main carer being his seventy-year old wife, all the memories flooded back. I could empathise and give appropriate guidance since I have “been there and done that”. At first I thought about writing an informal carers manual within the South African context. Many training manuals exist for formal training in home-based care, but informal carers have limited access to information. I then decided to research the phenomenon of informal home-based care, reach a larger audience and possibly impact educators as well as the managers of home-based services in the province.

4.2.2. A PROFESSIONAL REFLECTION

I worked as a registered nurse at one of the large academic hospitals prior to joining the faculty staff at the University of the Western Cape. Health workers focused on curative care and once patients have been discharged they became the responsibility of district nurses. At the time of discharge, informal carers were not involved in the discharge planning of the elderly patient. Sometimes preparation for caring occurred on the day before the discharge and at other times no preparation preceded the discharge of the elderly.

The random training of informal carers focused on the physical care of the elderly with little emphasis on the mental strain and exhaustion that accompany the role of the informal carer. Educating the family with regard to the need for respite, financial or other assistance around the house was not considered a priority. As long as the elderly received their tablets and follow-up hospital appointments,

health workers were contented. I need to confess that prior to 1994 I too was guilty of this type of behaviour.

Even though we claim to have a community-based approach to the training of health care professionals, traditional rehabilitation theories are taught. South African citizens do not have access to all the facilities and support structures referred to in textbooks on rehabilitation care.

With the focus on the management of the HIV-AIDS pandemic it appeared as though most of the resources were allocated to home-based care of patients who have HIV-AIDS. However as a result of diseases of lifestyle many patients would require home-based rehabilitation following strokes, amputation and open-heart surgery.

Post 1994, the curricula of student nurses had to change to accommodate the shift in focus of health care in South Africa, from curative services to primary health care services. Since theory impacts on practice and vice-versa the placement of student nurses were reviewed. Students were placed at primary health care service centers, including, amongst others, creches, homes for the aged and community health centres. Students also accompanied home-based carers and district nurses into the homes of clients.

During classroom discussions, the students expressed their disillusionment at the lack of support for the aged within their communities. They were also concerned about the fragmentation of health services, e.g. home-based carers would only do the client's bed-bath, the district nurses would do the dressings and the client had to "trek" to the community-health centre for physiotherapy services. Some clients did not know how to access their aged persons' grants once they have become disabled. Others did not have access to assistive devices like wheelchairs and were trapped in second or third-floor apartments.

Other issues that were raised during the classroom discussions centred on the lack of preparation offered to the family caregiver. In some cases no formal training was offered. Carers had to ask friends and neighbours for assistance. Others knew some one who knew a registered nurse. They had to find out from social workers where to access home-care services within their communities.

Following such discussions the students had to suggest solutions or plan the way forward. Their suggestions included the training and support for informal carers. How this would happen always ended in a theoretical debate about who should offer the training and support, i.e. the government of the day, the professional bodies or the community at large. What we agreed on was that such an initiative should start with an exploratory research study that would provide appropriate information to incorporate into the training programmes of professionals as well as the training manuals of informal carers.

4.3. THE CONTEXT OF CARE

4.3.1. A CLOSER LOOK AT CONTEXT

This study aims to explore the experiences of informal home-based carers during the transition of their elderly dependants from hospital to home and at home. The social context of care was compiled from demographic data, field notes, interview data and the informal observation of carers and the elderly in their homes. The demographic data is presented in a table format (Figure 3.3) while the context of care is presented in a narrative form.

Informal carers reflected all social groupings in the Cape Town metropolitan area. A white professional nurse (Resp: 03) took on the primary responsibility to care for her elderly mother who fractured her hip. She incidentally witnessed and managed the traumatic incident. When she related the incident and subsequent hospitalization, she frequently referred to her mother as being *head strong* and *stubborn*. She was not very satisfied with the hospital care and mentioned that they did not provide her with enough information with regard to accessing

assistive devices. At the time of the incident she was employed and her spouse worked in Central Africa. She could not secure leave to care for her mother on a fulltime basis and had to make alternate plans. The carer was supported in her task by her mother-in-law who offered to share the caring and supervise her mother when she was at work. Her mother was an independent lady who lived in a furnished outbuilding on their property. The incident happened just when the family (the elderly lady's daughter and her children) were on their way to visit her husband / their father in Central Africa.

A white man, (Resp: 06) married with children, assumed primary responsibility for his aged father who suffered a cerebro-vascular accident. He did not live with them at the time. The elderly lived in a low socio-economic suburb in a one-bedroom apartment. The bedroom was so small that they had to move the elderly's bed into an equally small living area. The carer's stepmother lived with his father at the time. Prior to the incident the carer referred to his father as having been an independent person who kept himself busy with household chores and tended to racing pigeons. Following the incident he regarded his father as *behaving like a child* who had unrealistic expectations of a full recovery.

A coloured man (Resp: 05) took on the primary responsibility to care for his partner who underwent a second lower-limb amputation. They lived in a sub-economic section of Belhar, a suburb where gangster activity was very high. Their house was filled with the most beautiful potted plants. He was a very religious person and saw caring as a test from God since he confessed to having had an adulterous relationship with this lady while his first wife was still alive. Some of the tasks and responsibilities of caring were delegated to his daughters who shared the house with them.

A young coloured lady (Resp: 11) was asked by her elderly parents and the family to give up their house to move in with her parents. Her mother, a diabetic, suffered a cerebro-vascular accident that left her incontinent of urine and faeces.

The carer was married and in addition to having a young baby and two children to care for, assumed the responsibility of supervising a schizophrenic brother. They lived in a comfortable home in an established suburb. Her mother was overweight, which complicated matters because even with the assistance of her elderly father they could not manage to mobilize her. She was willing to provide care and rehabilitation but could not cope with the demands of caring for so many dependants. Initially her mother was selected to participate in a structured rehabilitation programme but a professional panel overturned the decision and her mother was sent home.

An african lady (Resp: 07) took in her father following his hospitalisation for a hypo-calcaemic incident. Her father used to live in his own house, in a different suburb, with his son and grandchildren. The traumatic incident happened when nobody was at home. He apparently had convulsions and became comatosed and the neighbours called the emergency services. The daughter was very upset about the lack of supervision and negotiated her father's relocation following hospital discharge. The carer did not visit her father in the hospital as often as she wanted to because she could not afford the bus / taxi fare. She, however, telephoned the ward and received telephonic instructions with regard to special diets and medication. Neither she nor her husband worked. Her husband was a retired gentleman who provided a comfortable house for his family. Her father, who was receiving a private pension, moved in with them but insisted on supporting the jobless adults who lived in his house.

A young coloured gentleman (Resp: 09) also assumed the role of primary carer for his mother following an above-the-knee amputation. This happened despite him having two sisters who were unemployed. He had to resign from his job because employing a full-time carer would cost as much as he was earning at the time. His sister was prepared to take on the role of primary carer for a fee. They lived in a comfortable house in a well-established middle-class suburb. The house had all the basic amenities and everybody had their own bedroom.

What I found enlightening was the degree of involvement of males in the care and rehabilitation of their elderly dependants. This proved that my initial opinion, that women provide informal home-based care, was incorrect. Another real bias that I had to confront was my assumption that daughters would always assume the role of informal carer for their parents. I consciously had to refrain from expressing my opinion about participants' norms and values.

4.3.2. THE CONDITIONAL MATRIX

The conditional matrix is an analytical tool that enhances theoretical sensitivity to the range of conditions that may impact the phenomenon of informal caring, as well as the range of potential consequences that may occur (Strauss & Corbin, 1990: 161). The conditional matrix represents the distant (macro) influences on the phenomenon, e.g. international policies, national politics and provincial health plan services as well as those in close proximity (micro) to the phenomenon, e.g. the community, family and the elderly. The various roles that the carer may have had to perform represent internal conditions that could also have an effect on the basic social process. Examples of the conditions that may have influenced the social interaction under investigation are included in a conditional matrix created for this research study (Appendix: 7).

It is important to explore the research outcomes in relation to the conditions listed in the conditional matrix. In South Africa the remnants of the apartheid system still lingers. As a result of the group areas act people were relocated to the periphery of the city into blocks of flats with inadequate public transport systems in place. In some of our social groupings the extended family no longer exists and a sick relative may be perceived as a hindrance. Unemployment may impact on the ability of the informal carers to provide special diets and access assistive devices. Most carers are unemployed and occasionally they may receive a stipend from funded social development projects (Joubert, 2005).

From the initial literature review I became aware that in some countries laws protect the carers and that carer organizations were well established (Pijl, 2003: 33), while in South Africa, informal carers are not recognized within the formal health care system (Department of Health, 2002).

The conditional matrix sensitizes one to look beyond the primary interaction under investigation to influences beyond the control of the participants and to acknowledge the impact of macro conditions. This view deviates from that of Glaser and Strauss (1967), the founders of grounded theory who focused mainly on the socially constructed world of the participants (micro conditions).

4.4. FACILITATING CARE – THE MODEL.

My assumption was that care started when the elderly dependant was discharged from a tertiary hospital. The research, however, showed a broader interaction between the carer and the elderly. It showed that the basic social process (BSP) was influenced by their pre-existing relationship and that the nature of traumatic incident impacted the BSP. These links between different subcategories as well as the links between subcategories and the core category (basic social process) are described later in this section. Figure 4.1 illustrates the links.

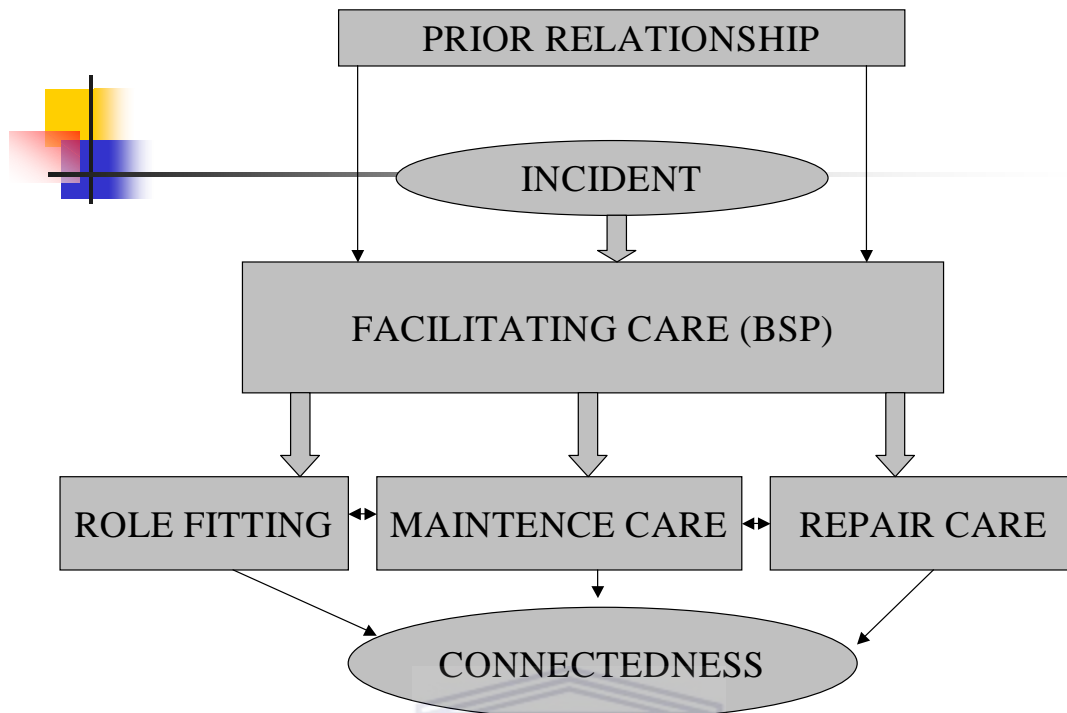


Figure 4.1: Facilitating Care – the Model

4.4.1. PRIOR RELATIONSHIP.

Prior relationship between the carer and the elderly would fit the concept of intervening conditions as described by Strauss and Corbin (1990: 96). They allege that these are conditions that help or hinder the process of facilitating care within a specific context.

During the interviews the carers invariably described the elderly, whether they were prompted to do so or not (Appendix: 9). It became clear that the prior relationship between themselves and the elderly person was meaningful to the carers. Their descriptions included the medical and psychosocial history of the elderly, and their views about the behaviour of the elderly. Carers described the elderly, prior to the incident as: I understand her well ... they are just like small children (Resp: 01), ...he was a very independent person (Resp: 06) ... look, they are old people ... they are just like babies at this moment (Resp: 02) ... she

was always very strict ... wanted things to be done her way (Resp: 04) ... she is stubborn (Resp: 03).

Resp: 01. Sister, you know they are just like small children, now they are all right and a few moments later they have a fever or something. She would say " You don't have time for me! Just like a small child... (Laughs)...that's true ... I have to give her attention. Para 39. Jan 2003 (Grandmother is 90 years old)

Resp: 02. ... that she is very healthy, she, she, she ... I...it is beyond me that she is such a healthy elderly woman. Para 78. Jan 2003 (Grandmother is 88 years old)

Resp: 05. First ...on the one leg and then later on the one foot developed...at the side of the heel ... and it has... the doctor said put a dry dressing... but it became so infected that it later affected the whole heel, and it became so... that there was no other way ... the condition was too far gone and the leg had to be removed. Para 34. Feb 2003 (Partner is 66 years old)

Resp: 06. As you can see from all these trophies, my father was a successful pigeon breeder. When he retired I built a small pigeon loft for him at my home, to keep him busy, and every morning he would come down and do things there. He and this auntie would do all kinds of things, they would climb up and wash windows and the light-bulbs and the walls. He really did a lot. He did washing and all... he was all right. Para 9. Feb 2003 (Father is 80 years old)

The prior relationship between the carer and the elderly was affected by distant factors (national level), i.e. whether the elderly owned a home and received an older persons grant. In many instances the elderly were homeowners while others lived with their daughters or granddaughters. All of them, however, received social or private pensions. One elderly dependant who lived alone in his house did not want the carer (Resp: 08) to move into the house despite being unable to walk without assistance. The carer and her family lived in an outbuilding on the property.

The living arrangements prior to the incident affected the ease with which the carer facilitated care. The action strategies associated with *facilitating care* was easier to manage by participants who lived with the elderly. Those who had to relocate shared the following:

Resp: 04. Last week Monday...no Friday! The special social worker from Tygerberg, phoned my sister-in law, Mrs J ... and...she said that we... if my mother was discharged...what then? And...we got together ... and, uh ... spoke about it and afterwards we decided that ...my father again called the family

together, and so we decided that only one person must take on the responsibility of coming to stay in the house.

Int: And how did it come about that they decided it should be you?

Resp: They all decide on me.

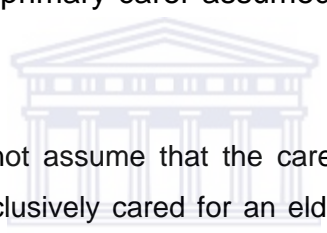
Int: And were you satisfied with this?

Resp: I was satisfied. Para 57. Jan 2003

A carer sold her own house to live with, and care for her elderly mother who suffered a CVA.

Resp: 11. ... I had my own home... but my mother...my parents asked me to give up my house and come and live with them... come and live here... and my family...they all asked me to do this ...so we agreed to come and live here...but it is taking its toll on me. Para 81. Feb 2004

The relationship between the carer and elderly varied from: husband, partner, mother and grandmother to second cousin. In some instances other people did the hands-on care while the primary carer assumed the role of facilitator of care from a distance.



Reflective notes: One cannot assume that the carers were related to the elderly. Neighbours and friends exclusively cared for an elderly lady who had a lower-limb amputation and lived in a third-floor apartment. Her sister (Resp: 12) who initially accepted the role of primary carer, lived 20 kilometers from her.

An amicable *prior relationship* between the carer and elderly, prior to the *incident* would favorably impact on the ease of *facilitating care* and a seamless *role fitting*. This fact was true irrespective of whether the carer and elderly were related by blood.

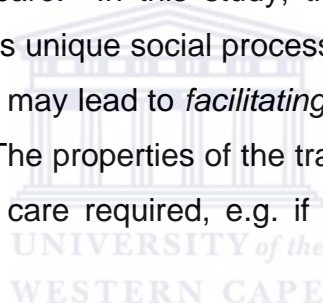
It also helped if the carer knew the medical and social history of the elderly. Sometimes a neighbour would know more about the elderly than a sister (Resp: 12) who assumed the role of facilitator of care. Unfortunately the *incident*, could change the emotional status of the elderly. A son (Resp: 06) states that his father was such an independent person but since he suffered a stroke he reacted like a

child by displaying unrealistic expectations. In addition their roles changed when he became the carer and his father the recipient of care.

A real *challenge* in regards to *prior relationship*, related to the other roles and responsibilities of the primary carer. These roles included: being a married daughter with small children (Resp: 11); a son who had to resign from work (Resp: 09); a son who had to renegotiate shift work (Resp: 14) and an elderly daughter who suffered severe arthritis (Resp: 07). The challenges related to *role fitting* are described in 4.4.3.

4.4.2. THE INCIDENT

Strauss and Corbin (1990: 96) refer to the *causal conditions* that lead to the phenomenon of *facilitating care*. In this study, the *incident* invariably causes participants to experience this unique social process. It is important to note that a variety of traumatic incidents may lead to *facilitating care*, following the discharge of the elderly from hospital. The properties of the traumatic incident will affect the dimensions of facilitation of care required, e.g. if the elderly suffered a stroke (see Figure: 4.2).



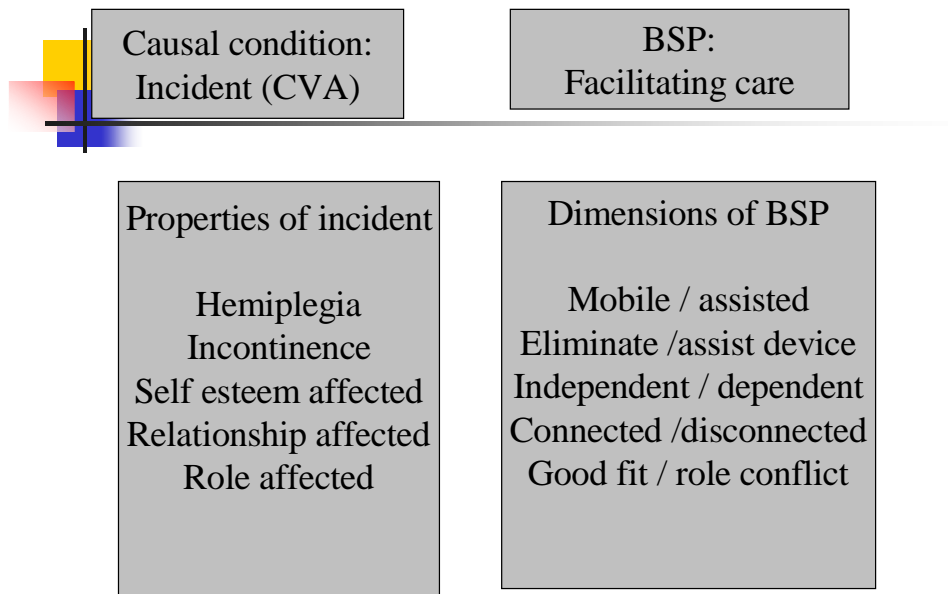


Figure 4.2: Properties of the Incident vs. Dimensions of Facilitating Care. Adapted from Strauss and Corbin (1990)

From the representation it becomes clear that if the traumatic *incident* has many properties it impacts the dimensions of *facilitating care*. A stroke may be slight and affect mobilization only. Facilitating care would therefore be limited to assisted mobility. In the case where the stroke is extensive and has a variety of properties, various dimensions of facilitating care would be required. It is unfortunate that carers are not informed about these dimensions and are not able to plan or develop specific skills to adequately facilitate care.

Reflective notes: I could see the benefit of drawing up simple instructions on facilitating care when an elderly suffered a specific incident. The dimensions could be listed and accompanied by illustrations, e.g. changing the elderly's position in bed. Some carers did not know how a stroke would affect the elderly.

The Department of health is currently piloting an assessment instrument to determine the level of care required by dependants within the home setting. Home-based care workers are trained to use the instrument to assess, plan and monitor the care of patients. It is unfortunate that informal carers who are lay workers are given minimal information to manage the dimensions of care of the elderly.

How did the incident create a need for facilitating care?

In most instances the incident marked the beginning of the process of facilitating care. Carers described the incident in a fair amount of detail. Some witnessed the incident while others were informed about it.

Resp: 02. ... to tell you the honest truth to me it was... shocking... you can believe me or not, when I lifted her to let her pee, I discovered. But I think she had, uh.... going... in to her...I discovered she wanted to pass out. And it was a...I had such a fright, I put her down immediately, and I shook her and then she asked me... why I was calling her back. So I said "but mama you can't wait for me to die!" Para 38 - 39. Jan 2003
(The carer had just arrived home from work when her grandmother fell and broke her hip)

Resp: 03. ... she walked out and I told her... seeing she was here now, let us have our meal as she lives in a little flat next to the house and she... uhm stood up and said... good, she is quickly going to fetch the beetroot salad and she walked out ... at the back door... uhm and just said "O! shit!" and I wondered what had happened now and when I turned around.....there mother was lying flat on her back and I asked "Ma and now?" and she said "but I have just fallen" Para 5. Jan 2003 (The carer's elderly mother fractured her femur)

Resp: 11. To tell you the truth I did not know my mother had a stroke, I only heard at the hospital that she had a stroke. Para 5. Feb 2004 (This daughter was not living with her parents at the time of the incident)

Carers recognized that the incident would lead to the elderly requiring assistance. They could, however, not anticipate the level of facilitating care that would be required. A son (Resp: 06) assumed that he would be able to continue

with a full-time job following his father's stroke. He did not anticipate that his father would need his assistance with every visit to the toilet.

Reflective notes: Being a qualified nurse allows one to have insight into the dimensions of facilitating care that would be required following traumatic incidents. It became clear that these details should be shared with carers prior to the discharge of the elderly dependant. I understand why some carers delayed the preparation for caring ...they possibly did not know what type of preparation would be required.

Did the carer's involvement in the incident impact facilitating care?

Carers generally distanced themselves from the traumatic incident. They related the medical history of the patient in great detail. In the case of traumatic injuries, the carers blamed the dog (Resp: 03), their family (Resp: 02) or some-one else for causing the injury. Some stated that the injuries could have been prevented. Skilled carers provided emergency care during the incident (Resp: 03) while others simply called the emergency services (Resp: 2 & 12).

In the cases where the incident was an elective surgical procedure, carers expressed gratitude that the chronic symptoms (in particular severe pain) had been eliminated (Resp: 05).

Analytical notes: These important findings would have been lost if I did not ask the question ... What happened to the elderly? Note that the question was not included in the pre-compiled interview schedule. This line of probing is allowed when doing in-depth interviews. It affirms that the method of data collection elicited appropriate responses ... that the experiences of the carers started prior to the admission of the elderly to the hospital.

Subsequent to the incident and hospitalization the carers employed specific action and interaction strategies to carry out the basic social process (see

Figure 4.3). These strategies included fitting *facilitating care* into existing roles and providing maintenance and repair care.

4.4.3. ROLE FITTING

A new role is created once a traumatic incident impact on the ability of an elderly person to perform self-care activities. These activities then have to be performed by somebody else and be fitted into that particular person's, other roles. Role fitting represents the first strategy devised by the carer to manage and carry out the basic social process, i.e. facilitating care (Figure: 4.3.1).

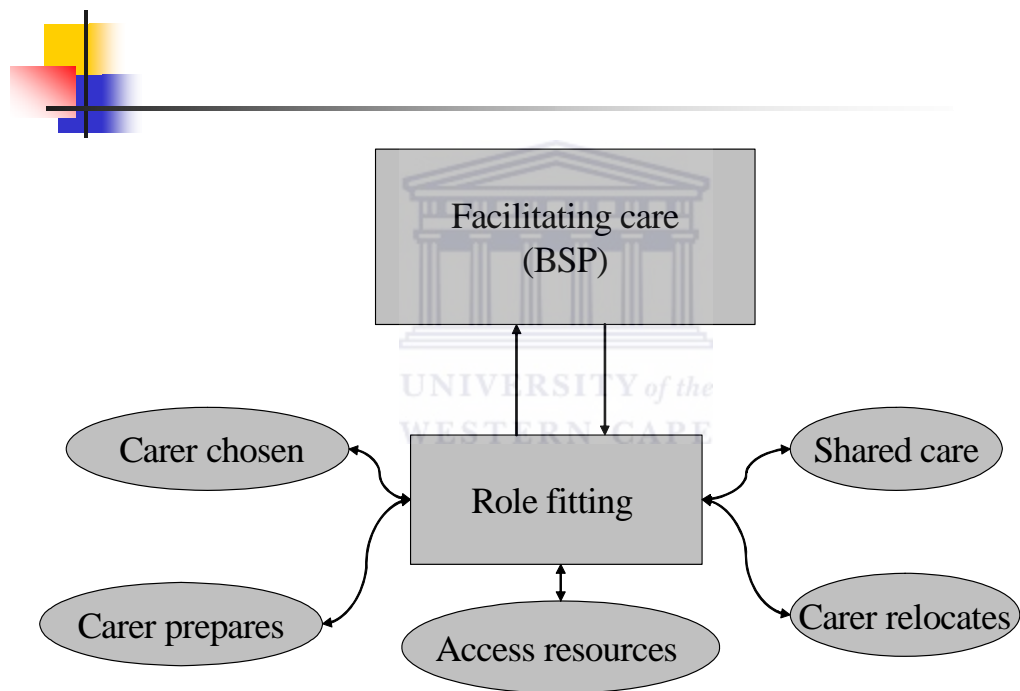


Figure 4.3.1: Action and interaction strategies – Role Fitting

Strauss and Corbin (1990: 97) state that action strategies occur under a certain set of perceived conditions. This implies that the more compromised the elderly, the more intensive, facilitating care becomes. Strauss and Corbin also suggest that all action strategies should be discussed in terms of their properties namely

process, purpose and goal. Process refers to a timeline, i.e. when does facilitating care start and does it really end? Researchers also have to specify the purpose and outcomes of fitting the role of facilitator of care into existing roles.

When does role fitting occur in relation to facilitating care?

The data indicated that, in most instances *role fitting* happens once the elderly has been hospitalized. Family and friends realize that someone has to take responsibility for this new role. *Prior relationships* become a key factor in the allocation of the role. Wives choose to accept the role (Resp: 10 & 13), partners (Resp: 05) feel as if it is their responsibility to do so, and daughters (Resp: 03, 07, 11) may feel compelled to care for their mothers.

Occasionally role fitting happened after the elderly has been discharged. This happened because the primary carers could not adequately fit the role into their portfolio of roles. The role was then allocated to someone else. Granddaughters re-allocated the role to the daughters of the elderly dependants (Resp: 01 & 02).

Analytical notes: In grounded theory it is important to indicate the relationship between the categories and indicate the relationship between the different concepts. It is also important to discuss the variations within the category (Strauss & Corbin, 1990: 253). In the case of role fitting, there is a close interplay between prior relationship, the incident and the current roles of the prospective carer.

What is the purpose and expected outcomes of role fitting in facilitating care?

The purpose of role fitting is to allow prospective carers the time to make sense of the new role. The goal of role fitting is to accept the role, to explore the expectations of the role and possibly to prepare for the role. It allows the

facilitator of care an opportunity to obtain information, develop skills and access appropriate assistive devices to perform the role.

The success of role fitting will depend on the following sets of perceived conditions:

- *the carer chooses to care*
- *the carer has experience*
- *the carer prepares for the role*
- *the carer is the sole provider of care*

The carer chooses to care

Most carers who chose to facilitate care had an established prior relationship with the elderly. A wife chose to care for her husband after fifty years of married life (Resp: 13). A gentleman chose to care for a partner with whom he had an adulterous prior relationship (Resp: 05). Two granddaughters (Resp: 01 & 02) whose grandmothers lived with them prior to the incident undertook to facilitate care even if it meant additional responsibilities. Two sons chose to reciprocate the care given to them by a loving mother who had an amputation (Resp: 14). In the cases where the carer chose to care a conscious effort was made to fit the role into their existing roles.

Role strain and role conflict developed when carers were chosen by others to facilitate care. A young mother (Resp: 11) was asked by her family to move back to her parent's house after her mother suffered a stroke. She and her husband had to sell their house and move, along with their small baby and two young children. In addition to having to fit the new role into her existing ones, she had to supervise a mentally compromised brother. These circumstances would clearly influence the degree of facilitating care this woman could offer her mother.

Resp: 11...You see I have this baby and I must see that everybody gets something to eat...my father and my brother...then I must see to it ... that my

baby is washed and...I must feed my baby and that the house must be cleaned and the washing must be done...and all those things... then at 12 o'clock I must fetch my kid from school ... and I have 2 children ...both of them wet their beds and this gives even more work ...more washing. Para 53. Feb 2004

An adult son (Resp: 09) had to resign from his work to care for his elderly mother who had an elective lower limb amputation. His sister, who did not work, was not prepared to care for their mother.

Resp: 09. ... he, usually paid her to look after my mom. When I used to work he'll like, tell her to come during the day, he don't like it... when we all had a meeting she also said, ... "I'll look after mommy but I can't do it for free". Para 311. Oct 2003. (Carer refers to his father who does not reside with them. His father used to ask his daughter to keep her mother company prior to the incident)

The carer (Resp: 09) also had a son and an ongoing relationship with the mother of his son. When he undertook to fit the role of facilitator of care into his existing roles his fiancé reconsidered their future as a couple.

Resp: 09. My son's mom, when I asked her, like, to get married and stuff like that, she's now thinking I'm doing it because my mom... but at the same time the way she's talking ... it's like she's... I'm the only one looking after my mom. And when we must go out or we want to go somewhere then mom is home alone then I'm okay, then I say... "but, I can't leave you at home." Stuff like that. Para 343. Oct 2003 (Carer cancels appointments because he does not want to leave his mother at home alone)

A family decided that a mother and wife (Resp: 04) had to move in with her parents and leave her own family to cope on their own. The carer accepted the decision because she states that... apparently our family is very close.

Carers chosen by others may experience difficulty (perceived or real) in fitting the role of facilitator of care into existing roles.

Reflective notes: Health care workers should become more sensitive to the concept of role fitting and how it impacts on facilitating care.

Analytical notes: Prior relationships clearly have an effect on role fitting. Carers are occasionally chosen on the basis of a prior parent-child relationship without

taking the adult child's current portfolio of roles into account. A consequence could be disconnected care resulting in severed social relationships.

The carer has experience

During the analysis I became aware that having had previous nursing experience did not adequately prepare one of the participants (Resp: 03), a registered nurse, for the role of facilitator of care. It did prepare her to provide all the basic health care needs of her elderly mother, but she struggled to access assistive devices, to fit the devices and to secure leave from her work. Fitting the role of facilitator of care into a busy working schedule proved to be problematic for her.

Analytical notes: After completing the first three interviews I realized that if I wanted to capture the experiences of carers I had to target those carers who have had the minimum of experience in providing care to adult dependants. I therefore set out to purposefully select participants who were novice carers. This did not work out as planned, since half-way through the second interview some of the participants would say..." Oh I remember that from working in a home for the aged many years ago"

Carers who have had some experience in providing care to elderly dependants could also face unique new challenges. A gentleman (Resp: 05) who cared for a partner could cope when she had a unilateral amputation. Following a bilateral amputation the role of facilitator of care became more demanding.

Carers who were novices generally adopted a wait and see attitude. They often did not know what to expect following the hospital discharge and were unclear about the role expectations. Novices would then consult with family members, acquaintances or professional staff regarding the responsibilities attached to the role.

Resp: 01. Yes. . uhm (laughs) I really didn't think about it (laughs) ... I thought ... we'll take it as it comes (laughs) and uhm. Para 272. Jan 2003.

Reflective notes: My found, that having had 15 years of clinical nursing experience prepared me adequately for the task at hand. It was a twist of fate that allowed me to fit the carer role into pre-negotiated sabbatical leave.

An incidental finding was that carers drew from past experiences related to facilitating care. When asked whether they have had any experience in providing home-based care they could initially not recall having had any. However, when asked how they knew to manage specific caring tasks they recalled having worked at an old-age home, at a private dwelling where the home-owner had some type of chronic illness or spent time as a volunteer at a day-centre. Others confessed to asking relatives who worked as nurse-aids for guidance.

The carer prepares for the role

The carers who set out to prepare for the new role were more successful in fitting the role of facilitator of care into their existing portfolio. Even though the preparation centered on the physical care such as the preparation of the room, it would indirectly impact the emotional preparation of the carer.

Analytic notes: There appeared to be a direct link between the experience of the carer and the level preparation done prior to hospital discharge.

The registered nurse (Resp: 03) embarked on an extensive preparation exercise that included re-arranging the furniture to allow for wheel-chair access, raising the toilet seat, raising the bed to facilitate post-operative care of her elderly mother, following hip surgery.

Some carers negotiated leave of absence from work, prior to the discharge, to re-arrange furniture but found, that once the elderly was discharged they had to revise the lay-out (Resp: 06).

Participants generally adopted a wait and see attitude and rarely engaged in pro-active planning activities. They stated that: ... this has never happened to our family... (Resp: 06) or ... I did not prepare anything because he will sleep in my bed and use my blankets... In the latter case the lady (Resp: 07) was instructed telephonically by the doctor, about the importance of a special diet as part of the care of the elderly. She, however, could not include this important instruction in her preparation of meals because she could not afford the expensive calcium-rich foods at the time.

Analytical notes: Once again a link between the prior relationship and the level of preparation was apparent. It appeared as if carers did not factor, the effects of the traumatic incident into their preparation to care. One may ascribe this to the lack of information and / or insight about the dimensions of facilitated care that would be required following the hospital discharge of the elderly.

A major impact of role fitting on the preparation to care, lies in the ability of the carer to access assistive devices. As part of their preparation carers were aware that the elderly would need a wheelchair following the discharge from the hospital. Many of them expressed frustration about the lack of information available to guide this aspect of preparation to care. A gentleman stated:

Resp: 05. The only thing that must be ... the only arrangements is ... I feel the hospital can give her a sort of a ... give her a chair ... so that I can...I see no difficulty ...I see no difficulty with anything! Para 70. Feb 2003

(Carer refers to a commode as a chair. The elderly has had bilateral lower limb amputations and the carer wanted the hospital to provide a commode to serve as a wheel chair as well as a commode).

One carer (Resp: 01) asked a relative, who knew somebody at the community health centre, to borrow a wheelchair for her ninety-year old grand-mother. Others (Resp: 06 & 07) borrowed assistive devices from family members or acquaintances.

Resp: 06. I knew...she is alone and the chair was from one of her friends. She loaned the chair to Uncle B...I was always under the impression that it was Uncle B's wheelchair. Uncle B had passed away and I asked his son to sell the wheelchair to me, as it would just be standing there. Then he told me that the chair was by Auntie BB. I went across and told her that M said that I could have the chair, that is, if she was not using it. She then told me that the chair does not belong to M, but to her. You never know what happens, I mean Uncle B sat in that chair for eight years and I did not know that it was not his chair. (chuckles)...You know sometimes things happen that you would never have thought about. Anyway, the chair is still in quite good condition, you know. Para 89. Feb 03

Resp: 07. My daughter had an accident, so she was lying at Karl Bremer Hospital. You see... she got the medical aid card. So the crutches were her crutches, so... fortunately now he's got something to lean on. Para 352 to 354 Aug 2003

One male carer (Resp: 05) approached various organizations unsuccessfully and ended up having to carry his elderly partner who had bilateral amputations around to the various rooms in their house.

Reflective notes: I remember that I had very little time to prepare for the role of facilitator of care. Simply by re-arranging the living spaces I eased the physical burden of care. Minimizing walking distances and drawing up schedules allowed me to fit the role of facilitator of care into other daily activities. I also discussed these plans with the elderly and re-arranged activities to accommodate the needs of both parties.

Analytical notes: Carers displayed different action / interaction strategies to deal with fitting the role of facilitator of care into existing ones.

The carer is the sole provider of care

Another condition that influenced role fitting during the preparation phase was the promises of family support to the carer once the elderly was discharged. With the exception of one son who diligently relieved his elderly mother (Resp: 13) from caring for his father, who suffered a stroke, in most cases these offers of relief were empty promises. A male carer (Resp: 09) remarked that his sisters

visited their mother in the hospital and pledged to support him but stated that he knew what they were like...they were always busy.

Analytical notes: It appeared as if many carers were prepared to fit the role of facilitator of care into their portfolio because they thought that the responsibilities of the role would be shared between family members.

Support from the health services also impacted on the process of role fitting. It would be easier to fit the role of facilitator of care into existing roles if the carer knew the dimensions of the role. In facility 1, minimal training was offered to the carers in the research sample. Some of the elderly were trained by physiotherapists to mobilize safely and do muscle strengthening exercises. They were also given referral letters for follow-up care. However, the carers did not receive any type of skills training. In many instances they had to resort to drawing on past experiences and coping with advice sourced from community members with regard to facilitating care.

In facility 2, a liaison person met with the potential carers prior to the discharge of the elderly and discussed the care of the elderly with them. However, on occasion, even this arrangement was inadequate since some carers were simply informed telephonically or during visiting hours that the elderly would be discharged.

A daughter (Resp: 11) had the experience of her mother being selected by the rehabilitation team to attend a structured in-patient rehabilitation programme. The family was very disappointed when this decision was overturned at the eleventh hour.

Analytical notes: The dimensions of facilitating care could be developed as a useful information tool. This tool could be presented to potential carers to guide the planning process and assist with role fitting. If one knows what to plan for, one could fit it into the other responsibilities that one may have.

A dimension of facilitating care that impact on the ease of role fitting was if the elderly accepted the disability and was keen to become as independent as possible. A single lady who had an amputation refused to move in with her sister (Resp: 12) who lived 20 kilometers from her. The sister was responsible to check whether the neighbours performed their delegated duties and undertook to arrange for the installation of a private phone. The sister assumed the role of carer, but shared out the responsibilities related to the role. Neighbours assisted with the following activities, e.g. bed-bathing, preparing meals and doing the laundry.

A male carer (Resp: 05) shared the responsibilities of facilitating care with his adult daughters. They provided the elderly's hygienic needs and prepared her meals while he assisted with mobilization, socialization and finances.

Being a sole facilitator of care hinders the process of role fitting. A daughter (Resp: 11) experienced role conflict when she had to fit facilitating care into her portfolio of roles. She had to juggle the roles of wife and mother to three young children, with the role of daughter to an elderly dependant parent.

4.4.4. MAINTENANCE CARE

Maintenance care represents the second strategy devised by the carer to manage facilitating care (Figure: 4.3.2). Maintenance care refers to Orem's dependent care activities. These include those self-care activities (activities of daily living) to which the elderly could no longer attend by themselves. These home-based activities were impacted on by the context in which facilitating care occurred.

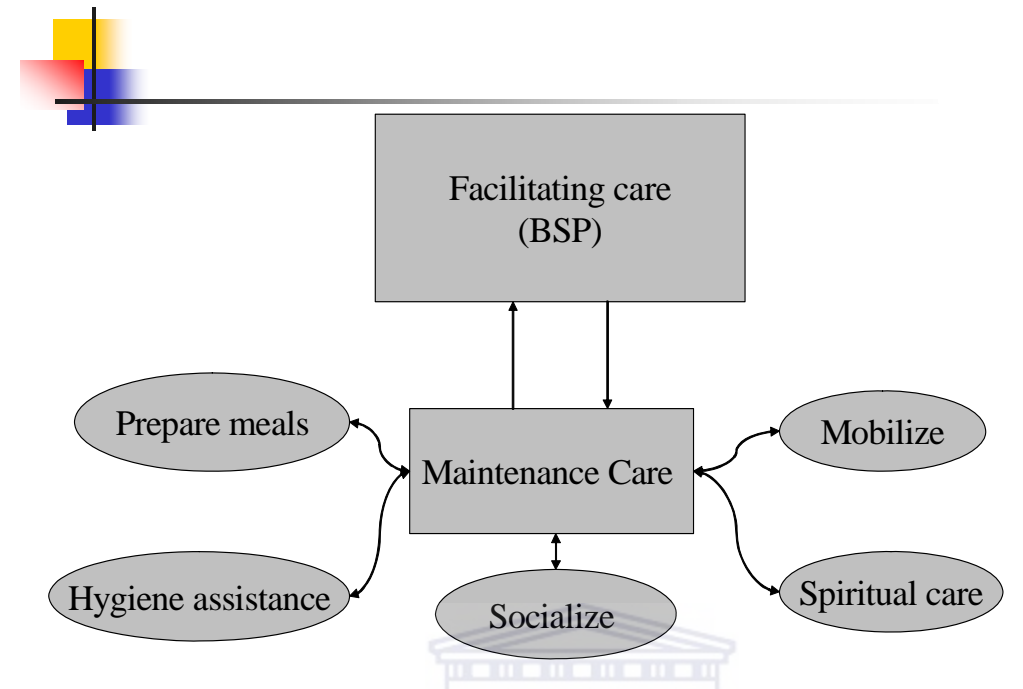


Figure: 4.3.2: Action and interaction strategies – Maintenance care

UNIVERSITY of the
WESTERN CAPE

When does maintenance care occur in relation to facilitating care?

Maintenance care is initiated once the elderly is at home. The dimensions of maintenance care required by the elderly, will depend on the severity of the incident and its subsequent impact on their activities of daily living. Carers generally regard these activities as their primary responsibility.

Analytic notes: When carers were asked to describe a typical day they would focus on washing, dressing and feeding the elderly. It would generally appear as if any other activities become secondary to the above-mentioned ones. The interviewer had to probe about activities like elimination, mobilization, socialization and financial management.

What is the purpose and expected outcomes of maintenance care in facilitating care?

The purpose of maintenance care is to sustain the elderly. Ideally maintenance care entails assisting the elderly to maintain optimal physical, emotional, spiritual as well as social well-being. It is thus important for carers to understand the limitations caused by a particular traumatic incident and the dimensions of facilitated care required by the elderly throughout the period of recovery. The categories identified in the data included: assist with hygiene, meals, mobilization and elimination. In addition carers provided emotional and spiritual support.

The initial goal of maintenance care is to assist with self-care activities but allow the elderly to progressively develop independence in performing these activities.

The conditions that may influence maintenance care are complex. They include:

- *The knowledge and skills of the carer.*
- *The context of care, i.e. the home.*
- *Caring and sharing caring activities*
- *Access to basic resources*

The knowledge and skills of the carer.

Knowledge and skills are linked to the experience of the carer. The registered nurse and the lady who worked as a nurse aid were able to provide maintenance care to the dependants. Those carers who had limited knowledge and skills become aware of the challenges associated with maintenance care activities. The assumption is that if novice carers are trained prior to the discharge of the elderly and become proficient in assisting with the basic needs of the elderly, this would not constitute an important variable in facilitating care. A lack of information limits the ability of the carer to provide maintenance care to the

elderly. Carers state that: providing care is a new experience for the family ...I thought we'll take it as it comes and...I thought it would be easier (Resp: 06).

In Facility 1 there was no evidence that carers were trained by nursing staff to provide the basic needs of the elderly. Despite having a liaison person in Facility 2, some carers of elderly patients who were discharged did not receive any training. In both facilities the elderly were given discharge letters that focused on specific interventions, e.g. wound dressings or the removal of sutures.

Analytical notes: Once again there is a close link between the concepts; knowledge and skills, preparing to care and assisting with hygiene, meals and mobilization. It is important to point out the relationships between the concepts that are generated during the data analysis process, to illustrate the empirical grounding of the study (Strauss & Corbin, 1990: 254).

According the Health Care 2010 plan of the Western Cape Department of Health (2002), trained home-based workers would provide the link between the various health care services. This type of support does not seem to be available, since an inadequate number of home-based workers are currently employed. The training of informal carers should, therefore, be included in the discharge procedure at all health care facilities.

The context of care, i.e. the carer, the elderly and the home-setting

Analytical notes: The categories, prior relationship and maintenance care are linked at many levels. It was relatively easy for a daughter to provide maintenance care to her mother. Cultural factors may impact on her ability to do the same for an elderly father. When a son, instead of daughters, provides maintenance care to their mother, society may frown on the daughters.

An african woman (Resp: 07) was not allowed to provide the hygienic needs of her father. She explained that it is not acceptable practice in their culture for a young woman to bath an older male.

The layout of the rooms in the house may also influence the provision of maintenance care. A niece (Resp: 08) struggled to get her uncle to take a bath. He refused to wash because of the inconvenience of not being able to get to the bathroom. He also refused to have an assisted bed-bath and simply wiped himself down. The male members of the family had to physically carry him to the bathroom for his weekly bath.

Carers (Resp: 06 & 14) moved the elderly from the bedroom into the living room to facilitate mobilization and socialization.

Analytical notes: Intensive maintenance care impacted on role fitting. If the incident affected many of the elderly's activities of daily living, the level of maintenance care required would take up much of the carer's time and leave little time to attend to other role expectations.

Caring and sharing caring activities

One of the elderly carer's day started at 06:30. She (Resp: 13) would do all of her household chores before 08:00 so that she could then fit her husband's ablutions and breakfast (maintenance care activities) into the rest of the day. Some carers were able to provide physical care and others found it difficult.

Resp: 02 It is... if I had bathed her, I dressed her ... she must be clean every day ...she wee -wee in the bed... we cannot take her to the toilet ... then we take everything off ...wash everything and that is how the day goes by... 2 or 3 times a day. Para 167. Jan 2003

I wash mama in the morning, we fight a little over the washing..."I am clean, I am not wet"...and so on, and she says she is getting sore. I can understand that, but I can't leave her, because as you know, people come here to my mother. Para 351. Jan 2003

Resp: 09...in the beginning, I actually preferred taking her to the bathroom on the wheelchair and ... the ... washing part is concerned ... I'll leave with a bath of water and she'll do, like, the private parts and so. And I'll wash her back and feet and so on. But she mostly... she does it on her own. I'll just wash her back maybe... Para 99. Oct 2003 (A male carer facilitating care to his elderly mother)

Resp: 08. He ate a sandwich this morning and now this afternoon he ... I had the polony and potatoesa cooked meal he had this afternoon... he did not eat all of it ... he does not eat a lot.... Para 109. Oct 2003

Resp 13 Oh...he eats a lot...he eats well... In the morning I give him the...no sugar and salt ... Weetbix. At eleven-o'clock a biscuit...cream-cracker and tea. And in the afternoon I give him boiled vegetables. Para 278. July 2004

Carers mobilized the elderly by placing them in a chair (Resp: 02) and accompanying them to the toilet. One elderly gentleman who had suffered a stroke, walked unassisted, fell and hurt his arm (Resp: 10). An elderly lady who had a lower limb amputation insisted that her grandson accompany her to the toilet. She refused to use the commode that was placed next to the bed. Her son (Resp: 09) who was the primary carer was not at home at the time.

Resp: 10. The arm is very sore.

Int: Uh-huh. Has he had a fall? He had a fall?

Resp: Many falls. I'm ... not listening. Para. 482- 485. Nov 03

(She points to her husband when she states, " I'm ... not listening" implying that her husband is the one who is not listening)

Resp: 09 ... so my mommy forced him to put her on the wheelchair. He said, "No, my daddy's coming now ... just to go wee in the toilet ... but the commode is right next to the bed." Then she told him, "no, but he just cleaned it now, I don't want to dirty it." He took her... but when she asked him to take her off the chair onto the toilet, he said, "No, but I can't do it." And she insisted and she fell, but it wasn't bad, she was more shocked than anything. Para 253. Oct 2003

Most carers tried to provide emotional support to the elderly. They seemed to be acutely sensitive to the emotional needs of the elderly and were able to interpret non-verbal cues.

Resp: 06. It's not so easy to explain it ... but as I know my father, if you sit with him every day, he speaks with his eyes. Like last night when I came here, I sat there on the couch and he did not talk to me... he just sat looking at me all the time...all the time. He just looked at me. I can see the fear in his eyes, he wants

to get up... but, he knows he can't. Para 222. Feb 2003. (Elderly suffered a stroke).

Resp: 09. ... she'll tell people straight ... she open up the leg and show it to them and stuff like that. But I feel at times ... and especially when she's alone ... I saw at times ... her eyes is closed and when she's slightly sleeping ... she's not sleeping, then she's, like ... crying... Para 301. Oct 2003. (Elderly had an amputation).

Carers involved the elderly in decision-making and provided them with time to accept their limitations.

Resp: 08. I think that he has had a bit of a shock...and now he cannot handle the fact that he cannot walk... that is why I do not bother him a lot... I let him carry on. Later on when he realizes that he has had this incident and that he has accepted the stroke then... Para 287. Aug 2003.

Resp 12. Then I said yes ... you can go home ...under the circumstances, I then asked her "do you want people in your house, or do you want us...or the neighbours ... to look after you?" She then said that she just wanted to go home. Para 9.

So we take it step-by-step, we also don't want to put too much pressure on her. At present she is satisfied with things ...I laugh when I ask her "Stump how are you?" Then she says, ..."it is fine." I do not want to have her think about a false leg at this time...she first has to regain her strength...she first has to get well. Para 111. Feb 2004.

Carers attended to spiritual needs by allowing the elderly to practice their faith. Others drew on faith to support and inspire the elderly.

Resp: 06. When he was discharged from the hospital he had a great faith that he would walk. But he was not able to walk. He kept urging us to get the Pastor for him. I don't know where this great faith in this pastor came from... he also lives here in Ruyterwacht. He belongs to the Church of Faith... or something. And he is one of those people who when he prays, touches you on the head and when he prays you fall to the ground. The people fall down. I don't know if it is the truth. I can't believe in that. I believe in God in my own way...He is there...and you believe in him. A miracle can only happen if you want it to happen. Para 218

Nobody can come and take you, a cripple, by the hand and say you will walk. Not if he himself wants to allow it to happen. So we got the pastor, and he came, he anointed him and all...I was here...and he prayed for him...and my father thought he was going to get up there. I could see it in his eyes. He has since not spoken about that man. You see, he had that faith, he thought that man was going to heal him. Para 222. Feb 2003

Resp: 11. I just looked at her and I tried to encourage her and I said to her... well the Word of the Lord tells us if a hand limits you, cut it off...and following the amputation...thank God...she was much better than before ...and the family...we prayed a lot and thanked God who gave us the strength ...and I have to confess to you that it is not easy ...but God makes all things possible... Para 5. Feb 2004.

In many cases carers would share the responsibilities related to maintenance care. Tasks were shared between family members, neighbours and acquaintances. Traditional roles seldom changed in a caring situation.

Resp: 01 ...then I ask my daughter-in-law to come just to help to wash her and so on... Para 171. Jan 2003

Resp 07. Ja, we help each other. Today, my lastborn... he's the one who washed his grandpa today...because he is very heavy for me... because I've got arthritis. Para 277. Aug 2003

Resp: 08. ...and the washing..."when did we bath him?"...the day before yesterday ...yesterday morning... that I do... but the men take him, Saturday I had his haircut and then we gave him a nice bath and so we see that he has clean clothes, under clothes and so forth...Para 207. Aug 2003

Neighbours performed maintenance care activities when the carer did not live with the elderly. One carer (Resp: 12) lived in a different suburb and would only monitor the maintenance care provided by various neighbours. In addition she would provide emotional and spiritual support and encourage her elderly sister to strive for independent functioning, despite having had an above-knee amputation. Acquaintances would assist by carrying the elderly down flights of stairs and carting her, by wheel-barrow, to the clinic or church.

Occasionally the elderly would insist that the primary carer provides maintenance care and would not accept assistance from family members or friends.

Resp: 06. ... there is also my friends downstairs, J and his wife, they are very helpful. Really, they are very helpful. She is a big, strong young woman ... she comes and helps him often. Then they also phone me and say: "R, you must come, your father is calling for you, he wants you". He calls me, he does not want other people to help him ... he wants me ...Para 142. Feb 2003.

Reflective notes. I could identify with the experience of this carer. I remember how my aunt insisted that I assist her with everything. Even when others would offer to dress her or feed her she would insist that I do it. I recall that I was frustrated by her behaviour but felt guilty and ended up doing almost everything.

Analytical notes: I think that professionals should be aware of this type of interaction between carers and the recipients of care. It adds to the burden of care and could lead to disconnected care. Professionals need to sensitize the carers to the value of sharing caring tasks and sensitize the elderly to the carers' need for respite from caring.

Access to basic resources

Maintenance care resources refer to those required to feed, bathe, clothe and provide comfort to the elderly. The underlying variable would be financial resources. All of the elderly people, who participated in the study, received the aged persons grants or private pensions. The carers did not receive grants and most of the primary carers did not have any income.

A carer (Resp: 08) who lived in an out-building was aware that her uncle needed a balanced diet, but because he did not buy vegetables, she could not prepare a balanced meal. She did not have an income and her husband did not work.

Feeding her elderly mother who had difficulty maintaining an upright position in bed was challenging to a daughter (Resp: 11). Encouraging her mother to wash herself was too time consuming. She reflected that she knew that it was the right thing to do (to build her mother's self esteem) but she had too many other responsibilities and could not waste time doing an assisted bed-bath.

Ensuring dry bed-linen proved to be a challenge when the elderly became incontinent of urine and faeces. Carers (Resp: 02) did not have enough linen or had difficulty drying linen in a winter-rainfall region.

Carers found it difficult to provide appropriate maintenance care if they could not access financial, human and material resources.

4.4.5. REPAIR CARE

The third strategy employed by the carer in the process of facilitating care is repair care. The incident placed functional limitations on the elderly (see the properties of the traumatic incident, Figure: 4.2). Repair care is the care given to the elderly to ensure optimal functioning within these limitations. Repair care is commonly referred to as rehabilitation. Carers may not be aware that their role includes facilitating functional repair care. They intuitively encourage the elderly to make independent decisions and push their (elderly) limits towards recovery

Repair care is a long and complex process that may be influenced by internal and external factors. Carers should ideally understand their role in this process and be able to monitor repair care. These action strategies involve the proactive management of factors that may influence the repair process. A simple example would be the carers' ability to access assistive devices. They also have a responsibility to actively involve others, i.e. community workers and professional experts to provide support and guidance to the elderly and to themselves.

Informal carers have to assist the elderly with most of the dimensions of societal functioning, i.e. physical care, mobility, social integration and financial management (WHO, 1980). The anecdotal evidence corroborates that carers helped the elderly to attain an optimum level of societal functioning despite the limitations caused by the incident.

The following findings indicate the carer's involvement in facilitating repair care. The range of activities (categories) included: carer provides special skin care,

provides special diets, positions limbs, accesses assistive devices, supervise special exercises and encourage independence. The findings also show the dimensions of repair care, i.e. how some carers could provide special diets and while others could not (see Figure: 4.3.3).

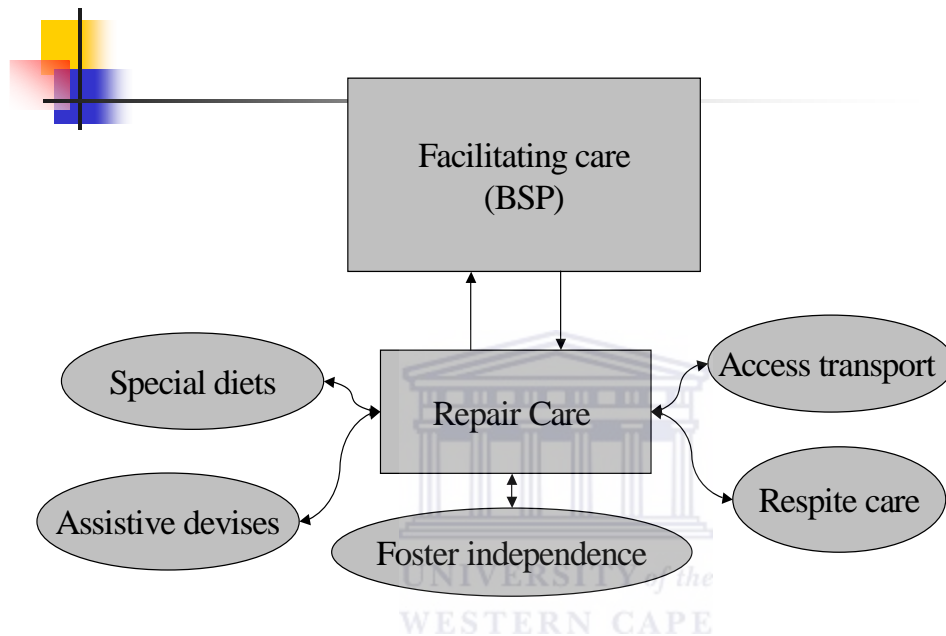


Figure: 4.3.3 Action and interaction strategies – Repair care

Analytic notes: It appears as if carers participate in these action strategies but do not link them directly to repair care. They rely on intuition and common sense to encourage and push the elderly to functional independence.

The outcomes of repair care would impact all the aspects of the conditional matrix.

Relationships within families are improved if the primary carer is supported. This was done by providing assistance in the acquisition of information and skills as

well as sharing in the caring tasks. Most of the findings showed limited or no support to the carer. Care that was shared became bearable to the facilitator of that care.

Reflective notes: Family members who exploit carers and sit in judgment of them should be educated. It was not clear from the research outcomes whether the family members exploited the carers intentionally or because of a lack of insight with regard to the burden of care and the need for respite.

The research outcomes indicate that neighbours and friends often share in facilitating care. This shows some involvement of the community in the rehabilitation of their elderly members.

Re-admissions to hospitals as a result of preventable complications of inadequate repair care could become costly to the state. Carers were generally ill prepared to prevent complications and to monitor the repair process. The lack of involvement of the family, community and professional health care providers, also impeded the repair process. There appeared to be a gap in the continuity of care across the different levels of health care services.

Conditions that impact on repair care:

- *Repair care is dependent on the gravity and properties of the incident (Figure 4.2)*
- *Repair care is dependent on the context of care, i.e. the carer, elderly and setting (4.3.1)*
- *The carer should monitor the repair process*
- *The carer should involve others in the process to ensure optimal recovery i.e. family, community and professionals.*
- *The carer should have access to resources*
- *The carer should have access to respite*

Repair care is dependent on the gravity and properties of the incident.

The properties of the incident impacts both maintenance care as well as repair care. Carers not only prepared meals but they have had to provide special or modified diets. The carer whose elderly father suffered a hypo-calcaemic incident had to buy calcium-rich foodstuffs.

Resp: 07. Dr. K. said he must eat... green vegetables, and all that. Yes, he told me the Wednesday, that he was going to be discharged on Monday, so he phoned me and told me that I must buy ... dairymaid ... cheese and milk, yoghurt ... custard, all those things. But now, I didn't have money that time, only now I can go buy vegetables ...beans, broccoli, spinach, and all that. Para 101. Aug 2003.

Another carer struggled because the elderly became constipated following a CVA.

Resp: 06. He is a little bit constipated ...I can understand that, because he is not active, you know, but he eats a lot, he eats well. And then, my wife, who works at the hospital, she is a dietician ... she makes prune juice for him. He does not drink all that she prepares, he drinks a little and then says that he does not want any more. She has to force him to drink it so that he can have bowel action. Wow, he really struggled initially, but we got him to a point where he has fairly good bowel action.

This morning at a quarter to six she (the carer's stepmother who lives with his elderly father) phoned me and said that he wants to go to the toilet. Okay, I got up, no big deal, he is my father, I came here, put him on the toilet. He did not toilet yesterday...I said: "what is one day?" I mean an ordinary person does not go every day... to have a bowel action. Para 206. Feb 2003. (The carer does not live with his father and stepmother)

A carer provided special skin care by purchasing an egg-box mattress.

Resp: 03. ... she did have some skin breakdown on her sacral part... and strangely enough, now when she came here (home from the hospital) and we put her on the bed...Fantastic! For me it makes an unbelievable difference, she doesn't lay herself through. Para 189-193. Jan 2003 (Carer used a egg box mattress)

Carers encouraged the elderly to do special exercises.

Resp: 08. The leg is relatively strong... he lifts himself very good ...he lifts himself from the bed. Yes, he moves.... he moves his arm up and down ... and he moves the leg up and down...Para 133-137

Then I tell him "move" ...P must move up and then he takes the weak leg and puts it across... and then he moves. And then we must move the arm. And sometimes he just throws the arm... but he carries on. Para 279. Aug 2003.

Carers did wound dressings and monitored the condition of the elderly's wounds.

Resp: 09. The one doctor was, like, worried. He said it looked, like, infected slightly. But then when he called the vascular surgeon, I think...

Int: uh, uh.

Resp: ...and he said, "No, it's fine. It's just, like, a small leaking." They, ... I don't know, ... they mentioned, like, clips that makes a mark on the skin ... and so on. But he said no, it's fine. As long as it's clean and the dressing goes on then it's fine.

Int: and about the dressing...who's doing them now?

Resp: uhhh...usually I just put...they...they said just a dry dressing. Para 277-281. Oct 2003

Carers supported the elderly towards independent functioning. Some encouraged them while others took a tough stance.

Resp: 01 Oh I'm laughing like this because my daughter-in-law said... "No grandma must get a wheelchair" and I said..."Man, the wheelchair is not such a good idea." I said... "its alright if one wants to come in here, or want to go out"... I said... "but to go to the toilet.... grandma should really be walking." Para 507. She said... "Why shame! It hurts when grandma has to walk". I said..."yes, but if grandma is just going to go on sitting, she is going to become as stiff as a poker." Para 511-512. Jan 03.

Resp: 08. I try and do things because I want P to walk again...or P must be as close to how he was...I don't want him to simply lie inside...He adopted this attitude the past week that he does not want to do anything for himself...it is as if he wants to challenge us. Then I scold him... I tell him ...P must get up... walk as far as the gate...walk to the cone-lorry...if P wants a sucker. The more you lie...it will cause swelling ...the swelling of his hand is because he only lies on the one side. Para 418. Aug 2003.

Resp: 12. Number one... I have made her to understand that her leg is off ... but her life is not over, she has to move herself... she has to take care of herself. She also don't want to share the house with other people... and so she... the Lord helps those who help themselves...because it does not mean that now that she has been discharged...and we help her...and the... neighbours help her

...that she does not need to do anything for herself. She has to help herself. I take it that I will not always be there ...neither will the neighbours...because we don't know what will happen tomorrow. Then she knows that she independent...because all these years she has been independent. She always lived by herself and...I feel that it is proper to continue... Para 37. Feb 2004.

One of the more pressing problems that many carers faced was an inaccessible public transport system in the Western Cape. Carers had to hire cars, borrow wheel-chairs and on occasion make use of wheelbarrows to get the elderly from point A to point B.

Resp: 01. They say I can take Grandma for physiotherapy at the Day Hospital. I said ... "how are we going to get grandma there if we go with the four-by-four? " [Laughter] I do not know how we are going to make it...to get there...because it is a struggle to go there with the car...to get in and out of the car is difficult. Para 568. Jan 2003 (The carer refers to the wheelchair as a four-by-four)

Resp: 05... we do not have transport to bring her to the pay-point. Para 82. Feb 2003

Resp: 09...Because, like, last week also we didn't have a lift to the Day hospital so I took her on the wheelchair, and it was nice for her to see the main road again where she used to like walking. But when we came back it was a bit uncomfortable so we stopped by the stadium. Para 124. Oct 2003. (The carer pushed the elderly in a wheelchair over a distance of more than two kilometres)

The anecdotal evidence shows that most informal carers assisted the elderly by preparing special diets, supervising mobilization, fostering independence and encouraging social re-integration. However, the dimensions and gravity of the incident, the availability of financial and other resources and the access to public transport, affected the carer's ability to perform the repair care activities.

Repair care is dependent on the context of care i.e. the carer, elderly and setting.

Context of care directly impacts on the quality of facilitated care that the carer is able to provide, i.e. maintenance and repair care. It is important to note that the planning of repair care starts prior to the discharge of the elderly. Once the

dimensions of facilitated care are established the team involved with the repair care should draw up a focused plan.

Carers were not directly involved in discharge planning or decisions about the type of rehabilitation planned for the elderly. Some were not informed about the discharge of the elderly:

Resp: 09. Then without phoning or letting me know, they just brought her like that.

Int: Oh.

Resp: But the night before she... when we got to the hospital she said, "Where were you the whole day?" The doctor said ... but it was not major, it was just like ... nobody actually told me that she was gonna be discharged.

Int: Uhhh-uhmm.

Resp: ... didn't know anything, anything. Para 85 to 89. Oct 2003

Other carers were informed telephonically

Resp: 07. Sometimes I got no money to go to hospital, then I phone the sisters and they say, No, he's coming on all right. So, until I got the...I phoned this Dr. K because he left a message because he... he's worried, because he wants to know where he's (elderly) going to be...

Int: Once he's discharged?

Resp: Yes

Int: Oh, Okay

Resp: So Dr. K. phoned me, so he asked me everything. He said okay, if you think that you can be responsible to take your father, and please ... it ... the problem is that we want somebody who is going to be responsible for the medicine, you see ... to look after him (elderly), and then, seeing he told the clinic that he's all by himself, he needs some people that he can talk to. Para 33-41. Aug 2003.

Carers had to deal with the decisions that the elderly did not fit the criteria of a structured rehabilitation programme.

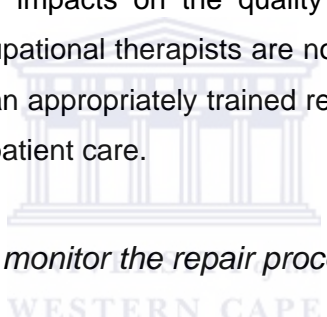
Resp: 11 The hospital did give a letter to me...there was a suggestion that my mother go for rehabilitation at C...they spoke to the family...my father...but at the end of the day nothing happened...they changed their minds because she won't ... Sr. W... everything was filled in and then they stopped the process...they said that she wouldn't qualify. Para 141. Feb 2004

There was no evidence that the carers were assisted by professionals to provide repair care within the confines of their homes / apartments. A carer stated that:

Resp: 06. He (the elderly) said that it is too much of a problem ... seeing that the flat is so small ... it is too difficult to get him to the room and to the toilet ... to get around all this furniture here. We have made the couch nice and stable for him, now I can just put him in the wheelchair and take him to the bathroom or toilet. Then it is not so far to move...as you can see it is not easy to... because you know ... to move a wheelchair around here. Para 73. Feb 2003

Reflective notes: It was clear that no professionals were able to visit the elderly at their homes. The carers were therefore not advised to adapt the environment to facilitate repair care.

Analytic notes: The lack of information with regard to the adaptation of the environment, negatively impacts on the quality of repair care. If professional physiotherapists or occupational therapists are not able to provide support within the home setting, then an appropriately trained rehabilitation worker could fill this gap in the continuity of patient care.



The carer should be able to monitor the repair process

It appears as if carers instinctively monitor the repair process. Their responses are often subjective, e.g. ... her health is improving (Resp: 12) or, he was very sick last night (Resp: 13). It also appears as if carers draw on prior knowledge and past experiences to manage crisis situations.

Resp: 12. Well for the past month I must say things went well, especially as far as my sister...her health is concerned ...her health is improving every day and I thank God for that. She is regaining her strength every day ...improving every day ... Para 120 - 124. Feb 2004

Resp: 13 Yes, because he was very sick last night, so I sponged him down with vinegar...like the older people would ... you can go and have a look ... it was worse last night ...and these things happen mainly during the night. Para 383 July 2004

Reflective notes: I found it relatively easy to monitor the repair process, having had fifteen years of clinical nursing experience. I cannot imagine how stressful it

must have been for some of the carers, whose family members suffered severe strokes. I think that by training and supporting carers, one could alleviate the anxiety associated with the management of crisis situations and the monitoring of the dependant's condition.

The carer should involve others in the process to ensure optimal recovery i.e. family, community and professionals.

There was evidence that carers attempted to involve others but it happened on an ad-hoc basis.

Resp: 11. Then my aunt phoned my sister ...anyhow so my sister came to the hospital and then I went home...so I left her there ...because I have the baby ...and the house. That day my baby was very difficult...and my father is weak. So she helped me for that week ...when she took leave. They help me in their own way, she was here for a few days and then she washed my mother and then she *sommer* ... she goes and lays next to her. I carry on with ...the house and the washing...you know. They help, but ... don't really help, that is always the case ...and the kimbies ... if I don't have the money... I will ask my sisters. Para 230. Feb 2004. (The carer refers to adult diapers as kimbies)

Resp: 13. I ask the neighbour...sometimes if I want to go to the shop, then she will come and sit here. She is also very concerned about him ...the neighbour across the road. Para 194. July 2004.

Resp: 06. So I spoke to the Social Worker ... told her ... listen... I spoke to my sisters ... both of them, and we would each contribute money if she could help us get a nurse or someone here. She said that a nurse would be very expensive, and then she told me about T, who would not be as expensive and who is a very nice person. She really is that. She needs to come three times a week and I need to pay her for every call ... R15 /call you know...which is really worth it. Para 126. Feb 2003. (T lives in the neighbourhood but has had no formal training. She assists with bed-baths)

Resp: 13. It is a young woman of 23 who comes on a Tuesday and... Thursday...but she comes very late...I feel that somebody like this (refers to elderly) you have to attend to earlier.

Int: Maybe she has other...

Resp: Yes attends to four...four people...or five...and I am the last person...So on Thursday ... she got here at half-past one...I feel that it is a bit late...to have him lie...you know...Para 210 – 214. July 2004. (Carer refers to a young woman, a home-based worker from a NGO, who assists with bed-baths)

The experiences shared by the carers, indicate a gap in the role-out of primary health care within the context of community-based rehabilitation. Inadequate numbers of home-based workers have been deployed and it questioned whether these workers are appropriately trained to provide the rehabilitation support needed by the informal carers within their homes (the community).

The carer should have access to resources

It is clear that carers were inadequately informed to access resources. They did not know how to deal with the additional expenses associated with facilitating care. They also did not know how to access assistive devices (see 4.4.3).

Resp: 11. I cannot get somebody to help because financially I am not capable to do that and ...my brother and sister are not help financially ...I mean the expenses of my mother ... I have to carry all the costs. Para 9. Feb 2004

Resp: 08. Yesterday he gave R20 for the assistance ... because I washed his things...so I said no, I don't want it. I said it is not a problem...I do for you... it is a pleasure. The only thing that I want is for P to eat healthy foods...I mean a tin of meatballs will not last a week...and it is not healthy foods...because I do not have cooked food so that I can offer him. We struggle at the back, we do not have gas... there is nothing that I can use to give P a plate of cooked food. "Buy the things and tell me ...then I will cook it... Then I will at least know that P is eating healthily. That is the most important. P cannot eat patties the whole week... you have to eat rice, a potato, a starch"...so this afternoon I brought him a plate of food. Para 414. August 2003.

Resp: 08. So this man comes along and he asks the man to check whether there is money in the bank. So I got so mad...but I didn't say anything. We struggled to get home ... so I confronted him I said: "if P does not trust us what then" ... (whispers) ... I told him "P, we are caring for you... we have to struggle with you" ...and then he shouted at me. However, the following day he apologised. Then he asked me to check his bank statements. So everything was quite hunky dory. Para 419. August 2003.

Reflective notes: Finances remain a scarce resource and carers should be encouraged to seek assistance from family members and accept donations from the elderly. The elderly, who receive aged persons grants, should also be encouraged to provide financial support to the carers.

Analytical notes: It appears as if the carers facilitate repair care regardless of financial constraints. In some cases there is a clear commitment to care, which is not dependent on socio-economic factors but closely linked to the prior relationship between the carer and the elderly.

The carer should have access to respite

Many of the carers express the need for respite care.

Resp: 13. What I would have liked ...I don't suppose it can happen...is for some one to come here for more than two days. Para 346. July 2004

Resp: 11. My father said this morning ...if there is not a hospital...If we cannot take her to a hospital...but I think that it is useless to take her back to the hospital ... they will ... you know they will take her for an hour or two... and then they will send her back again... but I can really not ...I can really not handle her, she is a bit too heavy to lift. Para 201. Feb 2004

Resp: 10. I'm not... They...I just think to myself that they should know they must come and relieve me. Para 817. Nov 2003. (Carer refers to her children)

Reflective notes: I think it is imperative that professionals take the lead in the education of the family and community, with regard to the need for respite care. The provision of respite services could also be included in the job description of rehabilitation or home-based workers.

From the research findings the consequence of facilitating care is reflected in the connectedness of that care.

4.4.6. CONNECTEDNESS

Connectedness refers to the consequences of the action strategies employed by the carers namely, role fitting, maintenance care and repair care. The challenges embedded in the action strategies and the level of support provided by others also impact on the connectedness of care. The dimensions of connectedness of care are *connected care* vs. *disconnected care* (Figure: 4.4).

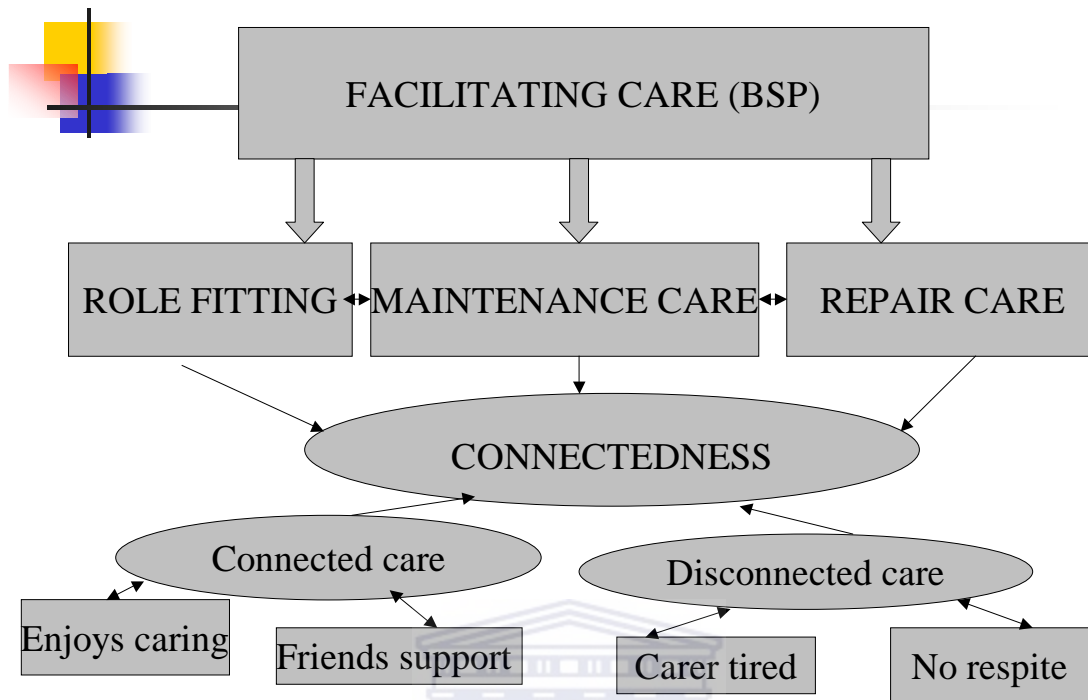


Figure: 4.4 Consequences of facilitating care - Connectedness

Connected care refers to the experiences of carers who: are able to fit the role of facilitator of care into their existing roles, are able to provide maintenance and repair care within a specified context, are able to manage challenges constructively and have the support of the family, community and the professional rehabilitation team.

Disconnected care refer to the experiences of those carers who: are unable to fit the role of facilitator of care into existing roles, are unable to provide adequate maintenance and repair care, are unable to manage challenges associated with facilitating care and are not supported by their family, community and the professional rehabilitation team.

Connectedness of facilitating care will depend on the following conditions:

- *Carers should be able to fit the role of facilitator of care into their portfolio of roles*
- *Carers should be able to manage the physical, emotional and social challenges of facilitated care*
- *Carers should receive personal and professional support while facilitating care*

Carers should be able to fit the role of facilitator of care into their portfolio of roles

The findings show that some carers are able to fit the role into existing roles by, e.g. scheduling activities around the caring responsibilities, sharing caring activities and planning time-out sessions. These are the carers who view caring as an extension of, e.g. marital responsibilities. An elderly lady (Resp: 13) stated that: ... it is a bit tough but...I actually enjoy it.

Other carers are unable to fit the role because of the extent of their existing expectations. When a wife and mother of three was asked to care for her elderly mother who suffered a stroke she experienced extreme role strain. She said: (Resp: 11) ... it is taking its toll on me...I feel that my life is on hold...I am not complaining...I am not complaining...

Carers should be able to manage the physical, emotional and social challenges of facilitated care.

The physical challenges were highlighted during the discussion of maintenance and repair care. The female carers were particularly burdened by some of the physical caring activities, e.g. mobilizing and bathing the elderly. These challenges were mentioned during the third interview when carers stated ...it is taking its toll...I am tired...(Resp: 11)

Participants experienced the following psycho-social consequences of facilitating care.

Connected care	Disconnected care
<i>Carer enjoys caring</i>	<i>Carer tired</i>
<i>Caring pleasures</i>	<i>Caring frustrates</i>
<i>Carer maintains social contacts</i>	<i>Carer isolated</i>

Once more the experiences of the carers in the study reflect a fluctuation between these dimensions. The carer who is not able to fit the role of carer into her existing responsibilities will become exhausted and experience carer fatigue. This in turn may lead to social isolation.

Resp: 02. I cannot go anywhere, now that mamma is back from hospital. Para 231. Jan. 2003

Resp: 11. I feel that my life is on hold. Para 81. Feb. 2004

Family members who visit and expect the carer to attend to their needs as well as those of the elderly add to the burden of care.

Resp: 11 ... Yes ... two weeks ago they came to my mother ... it was only the family you know ...and so on ... and served cookies ... like on a Sunday ... but I did not even know that they organized something ...it was to cheer my mother up a bit. They said I don't have to do anything ... "we will bring everything"...and when the people got here ...they were sitting and stuffing themselves ...and I had to... I washed up three times...so I said: "what is the use if you come and exhaust me more" ...no ... so my husband also said that I must tell them that the next time they must do it at their own houses... and they can come and fetch my mother ... Para. 278. Feb. 2004

Reflective notes: During the period that I cared for two elderly family members this was one of my personal gripes. Family would visit and leave without cleaning up before they go. They would tell you that you appear to be tired but do nothing to make your life a bit easier.

Analytical notes: There appears to be an interplay between the physical and psycho-social challenges, i.e. the carer who is physically tired, in particular the older carer, would become frustrated and would subsequently not have the motivation to socialize.

I intentionally used in-vivo codes when carers described the emotional consequences of caring. These phrases, grounded in the research data, gave a voice to carers who were seldom heard by the elderly, their family or the health care service providers. In-vivo phrases also allowed the researcher to set aside her personal experiences and focus on those of the participants.

Resp: 01 ... we had become used to it and adapted and so on ... Para 230. Jan 2003.

Resp: 06. ... we have been struggling Para 25. ... this has never happened to us before. Para 254. Feb 2003

Resp: 08 ... I do for you... it is a pleasure. Para 414. Aug 2003.

Resp: 09. I was so tired I actually went down and I fell asleep. Para 140 I...very tired lately. Para 215. Oct 2003

Resp: 11. ...you see it is too much for me ... Para 258. Feb 2004.

Reflective notes: Personally, this has been the highlight of the research findings for me. On countless occasions I thought to myself... been there, had the same experience. I was aware of my feelings and I consciously refrained from probing unnecessarily.

Analytic notes: The value of grounded theory lies in the use of data grounded in the experiences of the participants that reflect their own realities. Participants explain why they feel frustrated, hurt or angry. They link these feelings to their

prior relationship with the elderly, inability to access resources and some of the other variables.

Carers became aware of how others view their caring skills through conversations with members of the family and the neighbours. Family and friends would often comment about the carer's competence and commitment. Occasionally these conversations are initiated by remarks made by the elderly, which are then repeated out of context. Relationships become strained, role conflict develops and it places an additional burden on the carer.

Resp: 8. His sister lives in Mitchells Plain...I feel as if he was influenced by them... They wanted to know whether I am getting money. They influence him... they will not communicate with us here ...It looks as if he listens to what they say... if his sister comes here, they talk and ... we leave him if he wants to be on his own. Because he is always complaining ... so we leave him ...and then she says: "why is he alone in the house"...so I told her, " we know how to handle him we leave him ... we leave him if he wants to be alone" ...Para 405, August 2003.

Facilitating care impacted on the social interaction of both the carer and the elderly. Roles may change, e.g. children have to make decisions on behalf of a parent. Unforeseen expenses impact on the carer's budget. Carers may have to resign from a job or move house. They are not able to attend social functions. However, carers who are well connected with family and friends are able to manage these challenges.

Carers should receive personal and professional support.

The consequences of facilitating care (connectedness) were dependent on the level of support provided by the family, the community and health care professionals. The research outcomes showed that support varied from case to case and was largely influenced by the context of care.

Connected care	Disconnected care
<i>Support from family</i>	<i>no family support</i>
<i>Support from neighbours</i>	<i>no support from neighbours</i>
<i>Support from friends</i>	<i>no support from friends</i>
<i>Support from health care services</i>	<i>no health care service support</i>

It was also apparent that support varied during the different phases of the caring process. One may find that family would visit the elderly in hospital and promise to support the carer. However following the discharge of the elderly no support would be forthcoming.

Relationships between siblings are affected during the caring process. Some carers were offered support from neighbours and friends and not necessarily from family members.

Resp: 12. That very Friday that she got home from work ... she did my washing the Thursday evening...and the same afternoon that she got home from work...she went down to the wash-lines...came back up with the washing...dry washing...so she brought in my washing...folded it and everything ...Para. 236. Feb 2004 (Carer refers to a neighbour)

Resp: 06. And then there is also my friends downstairs, J and his wife, they are very helpful. Really, they are very helpful. She is a big, strong young woman, she comes and helps him often. Para 142. Feb 2003.

Resp: 09. Uhhh, I kind of have a lot of support from ... most ... more support from outside people than my own. Like there's people who phone and come around and she's okay, and they tell me, like, if she do need a lift, please phone. If we're at home we'll take her like here, or to the hospital. Wherever... like, the people who actually ... gentleman was at the hospital with my mom on the same date, their dates all the same and he'll, like, take her down or bring up the tablets. Nowadays I'll go and fetch his because I must go down for my mom. And he'll come around like on Thursdays and tell me they do their shopping at K Centre, I can go with them. Para 174. Oct 2003

The lack of respite also presented a major challenge to all carers. Occasionally, carers would be offered respite for a day. Sometimes even these offers would not be honored, forcing the carer to cancel their plans at the last minute. Unfortunately respite constituted the exception and not the rule.

Resp: 02. No, there is no one to relieve me... my dear... Para 418

Resp: 09 Uhhh...my sisters and brother came to me and they said that, no they were gonna help me and I don't need to worry. I ... gonna do stuff alone. But I didn't actually put my heart on it because I know them and I know what they're like. They're always busy; they don't have time... going out and stuff like that, so I prepared myself for the worst. And that's why I feel comfortable because it wasn't as bad as I'd thought it was going to be like. Para:105. Oct 2003

Another major finding was the lack of support offered by the professional health care workers. The lack of support was experienced throughout the caring process. Carers were not involved in the discharge planning and were given inadequate information prior to the discharge of the elderly from the hospital (Resp: 09). They were not adequately trained to provide maintenance and repair care and had to rely on instinct and past experience (Resp: 13). A positive response came from a carer whose sister had a lower limb amputation.

Resp: 12. and ... once more I need to thank the hospital and the personnel there who took good care of her...as well and the preparation before she was discharged... so that she could help herself... because that is of utmost importance, and she can help herself so well. Para: 9. Feb 2004

No supportive connections were established between carers and health care professionals. The elderly were given referral letters to community health centers (CHCs) for follow-up care but because of the long waiting periods at these facilities, the carers were unwilling to honor the appointments. A carer (Resp: 09) found the waiting time at the CHC unacceptable:

Resp: 09. You hand in your card ... you stand in a long queue ... hand in the card just for the dressing room and about a hour or so later they'll call your name and by that time ... it takes about two to three hours just for a dressing that takes about five minutes to do. Para: 200. Oct 2003

A home-based care worker visited one carer in this sample of 18 participants. The elderly carer (Resp: 13) did, however, not make use of her services because she presented to them at mid-day. By that time all the maintenance and repair care activities were already done.

Analytical notes: It is clear that the commitment of the provincial government to focus on primary health care and provide support to clients within their communities and homes has not been implemented successfully. Trained home-based workers would have classified all the elderly included in the sample as clients in need of support and supervision.

4.5. CONCLUSION

In this chapter the research outcomes were presented as a substantive theory. A theory grounded in empirical research data. My biggest challenge was to fracture all the transcribed data into phrases, sentences and paragraphs and put them back together in a conceptual way. Much of this process was done independent of the research report. The coding happened on a computer, using the N. VIVO data analysis software package, transcript and code reports were generated and printed and a lengthy process of inductive thinking followed. This process, which took the better part of an academic year to evolve has been presented in a clear research report that would allow readers to grasp the conditions and dimensions related to each of the emerging categories.

I do however have to confess that as a researcher I found this to be an essential process to allow for the internalization of the chosen research methodology. The research outcomes confirmed some of my assumptions about informal care but also provided novel information that needed to be shared with academics, professionals and the community at large.

CHAPTER 5: REFLECTION ON RESEARCH OUTCOMES

5.1. INTRODUCTION

The research outcomes were presented in the previous chapter in the form of a substantive theory. A theory generated from a systematic enquiry into the experiences of informal home-based carers of elderly dependants. In this chapter, the research outcomes are discussed in terms of the appropriateness of the research methodology; the aims and objectives of the study; the grounded theory that emerged from the empirical enquiry; the conceptual framework constructed for the study; the implications of the research outcomes for myself, the carers and the elderly and the implications for educators, health care workers and policy-makers. To enhance the fittingness of the theory, the literature related to each of the categories is referred to in my discussion (Chiovitti & Piran, 2003: 430).

The chapter is divided into the following sections and presented under the headings:

- ❑ Appropriateness of the methodology
- ❑ The research aim and objectives
- ❑ Facilitating care – a grounded theory
- ❑ Implications of the research outcomes

5.2. APPROPRIATENESS OF THE METHODOLOGY.

The qualitative methodology of grounded theory was used in this research study. To reflect on the appropriateness of the methodology, I have used an evaluation checklist proposed by Patton (2002: 40). The evaluation is based on the following themes: naturalistic enquiry, purposive theoretical sampling, direct personal experience and engagement, empathetic neutrality, context sensitivity and triangulated enquiry.

Informal home-based caring occurs in the real world and was thus not manipulated or controlled for the purpose of the enquiry (*naturalistic enquiry*). Since observations of informal carers occurred in real-world settings, interviews were scheduled either in the hospital ward (when visiting the hospitalized elderly) or in the home where carers were *facilitating care* (see 3.5.1.).

According to Patton (2002: 40) the qualitative researcher should be able to do purposive, *theoretical sampling*. It was, therefore, not important to control variables but rather to ensure that data was explored to its fullest. The qualitative data that I have gathered is thick in its description of the informal home-based carer, the elderly as well as the setting in which the caring occurred. When the category *prior relationship* was first coded I purposefully searched for data to explore its dimensions (see 4.4.1.).

Direct contact was sought with informal home-based carers (*direct personal experience and engagement*) whose personal experiences and insights became part of, and critical to the understanding of the phenomenon of informal caring. During the interviews a conscious attempt was made to display *empathetic neutrality* (Patton, 2002: 40). This meant that informal carers were shown respect, responsiveness and understanding. Being non-judgmental facilitated an environment where participants were willing to share information that allowed an insider's perspective of their realities.

Informal caring is a dynamic process that may change during the period of enquiry. The strategies used during the data analysis process reflected this dynamism. Each carer's reality was different and the detail of each case was reviewed before cross case analysis was performed. Emerging categories were explored, themes identified and interrelationships confirmed by analytical principles rather than statistical rules.

For *context sensitivity*, Patton (2002: 41) suggests that research findings be placed in a socio-historical context. Because of the uniqueness of the inquiry, I knew that generalizations about informal caring across time and space could not be made. It was more meaningful to identify patterns of behaviour during the enquiry for possible transferability to similar contexts. Field notes added substance to the data as it clarified the socio-cultural context in which the caring occurred. An overview of the context of caring is presented in Chapter Four (see 4.3.1).

Qualitative research requires of the researcher to reflect on the self (researcher), those studied (participants) and those receiving the study (audience). Patton (2002: 66) refers to the above processes as *triangulated enquiry*. My voice was an important part of the research process (*reflexivity*). I expressed opinions, interpretations and biases throughout the process of data analysis. Reflective and analytical notes became part of the research data and were exposed to the same rigorous enquiry by data analysis verifiers.

5.3. AIMS AND OBJECTIVES

In a grounded theory study the research process moves between the conventional research phases. The process starts out with selective sampling, moves to data collection and data analysis. However, the initial data analysis impacts on further data sampling and I found myself engaged in a number of research phases at the same time. This cyclical process makes it challenging to present the research outcomes in a logical fashion. To reflect on whether the aim of the study was adequately attained, my response is an unequivocal affirmation. However, the description of the experiences of informal home-based carers of elderly dependants in the metropolitan area of Cape Town, South Africa is spread across the whole research report. The grounded theory on informal home-based care is presented in Chapter Three and Chapter Four and the discussion of the theory is done in this chapter.

The objectives of the study were to explore the experiences of informal home-based carers during predetermined care-giving phases, i.e. preparatory, initial caring and established caring phase. However, during the early stages of the data collection process, I discovered yet another phase, namely the pre-traumatic phase where relational roles were established. Carers offered information that I initially thought to be insignificant. They described both the elderly as well as their prior relationship with the elderly in a fair amount of detail. When this happened consistently during the initial data collection, I knew that somehow the prior relationship must hold some meaning to the carers and subsequently analyzed the data coded *carer describes elderly* within the category *prior relationship*. Information about the prior relationship was purposively sought from all participants.

The issue of process and how *prior relationship* would impact on facilitating care is discussed in this chapter (5.4.3.1).

The description of the carer's experiences with regard to the rehabilitation of the elderly is discussed under the heading *repair care* (5.4.3.5) and the challenges faced by and support required by carers, under the heading *connectedness* (5.4.3.6).

5.4. FACILITATING CARE – A GROUNDED THEORY

In this section the grounded theory is discussed in detail. The core category or basic social process is explicated with a focus on how it was identified and how it related to the sub-categories. The sub-categories are discussed in relation to process and to research literature on informal home-based care. Specific mention is made about the conceptual framework constructed for this study. The issues of rigor, grounding of the theory and ethical compoment are highlighted throughout the discussion.

5.4.1. FACILITATING CARE – BASIC SOCIAL PROCESS

There was little doubt in my mind that the concept *care* would be part of the basic social process as it was included in most of the initial coding. Carers stated that ...*I found it difficult to care for ... caring is taking its toll ... I am the carer ... I was chosen to care for...* The difficulty lay in deciding what was significant about the care and what meaning did the concept hold for the carers. They used the concept as both an action verb *to care for* as well as a noun *carer*. As a noun the concept took on the sociological connotation of a social role, i.e. *carer* or *guardian* or *nurturer*. However, the sociological role of carer emerged mainly when issues of role conflict or role strain was raised, e.g. *I am the carer, but also a mother and wife ... I have a family...*

The term *facilitating* was a conceptual one. Seeing that *care* was the predominant concept that emerged from the data, I concluded that informal carers were *facilitating care* during the transition of the elderly from hospital to home. I decided on the conceptual label *facilitating*, after considering a number of alternative adjectives, e.g. *balancing care*, *mediating care*, and *caring connections*.

One of the reasons why I had decided on *facilitating care* as the basic social process was because I sensed that carers were trying their best to care for the elderly despite all the challenges that they were confronted with on a daily basis. They were not merely trying to find a balance but were inclined to focus on positive outcomes for themselves and the elderly within their specific contexts. Disconnected care was only evident when the carers' role expectations were overwhelming.

Robinson, *et al.* (2005: 563) in a qualitative study on the experiences of carers living with stroke patients in the UK, identified *loss of control* as a core category. What I found interesting was the report that carers ($n=14$) stated 107 times that they *cannot* or *can't*, e.g. *I can't cope... you can't prepare for that, you can't...*

These responses may be linked to what Joubert (2005: 3) referred to as the *duration of care*, which, in Robinson's study, was a period of two months to four years. The carers in my study shared specific challenging experiences and most of them would then explain how they dealt with these challenges.

Another reason for choosing the concept *facilitating care* was that my perception that males rarely engaged in informal care was proven incorrect. Even though males took on the responsibility of primary carer, some of the caring tasks were delegated to female members of the family. Males were *facilitating care* without actually providing *maintenance* or *repair care*. A recent study by Joubert (2005: 113) confirms that one in four male adults in South Africa was a carer.

Some primary carers did not live with the elderly. They lived in outbuildings or, on occasion, in a different suburb. Facilitation skills were demonstrated by their ability to organize the neighbours and friends to attend to the elderly's *maintenance care* needs while they focused on *facilitating repair care*. It became clear that carers were *facilitating care* rather than merely providing *informal care*. I concur with Pjil's (2003: 27) critique, that *informal care* is not the best way to describe the scope of the care provided to dependants within their homes (see 2.2.1). The term care facilitator would, in my opinion, be an appropriate one.

The studies done in developed countries are currently focusing on the unmet needs of carers or their expressed needs after a year of caregiving. Such studies are valuable and should ideally follow an exploratory research study such as this one. They would present researchers with a realistic opportunity for comparing contextual findings (Smith, *et al.* 2004; Kerr & Smith, 2001; Soothill, *et al.* 2001).

5.4.2. A CLOSER LOOK AT PROCESS

Strauss and Corbin (1990: 143) refer to *process* as the linking of action and interaction sequences. These links are illustrated in Figure: 5.1. Throughout the data analysis process I have drawn attention to changing conditions that

impacted on the basic social process of *facilitating care*. An example would be that *prior relationship* be incorporated as part of *process* as it influenced the ease with which *facilitating care* happened. The stronger the bond between the carer and elderly prior to the *incident*, the easier the processes of *facilitating care*.

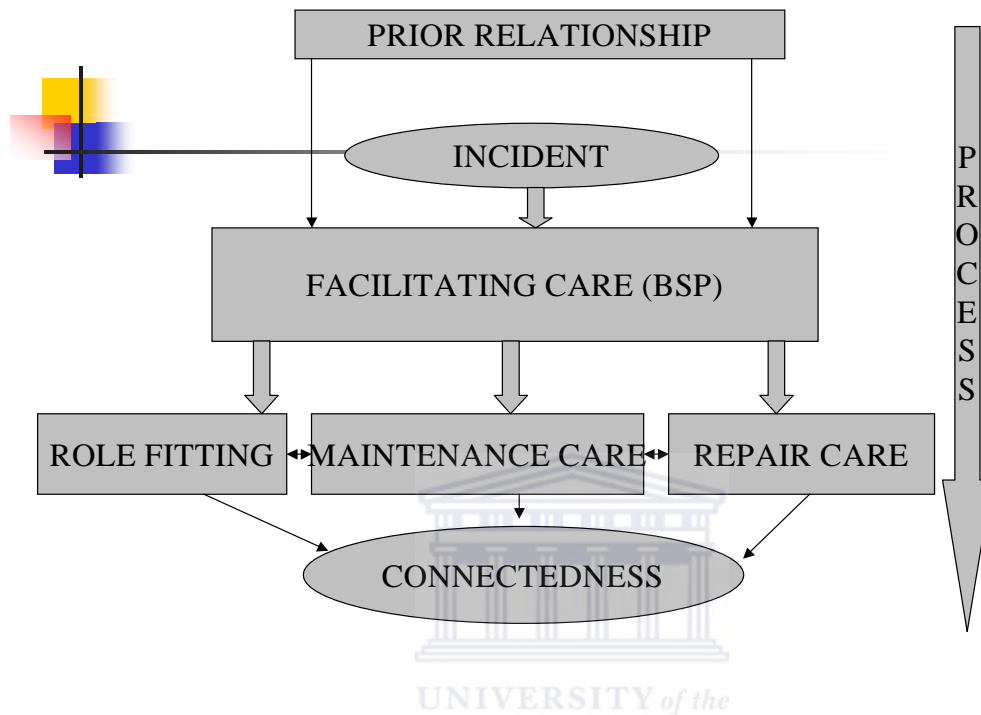


Figure 5.1: Facilitating Care – a Closer look at Process.

In terms of sequence, what happened next was the traumatic *incident*. Not only did the incident have an effect on relational roles of the participants but created the need for a new one, that of carer. Once again, conditions changed. The husband and provider became the dependant following a cerebro-vascular accident. The *incident* represented the second phase during which the severity of the incident negatively impacted *facilitating care*.

The next phase involved acknowledging the role of carer and consciously trying to fit the responsibilities of *facilitating care* into existing roles. The *role fit* appeared to be easier when the carer chose to care and was able to share the caring tasks with others. *Facilitating care* proved very difficult in the cases where

the carer experienced role strain or role conflict. Concurrently with *role fitting* the carer provided *maintenance* and *repair care*. A number of changing conditions had an influence on this phase. A granddaughter, who could not cope with facilitating care, chose to place her grandmother in a home for the aged. Another had her own mother take over the responsibility of primary carer. One carer could not afford the special diet that her elderly father needed because his pension could not service two households.

During this phase many of the levels of the conditional matrix (Strauss & Corbin, 1990:163) had an effect on the carer's ability to *facilitate care*. Amongst others: the meager state pension that was used for the needs of both the elderly and the carer; living on the second or third floor of an apartment building and being unable to access assistive devices (see Appendix: 7). A number of these process variables were discussed in the previous chapter.

The last phase, which was initially considered, the *established caring phase* proved to be less than established. After a month of caring, carers shared a variety of caring experiences. These ranged from being content to facilitate care to a partner or spouse of fifty years, to being in a situation that elicited statements like ... *it is taking it's toll ... it is more difficult than I expected*. The key issues during this phase, centered on the availability of respite care and the support from family, friends, the community at large as well as the professional support systems.

5.4.3. CATEGORIES

The categories presented in Figure: 5.1 are now related to the research literature on informal care. Most of the literature reviewed in Chapter Two focused on specific aspects of the carers' experiences. These aspects are described and compared to the outcomes of my research study. In addition, the categories will be related to the concepts included in the conceptual framework constructed for this study.

5.4.3.1. Prior relationship.

This category emerged during the initial data collection. It showed that a good relationship between the carer and elderly prior to the incident positively influenced the carers *facilitating care* experience. I could not find research literature that focused specifically on relational roles between carers and the elderly during the transition of the elderly from hospital to home. A study on hospital discharge (Procter, *et al.* 2001: 206) in the United Kingdom, found that the interpretation of the carer role, centred on moral obligation and expectations of care, rather than on personal choice. The carer was often defined by the social context of the situation, i.e. being a daughter or wife and found it difficult to challenge the moral expectations to care. By implication the carer was chosen based on the existing relationship between the carer and patient.

The value of the grounded theory research method is illustrated by the emergence of this category. During the planning phase of the study, I assumed that informal caring started with the discharge of the dependant from the hospital. I was not aware, at the time, of the value that carers placed on their prior relationship with the dependants. I, therefore, did not include the pre-hospitalisation period, into the conceptual framework constructed for this study (see Fig. 2.1).

5.4.3.2. The Incident

Many research studies focussed on informal carers of people with specific health problems, e.g. stroke victims, Alzheimer's disease, terminally ill and cancer patients. One of the objectives of this particular study was to describe the involvement of the carer in the rehabilitation of the elderly. To account for the variation required of grounded theory research, I sampled elderly persons with differing rehabilitation needs.

The incident was categorized because carers described the incident in a fair amount of detail. It seemed, as if carers perceived that *facilitating care* started

with the *incident*. Much of their emotional experiences centred on the incident. Some distanced themselves from the incident while others tried to put the blame for the incident on someone else. The incident also marked a change in their day-to-day life and stories were related as happening before or after the incident, e.g. before the stroke and after the stroke.

It was clear from the research outcomes that the traumatic incident was meaningful for the informal carers. The incident, however, occurred prior to the hospitalisation of the elderly dependant and was also omitted from the conceptual framework (see Fig. 2.1).

5.4.3.3. Role fitting

The category *role fitting*, included concepts like *choosing to care*, *preparing to care*, and *sharing caring*.

Kerr and Smith (2001: 428) found that carers were unhappy because they were not asked whether they were willing to care for stroke survivors in Scotland. This outcome was listed under the category, *role fitting* and sub-category, *carer chosen* which showed a negative impact on *facilitating care* if carers did not choose to care (see 4.4.3.).

Whilst *preparing to care*, some carers found it very difficult to acquire specific knowledge and skills. This need for information has been the focus of many research studies (Robinson, *et al.* 2005; Smith, *et al.* 2004; Morris & Thomas, 2002; Kerr & Smith, 2001; Ndaba-Mbata & Seloilwe, 2000; Mant, Carter, Wade & Winner, 1998; Wiles, *et al.* 1997). Most of these studies were done in the UK and Scotland and one was done in a neighbouring country, Botswana.

Ndaba-Mbata and Seliolwe's (2000: 218) study on home-based care of the terminally ill in Botswana, found that family carers lacked the knowledge and skills to provide appropriate care. Many carers in this study expressed frustration

at the lack of information available to guide them in their caring tasks. Another common outcome was the carers' inability to access resources. Despite the contextual differences between these studies, there were a number of similarities in the research outcomes, in particular, with reference to *preparing to care* (4.4.3).

Smith, *et al.* (2004: 235) found that carers lacked the knowledge and skills to care for stroke survivors within their homes in Scotland. They also found that carers were inadequately prepared for the caring role. This followed an earlier study by Kerr and Smith (2001: 428), which suggested that carers of stroke victims did not receive adequate preparation prior to hospital discharge. It appears that despite the acknowledgement of carers within the health care system of developed countries, the needs with regard to *preparing to care* (4.4.3) remain unchanged.

In England, Wiles, *et al.* (1998: 794) found that carers of stroke victims needed information about the dimensions of the traumatic incident and practical information about the day-to-day care. They suggested the development of information packages and recommended that both oral and written information be provided to carers. I concur with Wiles, *et al.* (1998) and have included a similar recommendation in Chapter Six (6.3).

Role fitting has emerged as an important action strategy employed by informal carers to manage the new role and responsibilities related to facilitating care. With hindsight gained from using inductive research processes, I discovered yet another gap in the pre-constructed conceptual framework. The inclusion of concepts related to *role theory*, would have raised my awareness about the challenges associated with role fitting. However, when one engages in grounded theory research, the conceptual framework does not drive the research process, but rather, sensitizes the researcher to the concepts related to the phenomenon under investigation.

5.4.3.4. Maintenance care

Participants in this study shared a variety of experiences with regard maintenance care activities. Many carers drew on prior knowledge and skills to assist the elderly in activities of daily living (ADLs). A few of the female carers could not perform some of the maintenance care activities unassisted. The research outcomes showed that gender and cultural beliefs also impacted on the provision of maintenance care. A son, despite having adult sisters, had to bath his mother and a daughter could, on cultural grounds, not bath her father (see 4.4.4.).

Akintola (2004: 34) found that caring activities performed by men and women in South Africa are aligned to socio-cultural expectations related to gender. Men perform physical activities and women focus on nurturing activities.

In Kerr and Smith's (2001: 432) study, carers complained that they had to teach themselves the skills to assist stroke victims with activities of daily living. They expressed the need to have been taught basic skills prior to the hospital discharge, with particular emphasis on the mobilization of patients to prevent falls. In my study carers drew from past experiences in their attempt to provide maintenance care to the elderly. They were able to deal with the challenges associated with the mobilization of the elderly and only two carers reported falls. One fall happened when the carer was not at home and the grandmother insisted that her grandson accompany her to the toilet. The other occurred because an elderly stroke victim did not listen to his wife's (the carer) advice.

Maintenance care relate to most of the theories that I have included in the conceptual framework (Fig. 2.1). The category illustrates how facilitating care impacts on the physical and psychosocial needs of the carers as they provide dependent-care to the elderly dependants. The research outcomes also show that some of the informal carers experienced difficulties in maintaining intimate relationships (4.4.6).

5.4.3.5. Repair care

The research outcomes presented evidence of the carers' involvement in repair care. Carers were encouraging the elderly to function independently. They were *facilitating repair care* despite having to deal with material and financial challenges. Some carers knew that the elderly needed special diets, but could not afford to buy the foodstuff.

This awareness of the need for nutritious meals and special diets was shared by carers of people living with AIDS (PWA) in the Western Cape (Orner, 2006: 238). These carers spent inordinate amounts of time preparing food as they considered serving nutritious meals a priority caring task.

The carers involvement in *repair care* meant that they encouraged the elderly to do special exercises, allowed independent decision-making and monitored the physical recovery process. And, when faced with the challenges of acquiring rehabilitation aids, they resorted to borrowing from friends and using insider connections to access wheelchairs from community health clinics (see 4.4.5.). Kerr and Smith (2001: 432) report that even in a developed country, like the UK, carers of stroke victims experienced delays in accessing rehabilitation aids.

Another major challenge was the inaccessibility to public transport. This constraint could be linked to the political legacy of the apartheid system. People were displaced to the outskirts of the cities without the guarantee of a safe and reliable public road and rail transport system. These socio-political changes had an effect on the ability of carers and the elderly to socialize. An innovative carer pushed his mother in a wheelchair over a distance of five kilometres to the community health clinic. Another made use of a wheelbarrow taxi to take his mother to church. Joubert, *et al.* (2002) found that public transport was inaccessible to the disabled and their carers whilst investigating the needs of informal carers in South Africa. Many carers verbalised the need for respite care. Carers share this view irrespective of the context of care (Orner, 2006: 236).

The research outcomes indicate that informal carers assisted the elderly dependants in most of the dimensions of societal functioning, amongst others: physical independence, mobility, orientation, and the financial management of their state pensions (WHO, 1980). The carers also involved the community in the provision of repair care by accepting assistance from friends, neighbours and acquaintances. However, eliciting support from immediate family members and professional health care workers proved to be more difficult. It is unfortunate that a community based rehabilitation strategy, specifically designed to involve the community in the rehabilitation process, is inadequately implemented in the metropolitan area of Cape Town.

5.4.3.6. Connectedness

Connected care implied that carers enjoyed the support of family, the community and the health care service providers. Family members supported a few of the carers. Most of them, however, received help from neighbours and friends. There was a lack of support from professional home-based workers. Of the eighteen participants in this study, a home-based worker assisted only one of the carers. Health care professionals did not support or supervise any of the other seventeen carers in their homes.

Orner (2006: 236), who explored the psycho-social needs of carers of PWA in the Western Cape, found that NGO home-based workers were valued by these carers. These workers provided material resources (groceries), palliative care and much needed respite to the carers of PWA. This indicates an acceptable level of NGO support to carers of PWA's, and a gap in the support offered to carers of stroke survivors, patients who have had hip replacements and amputees (see *disconnected care* 4.4.6).

As a health worker, the sub-category *disconnected care* caused some apprehension as it reflected the inadequacy of our health care system. The

research outcomes pointed to gaps at all levels of health care delivery. Carers were not involved in the discharge planning of the elderly. Some carers were informed of the discharge on the day of the planned discharge while others were informed telephonically. In Facility 1, carers were given inadequate information and skills training, prior to the discharge of the elderly. In Facility 2, a liaison person offered skills training. Unfortunately, some carers were unable to attend the individualized training sessions offered by this person. Payne, Kerr, Hawker, Hardey and Powell (2002) concluded from a systematic review, that the most effective strategy for information transferal during discharge planning is to appoint a “key-worker” as a link between hospital and community workers.

The lack of communication between the hospital staff and the carer in terms of the discharge date and the need for follow-up appointments impacted the continuity of care across the various levels of health care services: an outcome that is contrary to the aims of Healthcare 2010 which state that:

Patients will enter the health service and be treated at the most appropriate level of care with adequate provision for referral up and down the service (Department of Health: 2002: 3).

Kerr and Smith (2001: 428) found that in the United Kingdom there was little evidence of a seamless flow of care between various levels of health care provision in terms of comprehensive stroke care.

Another challenge was the lack of acknowledgement and support from professional health care workers. Carers were dissatisfied about long waiting periods at primary health care clinics. One carer refused to take her husband for follow-up clinic visits because of a perceived lack of empathy displayed by staff at the clinic. The lack of professional support was an experience shared by informal carers of stroke victims, terminal patients and PWA's (Orner, 2006; Kerr & Smith, 2001; Ndaba-Mbata & Seliolwe, 2000).

Some carers used the elderly's social grant money to purchase food, adult diapers and other requirements. Occasionally the elderly would insist on administering their own money. One such elderly gentleman did not buy foodstuff, but expected his unemployed carer to provide meals. Many informal carers had to deal with inadequate financial and material resources irrespective of the context of care (Orner, 2006; Ndaba-Mbata & Seliolwe, 2000; Kerr & Smith, 2001).

Connectedness of care, refer to the manner in which the carer is able to deal with the challenges associated with facilitating care. It also indicates the level of support offered by friends, family and the community at large. The concepts related to the challenges experienced by participants, include all the theories listed in the conceptual framework, in particular, Neuman's health care systems model. Neuman's model, which suggests a multi-dimensional view of individuals, groups and communities in constant interaction with the environment links closely with the conditional matrix proposed by Strauss and Corbin (1990, 1998).

5.5. IMPLICATIONS OF THE RESEARCH OUTCOMES

The main outcome of the study was to give a voice to the experiences of informal carers during the transition of the elderly from hospital to home. The implications of the research outcomes are discussed at an academic level as well as at an advocacy level.

5.5.1. IMPLICATIONS FOR MYSELF

The research outcomes represented the culmination of a long and challenging research process. I experienced the highs and lows of undertaking post-graduate studies as a full-time lecturer and novice researcher. The outcomes represented the lived experiences of carers within a specific context. I could relate to some of the experiences while others put a new perspective on the BSP of *facilitating care*.

A personal reflection on one of the categories that emerged from the initial coding process, i.e. *prior relationship*, led me to question why I had been willing to spend one quarter of my sabbatical leave *facilitating care*. I realized that following the death of my parents during my teen years, my two aunts were the ones in my family that provided the stability and support that I needed at the time. I could attest to the category *prior relationship* impacting on the basic social process of *facilitating care*.

The research outcomes affirmed that the most appropriate research method was used in this study as the grounded theory method allowed me to use the actual words of the participants and also permitted the participants to guide the research process (Chiovitti & Piran, 2003: 430). Participants' words form the bulk of the data presented as research outcomes in Chapter Four.

As an academic, I will be publishing the research outcomes and joining the scholarly debates about the experiences of informal carers, i.e. their needs, burdens and challenges. A publication of the research outcomes will also contribute to local literature on the research topic as recommended by Joubert (2005: 113). As an advocate for the carers, I will share the research outcomes with people who could positively influence their experiences, e.g. educators, health workers and policy makers.

5.5.2. IMPLICATIONS FOR THE CARER

The main implication of the research will be that the experiences of carers be shared with academics, professionals, and the community at large. Of particular note was that carers clarified the type of support that they needed and the myriad of challenges that they faced. They needed, amongst others, acknowledgement for the services that they performed. I concur with the suggestion of Joubert (2005: 114) that awareness be raised among government departments, NGO's, community- and faith-based organisations and the public about the important service delivered by these carers.

5.5.3. IMPLICATIONS FOR EDUCATION AND TRAINING

The term educator should be viewed in its broadest sense, i.e. any person engaged in sharing information and developing skills. Teachers of health care professionals should sensitise them to include carers in formal health care teams and involve them in the planning of home-based care, prior to the discharge of the patient.

Trainers of home-based workers should teach them how to support carers in the home. The study conducted by Orner (2006) in the Western Cape showed that home-based workers might have been appropriately trained but that they were inappropriately placed. Statistics show that not enough of this level of health worker is employed to comply with the demand within the Province (Uys, 2006). These factors may account for the discrepancy in the support provided to carers of PWA compared to carers of stroke victims.

It became quite clear that professional nurses in the hospitals should provide potential carers with information and appropriate skills training. This emerged as a major gap in ensuring the continuity of patient care following hospital discharge. Research has shown that carers prefer a combination of oral and written information and that they recommend that the information be given prior to the discharge of the patient (Wiles, *et al.* 1998: 794).

The type of information required by the participants in this study included:

- the dimensions of the traumatic incident, i.e. whether the stroke caused paresis or paralysis of the arm and leg.
- where to access assistive devices
- how to access the social pension of an elderly who is unable to get to the pay point
- how to elicit support from the family and community
- whether carers qualify for financial compensation

It was clear that carers needed information that the nurses did not provide during their contacts with potential carers. Currently, the preparation is focused on the physical caring tasks with not enough attention is given to the other information needs of the carers.

In-service training of hospital staff is important to ensure that patient care information is appropriately communicated between the various levels of health service providers. In some instances, information does not reach the home-based workers at the clinics. If carers are unable to accompany the elderly to the clinic because of lack of funds, a breakdown in the continuum of care occurs. I discovered this gap when I conducted a third interview with a carer who informed me that because the pension payout followed the hospital appointment they could not attend. At that stage the elderly 's skin showed signs of breakdown and they did not have any analgesics to ease her pain. This implication arose from the discussion of *disconnected care* (see 5.4.3.6).

5.5.4. IMPLICATIONS FOR HEALTH AND SOCIAL WELFARE SERVICES

The research outcomes could be used by health care services to strategically plan a continuum of care following hospital discharge of patients. The findings could be utilized at all levels of health care planning as carers spoke to tertiary hospital services, community health care clinics and other related support organizations. In addition they spoke to all health care disciplines in particular those disciplines that deal with health and social welfare. Specific recommendations are presented in Chapter Six.

With an increase in the number of elderly in South Africa over the short and medium term; an exacerbation of chronic disease of lifestyle; the AIDS epidemic draining the essential health and social welfare resources; the formal health services being stretched to the limit and private health care beyond the reach of the ordinary South African, we need to applaud the millions of carers contributing to various levels of care provision in this country.

5.6. CONCLUSION

In this chapter I concluded that the most appropriate research methodology was used to explore the research question. The research outcomes were compared with those of research studies from developing and developed countries. Many similarities were identified during such comparisons. Even when the outcomes were compared to carers within different contexts in South Africa, more similarities than differences were discovered.

The comparison of the emerging basic social process and categories to literature enhanced the trustworthiness of the research study. The implications of the outcomes were discussed in terms of the impact on the researcher as well as the researched. The recommendations made in the next chapter are aimed to support the informal carers as they continue with the basic social process of *facilitating care*.



CHAPTER 6: CONCLUSIONS AND RECOMMENDATIONS

6.1. INTRODUCTION

In this chapter, I reflect on the research study, how my personal experiences intersected with those of the carers and how a decision to use a specific research method allowed the carers to speak to those professionals involved in the provision of health care services in South Africa. The initial research outcomes steered the inquiry and assumptions were interrogated throughout the research process.

The conclusion of the study is presented as a research journey where the navigator was faced with many challenges. Specific challenges were identified during the exploration of the experiences of carers and recommendations will be leveled at government departments, non-governmental organizations, community and faith-based organizations, educators, professional health care providers and the public at large.

The chapter is divided into the following sections and presented under the headings:

- The research journey
- Challenges and recommendations
- Limitations of the research study

6.2. THE RESEARCH JOURNEY

In this section I wish to reflect on the journey that started with the question “How do informal carers experience the transition of elderly dependants from hospital to home?” A question formulated on the basis of personal experience, professional encounters and a formidable gap in local research literature. The initial literature search indicated a wealth of research publications on informal caring in developed countries. However, in developing countries where informal

caring is commonly practiced, limited research has been done to explore the experiences, needs and concerns of carers (Joubert, 2005; Akintola, 2004; Joubert, *et al.* 2002: see 2.2.2).

Once I decided on the topic for the research study, I had to find supervisors to facilitate the proposed study. With the assistance of the Dean of research I engaged the assistance of an expert in community-based education and an expert in education. Upon reflection they proved to be a good combination as they shared my view that researchers have dual roles, i.e. an academic role and an advocacy role.

The search to find an appropriate research methodology followed. As a novice researcher, the grounded theory method proved challenging, but also exhilarating. I experienced, what the founders of the method referred to as becoming the observer and the observed (Strauss & Corbin, 1990, 1998).

To locate the sample settings was fairly easy, to gain entry to the sites, however, proved more difficult. At one of the sites an administrative misunderstanding delayed the access to the site by two months. In addition, unforeseen events had an effect on the sampling of prospective participants. I purposively had to sample carers from social groupings other than the coloured group because of the population profile in the Western Cape. I could also not secure the support from fellow professionals in the identification of participants. I remember spending hours scanning spreadsheets of hospital admissions, drawing up shortlists of potential participants, only to find that they did not fit the sample criteria.

The highlight of the study, however, was the data collection process. Carers who were faced with a myriad of challenges, delivered the highest quality of care and rehabilitation assistance. I was amazed at how they coped with financial, material, and other constraints and was grateful for the opportunity to observe these carers as they interacted with the elderly. I can also attest to the

willingness of participants to participate in this research investigation and to welcome me into their homes.

I initially struggled with the coding process and grappled with conceptual labeling, but, in spite of this, I was able to generate a substantive theory that may yet impact on the lives of carers. I experienced an awareness of data saturation following interview fourteen and did not transcribe the last four interviews in full. The guidelines provided by Strauss and Corbin (1990, 1998) with regard to data collection and data analysis, as well as the mentorship by an expert in the field, facilitated the generation of the grounded theory. I recommend that any prospective grounded theory researcher, in particular a novice researcher, elicit the help of one or more experienced researcher in this methodological field.

The research outcomes were compared with research studies on informal care irrespective of context. The local studies focused mainly on informal care of people with AIDS (Orner, 2006; Akintola, 2004). Many of the findings compared well across different contexts locally as well as to studies conducted in developed countries (Robinson, *et al.* 2005; Smith, *et al.* 2004; Kerr & Smith, 2001; Wiles, *et al.* 1997). It seems as if the meaning of human interaction in specific situations remain unaffected by the issues of gender, race, colour or creed (see 5.4.3.4 and 5.4.3.5). However, in developing countries where carers experience extreme financial and resource constraints, their experiences may differ substantially. In my study some carers were unemployed while others suffered debilitating disease. This impacted on their ability to provide the care and rehabilitation assistance needed by the elderly dependants (5.4.3.4).

Another challenge was to write a qualitative research report that was easy to read, yet illustrated the fluctuation between inductive and deductive reasoning required of the grounded theory methodology. Finally, to recommend educational and health care service changes, in a country immersed in change, should, in my opinion, be done realistically and responsibly. The suggestions raised in Chapter

Five refer to an ideal scenario, whereas in this chapter I refer to specific strategies that could ease the burden of care for informal carers in situations, which are already trying without the added responsibilities of facilitating care.

The journey was also marred by disillusionment with the inadequacies of the health care delivery system, in particular, the gaps in the referral system and the lack of professional support, which negatively impacted on the experiences of informal carers. Strauss and Corbin's (1990, 1998) conditional matrix was used to explore these gaps and make recommendations to improve the system.

6.3. CHALLENGES AND RECOMMENDATIONS

There is no official recognition of the value of informal carers within the health care structures in this country. The incorporation of carers into the District Health System, would indirectly ease the burden of care from the formal health care services. These carers, if adequately trained and supported by paid home-based workers, would provide a formidable cadre of rehabilitation workers and form the basis of a true Community-based rehabilitation strategy. However, Akintola (2004: 44) warns that home-based care should not be seen as an inexpensive alternative to hospital care in South Africa.

I recommend that policy documents be developed to address the rights of the carers and to recognize their value as facilitators of care within communities. In particular, the right to be adequately prepared to provide care and rehabilitation services within the home (see *role fitting*, 4.4.3; *maintenance care*, 4.4.4 and *repair care*, 4.4.5). I also recommend that strategies be put in place to monitor the implementation of such policies.

These policies should be based on scientific inquiry. However, limited research has been done to explore the experiences, needs and concerns of carers (Joubert, 2005). Such a gap in research literature may account for the lack of

recognition of the value of informal carers locally. I recommend that research on informal care be added to the list of research priority and niche areas in this country. Policy makers have to be guided by relevant research in this area to strategically attend to the needs of carers by providing a scientific basis for the formulation and implementation of policy decisions.

A national strategy should include a campaign to engage with carers through the Carers Association of South Africa (CASA) and communicate a national appreciation for services rendered. A specific recommendation would be to include a “carer’s day” in the national health calendar with the focus on, e.g. *respite for a day*.

The shift in healthcare provision from curative, institutionalized services towards community- and home-based services required that additional resources be allocated to support these services. Lessons could be learned from developed countries, where resources were re-allocated to support home care service programmes, e.g. home visits by professionals and the accessibility of respite services (Nolan, 1999). Joubert, *et al.* (2002) found that a majority of carers in South Africa were involved in physical and mentally draining activities for extended periods of time and concluded that carers be valued as indispensable family and community assets. I concur with Joubert, *et al.* (2002) and propose that the redistribution of resources be used to ease the burden of care on these community assets. The paid home-based carer’s job description could, for example, include the provision of respite support to the carers within their communities.

A recommendation would be to re-allocate funding to specific resources in addition to those resources available through CASA. It is also recommended that the employment and deployment of trained home-based workers be reviewed. Orner (2006) found that home-based workers adequately supported carers of PWA in peri-urban areas in the Western Cape, while Akintola (2004) found that

these workers were not delivering hands-on services in rural KwaZulu-Natal. I agree with Akintola, as I found in my own study, that a home-based worker assisted only one carer, and that the help was, unfortunately, ill timed (see *repair care* 4.4.5).

A shift in the education of health professionals in line with the Health Plan 2010 (Department of Health, 2002) necessitates a review of curricula. Teachers of health professionals have a responsibility to sensitize students to acknowledge the value of carers in the health care team. Although students are generally encouraged to include the patients and their families in the team that make decisions about patient care, I find it necessary to recommend that the carers be included as equal partners to ensure a continuum of patient care following hospital discharge. I further recommend that in-service programmes be offered at health care facilities to highlight the role of carers in the care and rehabilitation of patients.

There seem to be gaps in the referral system between the tertiary hospitals and community health care facilities. Research, to explore these gaps in the referral system within the health system in the Western Cape, needs to be done as a matter of urgency. It is recommended that communication within the health system be improved and that home-based workers be informed of carers within their districts. Trained home-based care workers could then support informal carers within their communities.

In some hospitals (Facility 1) potential carers are inadequately prepared to facilitate care. It is recommended that a suitably trained person be appointed to act as liaison officer between the hospital staff, community-based personnel and home-based carers. It is further recommended that this officer involves the carers in the discharge planning of the elderly, and, in addition, ensures that the relevant professionals participate in the prepare-to-care process. Payne, *et al.* (2002) suggest that the appointment of such a “key-worker” is one of the most

effective ways of ensuring the transferal of information between hospital and community workers.

The preparation should include oral and written information, as well as skills training. Of particular note is, that some carers required additional information about the dimensions of care and the access to resources. They also needed assistance from family members, but found it difficult to approach them for help. Carers should be taught different strategies to request support from their families. They needed, amongst other, assistance with physical tasks, emotional support, financial contribution and respite to ease the burden of care (see *connected care* 4.4.6).

6.4. LIMITATIONS OF THE RESEARCH STUDY.

A small-scale study has its limitations in that the sample size may limit the transferability of the outcomes. In this context, two similar small-scale studies conducted on non-representative samples in South Africa, also found that the majority of carers were women (Akintola, 2004; Joubert, *et al.* 2002). In a profile of informal carers in South Africa, Joubert (2005: 105) established that 59% of the carers were women. Even though sample size may be considered a limitation, the depth and insight gained from such a study cannot be replicated by using quantitative methods.

Another limitation is one common to many qualitative studies. Qualitative studies are not aimed at presenting research outcomes that are generalizable but rather, outcomes that represent the realities of participants who provide informal care within their own unique contexts. However, even though the contexts were different, there were many similarities between the outcomes of this study and those of Akintola (2005) and Joubert, *et al.* (2002).

This study focused on the period of transition of the elderly from hospital to home, and in particular during the first month following hospital discharge. Even

though this study was limited to the early stages of care-giving important base-line information was collected. Ideally, a study that explores informal caring after a period of one-year, would be an appropriate follow-up study. The latter represent the types of studies that are currently being conducted in developed countries.

6.5. CONCLUSION

In this chapter I reflected on the research journey that allowed me to explore the experiences of important citizens of our country who unwittingly provide an essential primary health care service to the people of the Western Cape Province.

I discovered that other researchers have identified similar challenges in the experiences of informal carers in this country (Orner, 2006; Joubert, 2005; Akintola, 2004; Joubert, *et al.* 2002). These include the fact that carers: are not recognized as essential community assets, are not included in the health care systems, need financial and material resources and need the support of family, home-based workers and professionals alike.

I also concur with the local academics who recommend that carers be included in the district health system and are given the support and resources they require to become the primary providers of community-based rehabilitation services in this country.

To all the carers in South Africa who are facilitating care against all odds, I salute you.

REFERENCES

Aged Persons Amendment Act 100 of 1998. s. 3C (3).

Annells, M. (1996). Grounded theory method: philosophical perspectives, paradigm of inquiry and postmodernism. *Qualitative Health Research*, 6(3): 379-393.

Annells, M. (1997a). Grounded theory method, part I – Within the five moments of qualitative research. *Nursing Inquiry*, 4, 120-129.

Annells, M. (1997b). Grounded theory method, part II – Options for users of the method. *Nursing Inquiry*, 4, 176-180.

Akintola, O. (2004). A gendered analysis of the burden of care on family and volunteer caregivers in Uganda and South Africa Health Economics and HIV/AIDS Research Division (HEARD). University of KwaZulu-Natal: Durban. Available at URL: <http://www.ukzn.ac.za/heard/research/ResearchReports/2004/Gendered%20Analysis%20of%20Burden%20of%20Care%20-%20Uganda%20%20SApdf> accessed 6/30/2006

Arksey, H. (2002). Combining informal care and work: support carers in the workplace. *Health and Social Care in the Community*, 10(3): 151-161.

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

Blumer, H. (1969). *Symbolic interactionism*. Englewood Cliffs: Prentice Hall

Brink, H. (1996). *Fundamental of research methodology for health care professionals*. Cape Town: Juta.

Bull, M. J., Maruyama, G. & Luo D (1995). Testing a model for post-hospital transition of family caregivers for elderly persons. *Nursing Research*, 44: 132-138.

Burns, N. & Grove, S.K. (2001). *The practice of nursing research – conduct critique and utilization*. Forth Edition. Philadelphia: WB Saunders.

Chenitz, W. C. Swanson, J. M. (1986). *From practice to grounded theory: qualitative research in nursing*. Menlo Park, California: Addison-Wesley.

Chiovitti, R. F. & Piran, N. (2003). Rigour and grounded theory research. *Journal of Advanced Nursing*, 44(4): 427-435.

Constitution of the Republic of South Africa 1996 – Act 108 of 1996.

Cornell, J. Goudge, J. McIntyre, D. & Mbatsha, S. (2001). National health accounts: The private sector report. Pretoria: Department of Health.

Creswell, J.W. (1998). *Qualitative inquiry and design: choosing among five traditions*. Thousand Oaks: Sage Publications.

Denzin, N. K. & Lincoln, Y. S. (1998). *Strategies of qualitative inquiry*. Thousand Oaks: Sage Publications

Department of Health. (1997). Integrated National Disability Strategy White Paper. Pretoria: Department of Health. Available at URL: <http://www.info.gov.za/whitepapers/1997/disability.htm> accessed 8/15/2006

Department of Health. (2001). National guideline on home-based care / community-based care. Pretoria: Department of Health.

Department of Health. (2003). Healthcare 2010 approved by Western Cape Cabinet. Department of Health: Western Cape Provincial Government. Available at URL: <http://www.info.gov.za/speeches/2003/03032812461002.htm> accessed 6/30/2006.

Department of Health. (2004). Monitoring Review: Progress report on the implementation of the comprehensive HIV and AIDS care, management and treatment programme. Pretoria: Department of Health.

Department of Social Development. (2002a). National report on the status of older persons: 1994-2002. Report to the Second World Assembly on Ageing. Pretoria: Department of Social Development.

Department of Social Development. (2002b). Care and support for people who are affected and infected by HIV/AIDS Available at URL: <http://www.welfare.gov.za/Documents/2002/December/aidscares.htm>. accessed 2006/05/02.

Department of Social Development. (2003). South African Policy for older persons: Eleventh draft. Pretoria: Department of Social Development.

Draft Provincial Health Plan. (1995). Strategic Management Team. Ministry of Health and Social Services. Western Cape Province.

Ferreira, M. & Charlton, K.E. (1996). Towards an integrated, community-based social and health care programme for older residents of Mitchell's Plain: A study report. Cape Town: HSRC/UCT Centre for Gerontology.

Fontaine, K.L. & Fletcher, J.S. (1995). *Essentials of Mental health Nursing*. Third Edition. California: Eddison-Wesley Nursing.

George, J. B. (2002). *Nursing Theories. The Base for Professional Nursing Practice*. Fifth Edition. Upper Saddle river NJ: Prentice Hall.

Glaser, B. G. & Strauss, A. L. (1967). *The discovery of grounded theory: strategies for qualitative research*, Chicago: Aldine.

Grunfield, E. Gossop, R. Mc Dowell, I. & Danbrook, C. (1997). Caring for elderly patients at home: the consequences to the caregiver. *Canadian Medical Association Journal*, 157(8): 1101-1105.

Guba, E. & Lincoln, Y. (1985). *Effective evaluation: improving the usefulness evaluation results through responses and naturalist approaches*, San Francisco: Jossey-Bass.

Hartley, S. (2001). Commentary on 'community-based services delivery in rehabilitation: the promise and the paradox' by Kendall, Buys and Lerner. *Disability and Rehabilitation*, 23(1): 26-29.

Hoeman, S.P. (1996). *Rehabilitation Nursing: Process and Application*. St Louis: Mosby

Houts, P.S. (1994). Editor. *Home care guide for cancer. For family and friends giving care at home*. United States of America: American College of Physicians Homecare guides.

Joubert, J.D. (2005). A profile of informal carers in South Africa. Unpublished Master's thesis. Pretoria: University of Pretoria.

Joubert, J.D. Reddy, P. & Bryan, W. (2002). Informal care in South Africa: A carer perspective. Final report. Cape Town: Medical Research Council.

Katz, S. Ford, A.B. Moskowitz, R.W. Jackson, B.A. & Jaffe, M.W. (1963). Studies of illness in the Aged. The Index of ADL: A Standardized Measure of Biological and Psychosocial Function. *Journal of the American Medical Association*. 185 (12): 914-925

Kendall, E. Buys, N. & Lerner, J. (2000). Community-based service delivery in rehabilitation: the promise and the paradox. *Disability and Rehabilitation*, 22(10): 435-445.

Kendall, J. (1999). Axial coding and Grounded theory controversy. *Western Journal of Nursing Research*, 21(6): 743-757.

Kerr, S. M. & Smith, L. N. (2001). Stroke: an exploration of the experience of informal caregiving. *Clinical Rehabilitation*, 5: 428-436.

Lowenberg, J.S. (1993). Interpretive research methodology: broadening the dialogue. *Advances in Nursing Science*, 16(2): 57-69.

Mant, J. Carter, J. Wade, D. T. & Winner, S. (1998). The impact of an information pack on patients with stroke and their carers: randomized controlled trial. *Clinical Rehabilitation*, 12(6): 465-476.

Mant, J. Carter, J. Wade, D. T. & Winner, S. (2000). Family support for stroke: a randomized controlled trial. *The Lancet*, 356 (September 2) 808-813.

Mead, G. H. (1934). *Mind, Self and Society*. Chicago: University of Chicago Press.

McCance, T.V. Mc Kenna, H.P. Boore, J.R.P. (1999). Caring: theoretical perspectives of relevance to nursing. *Journal of Advanced Nursing*. 30(6): 1388-1395.

McCance, T.V. Mc Kenna, H.P. Boore, J.R.P. (1997). Caring: dealing with a difficult concept. *International Journal of Nursing Studies*, 34(4): 241-248.

McCann, T. & Clark, E. (2003). Grounded theory in Nursing research: part 2 – Critique. *Nurse Researcher*, 11(2): 19-28

McCann, S. Ryan, A. A. & McKenna, H. (2005). The challenges associated with providing community care for people with complex needs in rural areas: a qualitative investigation. *Health and Social Care in the Community*, 13(5): 462-469.

McGarry, J. & Arthur, A. (2001). Informal caring in late life: a qualitative study of the experiences of older carers. *Journal of Advanced Nursing*, 33 (2): 182-189.

McNally, S. Ben-Shlomo, Y. & Newman, S. (1999). The effects of respite care on informal carers' well-being: a systematic review. *Disability and Rehabilitation*, 21(1): 1-14.

Melia, K.M. (1996). Rediscovering Glaser. *Qualitative Health Research*, 6(3). 368-378.

Merrell, J. Kinsella, F. Murphy, F. Philpin, S. & Ali, A. (2005). Support needs of carers of dependent adults from a Bangladeshi community. *Journal of Advanced Nursing*, 51(6): 549-557.

Mignor, D. (2000). Effectiveness of Use of Home Health Nurses to decrease Burden and Depression of Elderly Caregivers. *Journal of Psychosocial Nursing*, 38 (7): 36-41.

Miles, M. B. & Huberman, A.M. (1994). *Qualitative data analysis: An expanded sourcebook*. California: Sage

Mitchell, R. (1999). The research base of community-based rehabilitation. *Disability and Rehabilitation*, 21(10-11): 459-468.

Mitchell, R. (1999). Community-based rehabilitation: the generalized model. *Disability and Rehabilitation*, 21(10-11): 522-528.

Modiba, P. Gilson, L. & Schneider, H (2002). Voices of service users. In Ntuli, A. Suleman, F. Barron, P. & McCoy, D. *South African Health Review 2001*, 187-202. Durban: Health Systems Trust.

Morris, S. M. & Thomas, C. (2002). The need to know: informal carers and information. *European Journal of Cancer Care*, 11:183-187.

Munhall, P.L. & Boyd, C.O. (1993). *Nursing Research: A Qualitative Perspective*. Second Edition. New York: National League for Nursing Press.

Munhall, P. L. (2001). *Nursing Research: A Qualitative Perspective*. Third Edition. Boston: Jones and Bartlett Pub.

Naylor, M.D. (1990). Comprehensive discharge planning for hospitalized elderly: a pilot study. *Nursing Research*, 39: 156-161

Ndaba-Mbata, R. D. & Seloilwe, E.S. (2000). Home-based care of the terminally ill in Botswana: knowledge and perceptions. *International Nursing Review*, 47: 218-223.

Neuman, W.L. (2003). *Social research methods: qualitative and quantitative approaches*. Boston: Allyn and Bacon.

Njongwe, P.Z. (2003). Foreword. In Ijumba, P. Ntuli, A. & Barron, P (eds), *South African Health Review 2002*, i. Durban: Health Systems Trust.

Nolan, M. (1999). National Strategy for Carers: The way forward. *British Journal of Nursing*. 8 (4): 194.

O'Connell, B. Baker, L. & Prosser, A. (2003). The educational needs of stroke survivors in acute and community settings: are they being addressed? *Journal of Neuroscience Nursing*. 35: 21-28

O'Connell, B. Baker, L. (2004). Managing as carers of stroke survivors: strategies from the field. *International journal of nursing practice*. 10: 121-126

Office of the Deputy President. (1997). White paper for the Transformation of the Health System in South Africa. Pretoria: Department of Health. Available at URL: http://www.polity.org.za/html/govdocs/white_papers/health.html accessed 8/7/2006

Orem, D.E. (1985). *Nursing Concepts of Practice*. Third Edition. New York: McGraw – Hill Book Company.

Orem, D.E. (1991). *Nursing Concepts of Practice*. Fourth Edition. St Louis: Mosby-Year Book.

Orner, P. (2006). Psychosocial impacts on caregivers of people living with AIDS. *AIDS Care*, 18(3): 236-240.

Patton, M.Q. (2002). *Qualitative research & evaluation methods*. Third Edition. California: Sage Publications.

Payne, S. Kerr, C. Hawker, S. Hardey, M. & Powell, J. (2002). The communication of information about older people between health and social care practitioners. *Age and aging*, 31, 107.

Perold, A. & Muller, M. (2000). The Composition of old age homes in South Africa in relation to the residents and Nursing Personnel. *Curations*, (March) 87-94

Pijl, M. (2003). The support of carers and their organizations in some Northern and Western European countries. In Brodsky, J. Habib, J. & Hirschfield, M. (eds), *Key policy issues in long-term care*, 25-60. Geneva: World Health Organization.

Procter, S. Wilcockson, J. Pearson, P. & Allgar, V. (2001). Going home from hospital: the carer/patient dyad. *Journal of Advanced Nursing*, 35(2), 206-217.

Provincial Government of the Western Cape. (2000). Draft strategic and service delivery improvement plan (SSDIP): specific issues. Department of Health: Western Cape Provincial Government. Available at URL: http://westcape.wcape.gov.za/health_social_services/default.asp accessed 3/26/02.

Provincial Government of the Western Cape. (2000). Draft strategic and service delivery improvement plan (SSDIP): Demographic socio-economic and health status profile. Department of Health: Western Cape Provincial Government. Available at URL: http://westcape.wcape.gov.za/health_social_services/policy_planning/chapter_04.asp accessed 3/26/02

Robinson, L. Francis, J. James, P. Tindle, N. Greenwell, K. & Rodgers, H. (2005). Caring for carers of people with stroke: developing a complex intervention following the Medical Research Council framework. *Clinical Rehabilitation* 2005, 19: 560-571.

Sharma, M. (2004). Viable methods for evaluation of community-based rehabilitation programmes. *Disability and Rehabilitation*, 26(6): 326-334.

Shyu, Y-I. L. (2000) The needs of family caregivers of frail elders during the transition from hospital to home: a Taiwanese sample. *Journal of Advanced Nursing*, 32(3): 619-625.

Smith, L. M. Lawrence, M. Kerr, S. M. Langhorne, P. & Lees, K. R. (2004). Issues and Innovations in Nursing Practice - Informal carers' experience of caring for stroke survivors. *Journal of Advanced Nursing*, 46(3): 235-244.

Smith, M. (1999). Editor. *Rehabilitation in Adult Nursing Practice*. London: Churchill Livingstone.

Social Assistance Act 13 of 2004 s. 10.

Soothill, K. Morris, S. M. Harman, J. C. Francis, B. Thomas, C. & McIlmurray, M. B. (2001). Informal carers of cancer patients: what are their unmet psychosocial needs? *Health and Social Care in the Community*, 9(6): 464-475

Statistics South Africa. (2003). Census 2001. Census in Brief: Report no. 03-02-03 (2001). Pretoria: Statistics South Africa.

Statistics South Africa. (2005). Mid-year estimates. Pretoria: Statistics South Africa.

Stern, P.N. (1994). Eroding grounded theory. In Morse. J. Editor. *Critical issues in qualitative research methods*. Thousand oaks: Sage.

Stewart, S. Marley, J. & Horowitz, J. (1999). Effects of a Multidisciplinary, Home-based intervention on unplanned readmissions and survival among patients with chronic congestive heart failure: A Randomized controlled study. *Lancet*. Vol. 354(9184): 1077-1084.

Strauss, A. & Corbin, J. (1990). *Basics of qualitative research: grounded theory procedures and techniques*, California: Sage Publications.

Strauss, A. & Corbin, J. (1998). *Basics of qualitative research: techniques and procedures for developing grounded theory*, Thousand oaks: Sage Publications.

Turmusani, M. Vreede, A. & Wirz, S. L. (2002). Some ethical issues in community-based rehabilitation initiatives in developing countries. *Disability and Rehabilitation*, 24(10): 558-564.

Twigg, J., Atkin, C. & Perring, C. (1990). *Carers and services. Review of research*. London: HMSO Department of Health

Tyson, S. & Turner, G. (2000). Discharge and follow-up for people with stroke : What happens and why. *Cinical Rehabilitation*, 14(4): 381- 393.

Uys, L.R. & Hensher, M. (2002). The cost of home-based terminal care for people with AIDS in South Africa. *South African Medical Journal*, 92(8): 624-628.

Uys, P. (2006). Vote 06: Health Budget speech 2006 by Mr Pierre Uys, Western Cape Provincial Minister of Health, Provincial Legislature. Department of Health: Western Cape Provincial Government. Available at URL: <http://www.info.gov.za/speeches/2006/06060515151001.htm> accessed 8/7/2006

Wiles, R. Pain, H. Buckland, S. & McLellan, L. (1998). Providing appropriate information to patients and carers following a stroke. *Journal of Advanced Nursing*, 28(4): 794-801.

World Health Organization. (1976). Resolution on disability, prevention and rehabilitation. Geneva: World Health Organization.

World Health Organization. (1980). International classification of Impairments, Disabilities and Handicaps: A manual of Classification relating to the consequences of disease. Geneva: World Health Organization.

World Health Organization. (2002a). Home-based long-term care. Report of a WHO Study Group. WHO Technical Report Series. Geneva: World Health Organization.

World Health Organization. (2002d). Lessons for long-term care policy. Geneva:
World Health Organization.



APPENDIX 1: DEMOGRAPHIC DATA QUESTIONNAIRE: CARER

1. GENDER

Male	
Female	

NOTES

2. AGE

18 – 30 yr	
30 – 45 yr	
45 – 60 yr	
60 -	

3. POPULATION GROUP

White	
Coloured	
Black	

4. HOME LANGUAGE

English	
Afrikaans	
Xhosa	

5. MARITAL STATUS

Married	
Single	
Divorced	
Widowed	

6.EMPLOYMENT

Employed	
Unemployed	

7. INCOME

Less than R500.00 / month	
R 500 – R1499 / month	
R 1500 – R2499 / month	
More than R2500 /month	

8. HEALTH STATUS (SELF-RATED)

Good	
Fair	
Poor	

9. CHRONIC DISEASE (LIST)

--

10. RELATIONSHIP TO DEPENDANT

Parent / Parent -in -law	
Child	
Spouse / Partner	
Friend / Neighbour / Other	

11.CARER LIVES WITH DEPENDANT

Yes	
No	

12 CARER'S RESPONSIBILITY RE. HOME-BASED CARE

Sole responsibility	
Assistance (Specify)	

RESEARCHER:.....

DATE:.....

APPENDIX 2: DEMOGRAPHIC DATA QUESTIONNAIRE: DEPENDANT

ADDRESS

NOTES

1. GENDER

Male	
Female	

2. AGE

18 – 30 yr	
30 – 45 yr	
45 – 60 yr	
60 -	

3. POPULATION GROUP

White	
Coloured	
Black	

4. HOME LANGUAGE

English	
Afrikaans	
Xhosa	

5. MARITAL STATUS

Married	
Single	
Divorced	
Widowed	

6.EMPLOYMENT

Employed	
Unemployed	

7. INCOME

Less than R500.00 / month	
R 500 – R1499 / month	
R 1500 – R2499 / month	
More than R2500 /month	

8. HEALTH STATUS (SELF-RATED)

Good	
Fair	
Poor	

9. CHRONIC DISEASE (LIST)

--

10.DIAGNOSIS

--

11. DEPENDENT IN THE FOLLOWING ACTIVITIES OF DAILY LIVING (ADL)

Bathing	
Feeding	
Mobility	
Toileting	
Dressing	

RESEARCHER:.....

DATE:.....

APPENDIX 3: INTERVIEW GUIDES

FIRST INTERVIEW

- 1 Describe your feelings about the hospitalization of X
- 2 What are your feelings about the discharge of X?
3. Why are you going to / have you chosen to take care of X?
4. Do you have any specific needs with regard the discharge of X? What are they ?
5. Do you have any specific concerns with regard the discharge of X? What are they ?
6. What changes have you made in preparation for the discharge?



SECOND AND THIRD INTERVIEW

1. Describe your feelings about caring for X at home.
2. What things are different from what you expected prior to the discharge of X?
3. What changes have you had to make in your life since the discharge of X.
4. Do you experience any difficulties in providing care for X?
What are they? What did you do about these difficulties?
5. What type of support have you received from the rest of the family, the community and the health services providers?

APPENDIX 4: SAMPLE CRITERIA

RESEARCH PROJECT / STUDY:

A THEORETICAL REHABILITATION FRAMEWORK BASED ON THE EXPERIENCES OF INFORMAL HOME-BASED CARERS DURING THE TRANSITION OF THEIR ELDERLY DEPENDANTS FROM HOSPITAL TO HOME: A SOUTH AFRICAN STUDY.

RESEARCHER / RESEARCHERS REPRESENTATIVE:

REGISTERED NURSE / UNIT:

POTENTIAL PARTICIPANT/S:

CRITERIA:

CRITERIA	YES	NO	COMMENTS
(i) older than 65 years			
(ii) resident in Cape Town Metropolitan Area			
(iii) able to speak English /Afrikaans/ Xhosa (specify)			
(iv) needs assistance with the following activities of daily living (AT LEAST TWO)			
a) bathing			
b) dressing			
c) using the toilet			
d) mobility			
e) continence			
f) feeding			
(v) will be discharged to private dwelling			
(v) potential carer is contactable (specify)			

CONTACT DETAILS:

J D Jeggels (Ms)

Tel: (h) 021-9816945 (w) 021-9592271 /2278
(c) 083-4952214

E-mail: (h) junejeg@mweb.co.za (w) jjeggels@uwc.ac.za

Fax : (w) 021- 9593686

APPENDIX 5: CONCEPT INFORMATION AND CONSENT DOCUMENT

TITLE OF RESEARCH PROJECT / STUDY

INFORMAL HOME-BASED CARERS OF ELDERLY DEPENDANTS DURING THE TRANSITION FROM HOSPITAL TO HOME : A SOUTH AFRICAN SAMPLE.

Reference number: _____

I the undersigned: _____ (Participant)

ID: _____

Of: _____ (Address)

A. *I confirm that:*

1. I, the participant have been invited to participate in the above research project / study undertaken by a staff member of the University of Western Cape.
2. It was explained that:
An exploration is being undertaken to determine the experiences of informal home-based carers of elderly dependants in the metropolitan area of Cape Town. The purpose of the study is to gain an understanding about the capabilities of the carer in relation to the demands of dependent-care. This will enable health care workers to use the information when planning the hospital discharge of elderly dependants. It will also inform them about the type of formal and informal support the carer needs following the discharge of the patient from the hospital.
3. My participation include the following:
Interviews will be conducted with me in which personal questions will be asked. The interviews will be audio-tape recorded. The first interview will be done prior to the discharge of the elderly patient from the hospital.
The second interview will be scheduled within the first week following the hospital discharge and a third interview two months after the hospital discharge.

The second and third interview will be conducted in the home of the participants. An observational guide will be completed during the home visits.

4. My participation will not have any negative implications for me
5. I have been informed that although the results of the study will be published I will remain anonymous
6. The information obtained will be confidential but will be used for a doctorate degree and in professional journals.
7. There is no personal gain, financial or other, in my participation in this study.
8. I will not be pressurized to participate in the study and may withdraw at any time if I so wish to.

I hereby agree voluntarily to participate in the project / study.

Signed at _____ on _____ 20_____

Participant _____ Witness _____



Statement by / for Researcher

I, the undersigned _____ declare that I explained the content of the document in English / Afrikaans / Xhosa to the participator, Dr / Mr / Mrs / Ms _____ and requested him / her to ask questions if uncertainty existed about any aspect of the document.

Signed at _____ on _____ 20_____

Researcher / Researchers representative _____

Witness _____

APPENDIX 6: CONSENT FROM TRAINING HOSPITAL

The Medical Superintendent
Tygerberg Hospital / Groote Schuur Hospital
Private Bag

Dear Sir / Madam

CONSENT TO CONDUCT RESEARCH WITHIN THE INSTITUTION.

I hereby wish to obtain consent to conduct one aspect of a research project / study within your institution.

I am a registered doctoral student of the University of the Western Cape (Student Number: 7200899). The title of my proposed study is : Informal home-based carers of elderly dependants during the transition from hospital to home within the South African Context. Attached please find a copy of my research proposal.

Permission is requested for:

registered nurses to identify potential participants by using sample criteria.
researchers to obtain informed consent from potential participants in the ward
researchers to interview participants prior to the discharge of the dependant from the hospital.

A copy of the research report will be forwarded to your institution

I thank you

Ms J D Jeggels

Tel: (h) 021-9816945 (w) 021-9592271 /2278 (c) 083-4952214

e-mail: (h) junejeg@mweb.co.za (w) jjeggels@uwc.ac.za

fax : 021- 9593686

APPENDIX 7: CONDITIONAL MATRIX

International:

South Africa is a developing country / until 1994 the rest of the world applied sanctions to force the country to change national policies / there is a focus on third world issues like poverty, corruption and crime / there is evidence of diseases related to third world dynamics e.g. HIV/AIDS, tuberculosis and malnutrition.

National:

We have a new democracy / currently the culture of human rights is being entrenched in our constitution / National Department of Health has adopted a CBR strategy / Department of Social Development provide Older persons grants / diverse population / remnants of the apartheid system of separate development and group areas / traditional family structure disintegrating / adopting western culture / unbalanced economy / high levels of crime and violence.

Provincial:

Western Cape province / majority population group is coloured / language of preference is Afrikaans / developing infrastructure / combination of first and third world situation / district health system / formal healthcare include provincial and private facilities / two tertiary referral hospitals / agriculture and industry main income generators

Community:

Tend to be culturally defined / urban and peri-urban / variety of socio-economic backgrounds / variety of housing units / variety of religions / regional hospitals and community health centers represent formal health care facilities / community health workers / non-governmental organizations and faith-based organizations .

Organizational and institutional:

Tertiary hospitals with medical, surgical orthopaedic wards / formal health care team consist of specialists from all health and social development disciplines / referral to home-based care

Homes with range of facilities / single or semi-detached dwellings / single bed roomed units in apartment buildings / informal settlements

Group, individual & collective:

Dyads of carer and elderly may or may not be related / elderly have their roots in their communities / women do most of the caring / carers may or may not reside with elderly / both are dependent on public transport / carers are unemployed / carers have to attend to many other chores

APPENDIX 8: EXAMPLES OF TRANSCRIPTS

NVivo revision 2.0.163 Licensee: Default

Project: Informal Home-based Care User: Administrator Date: 2006/02/24 - 05:48:29 AM

DOCUMENT TEXT REPORT

Document: PARTICIPANT 09
Created: 2004/08/16 - 05:48:00 PM
Modified: 2005/06/13 - 10:53:58 AM
Description:
INTERVIEW A-0031

Document Text:

1: PARTICIPANT 09 01/10/03

2:

3: Int: Mr H, I just want to thank you for allowing me to interview you and to ...from what I see in the records your mother was in hospital. She was discharged on the 29th of August after she had her first operation and that was for the ...

4:

5: Resp: ... The ankle...

6:

7: Int: The amputation as far as the ankle.

8:

9: Resp: As far as the ankle.

10:

11: Int: And then, on the 12th of September they did the operation above the knee.

12:

13: Resp: Above the knee.

14:

15: Int: How did you experience the fact that your mother had to have these...?

16:

17: Resp: First of all, my mother used to... always used to say she would rather live with it and die like that ... so bad... every night she was awake. The pain is too bad. It's...

18:

19: Int: And when she was in hospital, how did you experience her hospital ... at her side at the hospital?

20:

21: Resp: Ja, I was...I was.

22:

23: Int: Before she was discharged.... have any concerns about ...having to care for her ?

24:

25: Resp: Not really, because as far as I can remember, we.. my brother then got married and I was worried at first[1] because...

26:

27: Int: Ummm. Ummm.

28:

29: Resp: and just leave her.

30:

31: Int: So it was just taken for granted that because you are living with your mother you would be the one to look after her?

32:

33: Resp: Ummm.

34:

35: Int: Your brothers and sisters, how many do you have?

36:

37: Resp: I've got...

38:

39: Int: Living close by.

40:

41: Resp: They're right in the other road and the one just around the corner...

42:

43: Int: So they're quite close by?

44:

45: Resp: Ummm.

46:

47: Int: We'll come to their participation soon. Now, before your mother was discharged, were there any things that you felt that you needed to do... to get, before your mother could come home after she had the above-knee amputation?

48:

49: Resp: Because I don't have a car, I had to make arrangements.

50:

51: Int: So you asked around and you felt that you got enough information that you needed[2]?

52:

53: Resp: Ummm-hmm.

54:

55: Int: Okay. You said that the dressings are done at home. Who is doing the dressings?

56:

57: Resp: Not in that case. They showed me how to[3]...

58:

59: Int: Are you comfortable about it?

60:

61: Resp: Ummm-hmm. Yes.

62:

63: Int: Okay. You said that you got the commode and you got furniture that you had to rearrange[4].

64:

65: Resp: I had to move the furniture slightly. Actually, I must still move it around just like here... she used to like it.

66:

67: Int: Ummm.

68:

69: Resp: I must as it is now, she can't just come...

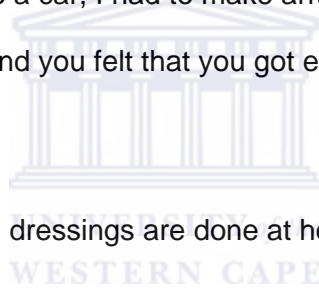
70:

71: Int: Ummm. Ummm.

72:

73: Resp: I've got to change the furniture.

74:



75: Int: Uh-huh.
76:
77: Resp: And put in stuff like this outside.
78:
79: Int: Oh. Oh, okay. So are you did you find that you had to move things in her bedroom as well?
80:
81: Resp: I had to move it.
82: Int: How, uhm, when your mother came home, were you quite comfortable about caring for her?
83: Resp: Uhmm, I was happy that she was home because she ... she actually missed home a lot and ... now she's coming home again...[[5] I didn't expect her that... home that particular day ...to go visit her[6].
84: Int: Uhmm-uhmm.
85: Resp: Then without phoning or letting me know, they just brought her like that.
86: Int: Oh.
87: Resp: But the night before she ... when we got to the hospital she said, "Where were you the whole day?" The doctor said ... but it was not major, it was just, like, nobody actually told me that she was gonna be discharged.
88: Int: Uhmm-uhmm.
89: Resp: ... did'nt know anything, anything.
90: Int: But...uhmm...once she was at home you felt quite comfortable...
91: Resp: A...
92: Int: About her being home.
93: Resp: Ja, I was comfortable because I gave up my wor[7]k. I didn't have the problem making food nowadays and...
94: Int: Uhmm-uhmm?
95: Resp: But I'm ... if I'm needed to go out.
96: Int: Uhmm, so you say once your mother was now at home...uhmm...everything is falling into place and you feeling okay, you feeling comfortable again.
97: Resp: Ja, comfortable.
98: Int: Ja, I think. Okay...uhmm...it's a bit different having a male looking after a female parent, ja. Did you have any reservations about ... or did your mother have any reservations about, you know, the intimate part of her toilet and so on, or or...was she quite capable of caring after herself in that regard?
99: Resp: She's just quite capable because I used to ...like, in the beginning, I actually preferred taking her to the bathroom on the wheelchair, to the toilet because the bedpan was, like, tiring her out. Or the way it was uncomfortable for her to use. So it was quicker for me just to lift her onto the wheelchair and take her to the toilet and lift her straight onto the toilet, like. And it was comfortable for her. And ... like, we... the washing part is concerned I'll leave with a bath of water and she'll do like the private parts and so. And I'll wash her back and feet and so on. But she mostly ... she does it on her own. I'll just wash her back maybe...
100: Int: Uhmm-uhmm.
101: Resp: And maybe and the one foot.
102: Int: Uhmm...okay. So you feel that you're coping quite okay with the situation?
103: Resp: At times she... I get somebody comes around now and then like my one my mom's cousin will come, like, and she'll, like, help my mom to wash. Or once in a while my brother's wife will help, like, you know...bath
104: Int: Uhmm-uhmm. Okay. Okay. Uhmm...now that your mother has been at home for over a week, are things ... you probably had some anticipation of how things were

going to be before discharge and now the reality is your mom is here, and how are finding things? Are they as you had thought they would be, or are things different?

105: Resp: Uhhh...because of what I was promised in the hospital, like my brothers and sisters, came...my sisters and brother came to me and they said that, no they were gonna help me and I don't need to worry. I ... gonna do stuff alone. But I didn't actually put my heart on it because I know them and I know what they're like. They're always busy; they don't have time... going out and stuff like that, so I prepared myself for the worst. And that's why I feel comfortable because it wasn't as bad as I'd thought it was going to be like.

106: Int: Okay. Uhhh...the advantage is your mom is a slender person and she's able to move herself so I suppose that does help a lot.

107: Resp: It helps a lot.

108: Int: Uhhh-uhmm. Uhhh...so you say that your brothers ... your brother and sisters aren't really helping as much as you thought they would.

109: Resp: Uhhh...like for instance...like the weekend past they promised to come and fetch her the Saturday and when I phoned them... they said they'll be here, like, my brother six o' clock. And when it came to something to ten the night he came in here and I said: "But it's too late to take her out now," and he said, "Okay, I'll come and fetch her tomorrow ... Sunday, like, twelve o' clock," and I thought to myself, why not come and fetch her, like, the morning...

110: Int: Uhhh-uhmm.

111: Resp: ...and spend time and I can do my things; go to the shop. But when it came twelve - quarter past twelve he phoned to find out if she still wants to, like, come down. He didn't say, "I'm coming to fetch her." And when I put the phone down she shouted, "Say yes, now okay I'm going. I gonna go down" and 'cause she, like, when he asked is she still coming down so she said, "No, leave it, maar." And, I mean, they actually said they wanted, like, her to come stay with them also, like my two sisters like... and she refuses because she doesn't get along with them. They don't understand her and at times she'll say something in the wrong way but she don't mean it like that and then they'll have an argument with her instead of keeping quiet...

112: Int: Uhhh-uhmm.

113: Resp: And just saying, "Agh, she's just talking again."

114: Int: So they don't get on so well?

115: Resp: No.

116: Int: Okay, uhmm. So you... you haven't found that since your mother has been... has had the operation you people have been closer, you it's not as though your mother's illness has brought you more close together.

117: Resp: I thought it would and I mean, when she was in hospital they'll go out of their way to go visit her at night, visiting time during the day. But when she's home, I mean, it's not gonna cost them transport, it's not gonna cost them parking. There's nothing like that. I would've expected them to come here, I mean, they take in that close tie...

118:

119: Int: In that close tie. Okay. Uhhh...now, the question that probably is going to affect or you have probably been affected. What changes have you had to make in your own life since your mother has been discharged?

120: Resp: Like ...who was for instance, I had this son to look after as well. I can't, like, because say I'm gonna take him to the bioscope or we're gonna go to the beach without thinking, like, how's my mom, who's gonna look after her, is she gonna go worse?

Because, I mean, at times I like taking her places but then she'd get uncomfortable in the car and she'll say like: "Come, let's rather go home." She used to like to go to Clifton

beach but nowadays it's not nice anymore because once you get there, she'll say she's not feeling nice, or...

121: Int: Have you taken her since she's had the above-knee amputation? Have you taken her out? Ummm...say to the shop?

122: Resp: Not in this week, I wanted to but not as yet. I was planning to do it like this week coming now, like, in this week I was supposed to go to the to the shop and take her with because before when we went to Century City she could still walk that time. But once we came into one of the doors there, we looked at the place and it's so huge and big and she say "Okay, I'm gonna sit on the bench here and you go do your shopping".

123: Int: Ummm-uhmm.

124: Resp: So I actually told her, "Naai, you can't, like, say I'm gonna sit on this bench here. I'm gonna push you through this whole shop for this weekend. You can see what's going on here." Because, like, last week also we didn't have a lift to the Day hospital so I took her on the wheelchair, and it was nice for her to see the main road again where she used to like walking. But when we came back it was a bit uncomfortable so we stopped by the stadium. And she used to like stuff like that, and ... "Hands off our children" thingy there. And we went in there and they actually wanted to put us in the presidential suite. And she was excited but then it was so uncomfortable for her sitting in the chair so she said "No, man. Let's go home and then I can, like, go back down." But I knew I couldn't go down and leave her here...

125: Int: Ja, because there was no one with her. Okay. Ummm...so you find that your movement ... your going out is restricted...

126: Resp: Restricted, ja

127: Int: And your life, okay. But when you do go out who do you have who is there at the moment, besides having to ask your sisters who ...?

128: Resp: If I want to go out I must, like, restrict my time. I must, like, say, like, before I go out and then I can, like, come back any time but now I must say, okay, if I ask my sister, I have to say she can't, like, she can't like - she don't like staying too late and I'll say, "Okay, I'll be in at ten o'clock again." We come back ten or eleven.

129: Int: Ummm-uhmm.

130: Resp: Or, at times, like, I'll get somebody to stay here who goes out with me, my son's mom, like. And I can go out wherever, go to Century City ... the shops close at nine there ... then I'll do the shopping. Then at times then there's stuff we need to do, together, like for my son, like, then I'm forced to ask somebody and I found that if I asked my sister's children ... the one sister, they're, like, happy to do it and I actually told them I'll give them something. I'll, like, pay them this night to come and, like, cover for me, sort of, if I need to go somewhere. And I find that they're quite eager to do it that way.

131: Int: Oh!

132: Resp: If I give them something, like.

133: Int: Ja, hey. So... even though it's their granny you have to pay them. Okay. So you've overcome that difficulty of ... of babysitters sometimes. Okay. Where there any other difficulties that you experienced in dealing with your mother?

134: Resp: Uhhh, the only problem I have is at times, it's not really a problem for me because I understand if she's got, like, a slight Alzheimer's problems she forgets very quickly. She'll remember the olden days, she will remember a lot of stuff that we can talk about when she was young, and in her days. But at times, now say for instance somebody will come and visit her now and give her something, ten minutes later she will forget who was here, like, and then say, "When was this person ... when last was this person here?" Something like that. Even before she went to hospital, she'd, like, leave her pension money somewhere and then she'll forget where it is and then I have to look through all the cupboards and stuff. And, it's at times you can tell her, like, the hospital

said she mustn't keep the leg under the pillow anymore, she must keep it down, but she won't listen. She'll say, "No, but it's comfortable up like this."

135: Int: Ummm.

136: Resp: And now, I'll explain to her, and still she won't take the pillow out, like, like, they told me, if she keeps it too high, one solution for that type of amputation, it has a tendency to stay in that position...

137: Int: It's gonna pull tight, and then when they fit the prosthesis it's going to be difficult.

138: Resp: It's going to be difficult. But I explained to her lots, at times she listens, but most of the times I'll walk out of the room she pulls the pillow back there. But it's not a high pillow, really.

139: Int: So it's just that it's more comfortable for her. Has she ever forget that she were fed that she has had something to eat and...?

140: Resp: That's...uhmm...also ja. Like I'll give her breakfast, she don't want porridge. Even if I buy Pronutro, or Weetbix. She'd prefer to eat, like, sandwiches and a cup of tea and if somebody tells me she'll say, "No, I haven't had a cup of tea yet." And I'll give her tea again, but then she'll forget again then tonight, like, I'll tell her "Jo, but Mommy, you had a lot of tea today." Then she'll say, "No, it can't be", like. Like, on Sunday when she came from her brother's house, we actually went to go fetch her. She didn't feel well the evening. And I said, "No mommy, come let's rather go home." But when we got home, as we came in here, so she said she wanted to go to the bathroom and she actually had diahorrea right through the night, till the morning, till Monday morning. Every hour during the night I had to get up and take her to the bathroom. So until about, five o' clock the morning. So I woke up at six again, after six she said she just wanted to wee, then she told me she helped herself over to the commode and she didn't know her stomach was still working but by then it stopped because I gave her she used to give us like, flour with water and a pinch of salt. I gave her that and then I just, a little bit of calcium which they say is also good for dehydration and I gave her that. And after that attack stopped the morning. But by that time I was so tired I actually went down and I fell asleep and I woke up about something to ten and she actually had to be at the hospital at eight o' clock.

141: Int: Oh.

142: Resp: And my brother promised that he will take her, and never pitched up. And so she missed her appointment.

143: Int: So she didn't...okay.

144: Resp: And that's the only problem I have at the moment, because I don't have a car anymore. I'm planning to get one, but because I'm not working at the moment ...

145: Int: Ummm. And then running a house and then having to provide because your mother being a diabetic needs special things and so on. The other thing I wanted to ask you ... you mentioned that she had diahorrea, but before she had the diahorrea, how were her stools? Did she have regular bowel actions?

146: Resp: Uhhh... come to think of it, not that often, because, like, if I can now think, she never went to the ... to, like, the bathroom again. Only once and then...

147: Int: Is it? So is she getting enough fluid? Enough water during the day?

148: Resp: Ja, I give her lots of water and tea, she likes tea, so, like, the whole day she will drink tea and she will ask for sandwiches, bread like. And at night she will get a plate of food. At times she'll refuse to eat food, but then she took tea and at one stage I had to buy her the diabetisis powder form of food, I just threw the one away now.

149: Int: Uhhh.

150: Resp: But I used to give her the one that the hospital...

151: Int: Is it a drink?

152: Resp: Ja, and I bought her that and then somebody told me that that's not actually good for diabetics but I thought that it's fine.

153: Int: For diabetics

154: Resp: I went to the chemist and they told me it's fine. But that's one of the problems I have with the one sister. She came here. She never comes to me and tell me, ask me questions about my mom. She look around and she goes to her neighbour and then she come and say, "Mommy, my neighbour says you can't have this. Mom, my neighbour say you can't have the iron tablets because it's gonna make you constipated." Even if my mother don't wanna take the stuff, and I mean, they give it to me at the hospital and they tell me to give it to her.

155: Int: No, that's true, the iron tablets would for example do make you constipated but then you should drink a lot of fluids...

156: Resp: Fluids with it, ja.

157: Int: And you should also eat roughage, like the vegetables and fruit and things like that. But you must obviously check the amount of fruit because she is diabetic and so on. Uhmm... the other thing I wanted to ask you about was ... uhmm... medication. What medication is she on at the moment?

158: Resp: At the moment, it uhmm...like the anti-biotic is finished so it's ... used to get at the hospital. It's, like, the diabetic tablets, the diamicon, the blood pressure tablets, half in the morning, half at night. She gets the water tablets, it's only in the morning now because it used to be in the morning, then at two in the afternoon, but the they only giving it in the morning now again.

159: Int: Uh-huh.

160: Resp: And then there' one other tablet she also gets.

161: Int: For her blood pressure?

162: Resp: With blood pressure, ja. And a ... asprin, half a asprin in the morning.

163: Int: Okay and ... and...okay, and the iron tablets, you say she's still taking the iron tablets. Is it finished now?

164: Resp: That is finished now.

165: Int: Okay, you're not giving her anything for her bowels and that you don't think it's necessary to give her anything

166: Resp: I ... they told me to let her eat, like, Weetbix a lot and stuff like that or ... high fibre bran, all bran but she refused to eat it because she tells me her stomach works when she drinks cows milk. But ever since my mom got sick the last time, I totally took her off condensed milk because it shot her sugar levels up. And she never wanted to get off that. I bought cows milk and I made her tea with cows milk and she'd drink it. But whenever she comes into the kitchen herself, "Why you throwing cows milk into my tea?" Then she'll go to the shop and she'll buy a tin of condensed milk.

167: §3 Int: Ja, but now she won't go to shop now will she?

168: Resp: No she can't, but then I totally stopped it, it's been now, must be more than six months now that I haven't bought condensed milk. I actually never bought it again.

169: Int: It's not good for her.

170: Resp: It's more than six months, ja, that she stopped using it. But if she goes to my other sister she says, "But then it's nothing for mommy to have sweet stuff now and then," and they used condensed milk and

171: Int: Uhmm. Well. I suppose now and then it isn't so, but not for every day and especially as you say she likes to drink tea during the day.

172: Resp: And she likes fruit and then I'll tell them "She can only have one banana." That's what I know they told me. And a portion of that, and maybe that. But then they'll bring a bunch of bananas and she'll eat one and another one.

173: Int: Okay, so you say that the rest of the family are occasionally, but not as much as you would've hoped. Besides the direct, the immediate family, friends, relatives other support that you have?

174: Resp: Uhhh, I kind of have a lot of support from most ... more support from outside people than my own. Like there's people who phone and come around and she's okay, and they tell me, like, if she do need a lift, please phone. If we're at home we'll take her like here, or to the hospital. Wherever. Like, the people who actually ... gentleman was at the hospital with my mom on the same date, their dates all the same and he'll, like, take her down or bring up the tablets. Nowadays I'll go and fetch his because I must go down for my mom. And he'll come around like on Thursdays and tell me they do their shopping at Kenilworth Centre, I can go with them.

175: Int: Oh, good.

176: Resp: I can just get somebody to look after my mom.

177: Int: Hmm. Thats good.

178: Resp: My mom's cousin, they don't come as often but when they do come they see to it that she gets a nice bath, like, they will wash her and...just put other bedding on, which I also do.

179: Int: Hmm... So you have friends who at least are still very supportive of her. That's good. That's good.

180: Resp: My mom's sister actually gives me a lot of support because whenever she can she comes through weekends and she'll help me make the food. And her children will come, I mean, I kind of ... sometimes I tell them, "Jo, you must never change because your mom's still well," she's also diabetic. And at one stage when my mom went to hospital she was worried and she thought she had a boil on her stomach and it was actually a diabetic ulcer.

181: Int: oh.

182: Resp: But I mean, their mom is still fine and they take care of their mom, they pick her up and take her out shopping and they bring her stuff. And at times I just think, jong, why aren't my sisters and brother like that?

183: Int: Ja, we're all different, hey. And tell me the health services. Groote Schuur is where your mom ... you said your mother had to go there for rehab.

184: Resp: Ja, she's going on Friday for the rehab clinic. She had to be there on Monday for the surgery ...

185: Int: Oh, for the outpatient

186: Resp: For the out patient ...

187: Int: So have you changed for that?

188: Resp: ... go through its changes because ... because of my position, I only got paid today...

189: Int: But can't you phone?

190: Resp: Ja, I've got a pre-paid phone and I only got paid today and so I was gonna phone them because I must definitely change appointments. And I had a lift on Monday, we I just had to confirm Sunday evening but when my brother told me its Ok he's gonna take her and I had to confirm with the gentleman.

191: Int: And then you overslept.

192: Resp: Then I overslept and he never came.

193: Int: Okay, so uhhh... Groote Schuur is there where you take your mom and then the day hospital you ... where they do the dressing?

194: Resp: Ja, near the stadium ... Doctor Abdurahma[8]n

195: Int: And your mom gets her tablets from there?

196: Resp: That's right.

197: Int: Okay. Are you quite satisfied with the health provision that you're getting at the moment.

198: Resp: Uhmm, when they ... when they ... when I usually go down for dressing it used to be a big problem because there's no one in the dressing room at the moment when I get there or maybe there's one or two people. But the whole part of getting the folder takes two hours.

199: Int: Uhmm.

200: Resp: You hand in your card, you stand in a long queue, hand in the card just for the dressing room and about a hour or so later they'll call your name and by that time it takes about two to three hours just for a dressing that takes about five minutes.

201: Int: Ja.

202: Resp: But ... but when was it now...the last time I went now I told the lady behind the counter my mom's in the wheelchair because I find at time if they know you with that person they let you wait but if you tell them that person's in a wheelchair they'll like, get the folder quicker there

203: Int: Uhmm. Uhmm.

204: Resp: Get the...now you must sit in the waiting room but the last experience I had was quite quick. They gave me the folder and I went straight to the dressing room, and I got done inside ten minutes' time. With Groote Schuur I had no problems. It's just ... I can't complain. You get the occasional person whose got maybe problems at home now. Some people don't understand like, you can't make the hospital patients your personal problem, I understand that, but at times if you don't remind the person working with that particular patient that she's forgetful or she sometimes makes jokes, then I find some people didn't like it and they'll, like, give her, like, a funny face and stuff like that. But I had no problems, no complaints.

205: Int: Okay, okay. Okay. So you feel at the moment there are a little bit of hiccups but you coping and your mom seems to be quite happy and comfortable under the circumstances.

206: Resp: 'Cause it's like, she's happy, and, like, she agreed that she'll go to my brother the weekends, like, not to my sisters, to my brother. But when it comes to the day that she must go she'll tell me "please don't go out. I want to come back home tonight. I don't want to sleep out."

207: Int: Oh, okay.

208: Resp: But other than that then it's fine.

209: Int: Ja, there are many people who feel more comfortable in their own bedroom, they're more comfortable at home. Oh, but I just want to say thank you very much Mr H for your time. And God willing we'll chat again in about a month's time to see how things are going and how your mom's rehabilitation is coming. Thank you very much

210:

211: Int: good afternoon Mr H I'm very glad that ...it's hard to believe that a month has gone by since we've seen each other

212:

213: Resp: Time went quickly

214: Int: time went quickly. So how's things going with you and your mom at the moment?

215: Resp: it's going okay...not doing too well lately. Very tired lately.

216: Int: Uhmm-uhmm.

217: Resp: so...five, ten minutes.... last week she went to the then on the twenty-second I went to go fetch her tablets but then we took it down. And...uhmm...they tested her because she felt a bit, like, nauseaus. And she her blood pressure was very low...

218: Int: Uhmm-uhmm.

219: Resp: and they took her off the blood pressure tablets for a month.
220: Int: ... has stopped now.
221: Resp: ja, they stopped it.
222: Int: okay.
223: Resp: otherwise she's doing okay. They gave her an iron tablets, but I found now it made her stomach work, like.
224: Int: is it? Because the iron tablets usually make them constipated.
225: Resp: constipated, yes. But I don't know whether it's because she don't want to eat, or don't eat so well... food like... but other stuff she'll nibble on... but...uhmm...I found the first day her stomach worked, that was on the twenty-seventh on a Monday morning. Worked, like. It was, like, grey. I don't know why.
226: Int: Uhmm-uhmm.
227: Resp: and the next day she ... she was constipated again, but then when it came out it was, like, black.
228: Int: Uhmm-uhmm. Because of the iron tablets.
229: Resp: uhmm. But after that things was okay.
230: Int: was okay again. Regular now?
231: Resp: uhmm...I won't say everyday, just because she's not eating as she must be eating.
232: Int: yes, yes.
233: Resp: I've got the Nutrific for her, but she refuses to eat it.
234: Int: is it? Uhmm.
235: Resp: but if I leave it there she gets cross at me, she tells me, "No, I don't eat this. It makes my stomach work," and other stuff she'll eat again.
236: Int: Uhmm. Uhmm. Now that's past is she fasting or is she not[9]?
237: Resp: no, she's not.
238: Int: okay. So, is she eating...uhmm...vegetables at all?
239: Resp: ja, I buy the mixed veg and that.
240: Int: okay, fresh veg? Fresh fruit?
241: Resp: fresh fruit a lot. Ja, she loves to.
242: Int: she eats that? Okay, so that's good fibre. And fluids? How's she taking fluids? Water?
243: Resp: tea and water.
244: Int: is she passing urine okay? No no problems
245: Resp: ja, no problems.
246: Int: and...uhmm...how are you coping with her washing and her toiletries. Are you coping?
247: Resp: I'm still coping. Just that at times I never really gets to me... when I think ...beside one... They don't' seem to care but if I meet people along the road they tell me, "Your sister said this about you and that about you, you don't look after your mommy right," but I mean if I was really not looking after my mom, why don't they, like, come around and do the stuff that I'm not doing according to them.
248: Int: so haven't they been helping this past month? They haven't been coming.
249: Int: Uhmm...my sister actually ... something happened that Friday just after you came, I think you came the Wednesday. And ... uhmm...Friday morning, gave my mom her tablets and breakfast, everything. But the afternoon ... ja it was the afternoon went down the road to the shop and my son was here and I made sure my mom went to the loo to wee and stuff like that the commode was right next to the bed. So when I went to the shop and I came back my mom wasn't at home and I was worried.
250: Int: and your son?
251: Resp: he ... he wasn't here too.

252: Int: oh.

253: Resp: but then I thought, "Wait, I'm going to tell my sister," then she came in here and she came here shouting, "Who was supposed to look after mommy?" so my mommy forced him (carer's son) to put her on the wheelchair. He said, "No, my daddy's coming now, ... just to go wee in the toilet ... but the commode is right next to the bed." Then she told him, "no, but he just cleaned it (the commode) now, I don't want to dirty it." He took her, but when she asked him to take her off the chair onto the toilet, he said, "No, but I can't do it." And she insisted and she fell, but it wasn't bad[10], she was more shocked than anything. And then I went around and my sister said, no ... it's okay, she's okay, she's just in shock.

254: Int: so then did they phone did you phone your sister? Or how did your sister get here or did she just come here?

255: Resp: no, it's just around the corner here. He ran around just to go call her.

256: Int: call her, okay.

257: Resp: but usually he sends me a... call m[11]e, or he phones me. But he was so shocked that he just ran around to go and call her. I wasn't gone for ... not even forty minutes and I came back. But then my mom stays there for the weekend and on Monday ... the Monday I was so cross because I was trying to get hold of her and her cell phone was off. I phoned at the house, nobody answered. The phone just rang. And in the evening we went out the afternoon and about eight o' clock, past six and then my cousin phoned me, "where's your mommy? We came to visit her,". And I said, "She's by my sister but I'm worried too because I can't get hold of them." So finally when I phoned my sister's son ... I got hold of him on his cell phone and then he told me, "But Earl, go pick them up," I asked him, "now, where must I go pick them up?" "The hospital." they took my mommy to the hospital and my mom was kept in the Monday.

258: Int: what did they ... why did they take her in?

259: Resp: according to them it's because she fell the Friday... my sister. But then I it wasn't about that, she had an infection in the stomach ...uhmm... they called it ... some pancreatitis .

260: Int: gastritis?

261: Resp: Ja. And we gave her something but they discharged her the very next morning because I went through early and they told me, no she can come home. And she's fine.

262: Int: okay, and on Monday you went you took her for physio?

263: Resp: uh...she went for physio... she had to go for physio.

264: Int: Uhmm-uhmm.

265: Resp: and for the amputation clinic.

266: Int: Uhmm-uhmm.

267: Resp: but...uhmm...because they called they actually called me the morning to cancel to say it's okay, don't come...uhmm...

268: Int: to the amputation clinic?

269: Resp: I must come...to the physio.

270: Int: to the physio, okay.

271: Resp: I'm supposed to come today, but then about, ten, eleven o' clock they called me back to say, "no, she must come, because she's got an appointment to see the amputation ... at the amputation clinic too.

272: Int: Uhmm.

273: Resp: and then I looked on the card and that appointments was, like, right on top. Right behind all the other appointments and I said, "okay, I'm going to bring her through. Get hold of my brother and find out about a car," and I took her to...

274: Int: what did they have to say there at the...

275: Resp: they said it looks fine.
276: Int: healing well?
277: Resp: healing well. The one doctor was, like, worried. He said it looked, like, infected slightly. But then when he called the vascular surgeon, I think...
278: Int: uh, uh.
279: Resp: ...and he said, "no, it's fine. It's just, like, a small leaking." They I don't know, they mentioned, like, clips that makes a mark on the skin.. and so on. But he said no, it's fine. As long as it's clean and the dressing goes on then it's fine.
280: Int: and about the dressing ... who's doing them now?
281: Resp: uhmm...usually I just put ... they ... they said just a dry dressing.
282: Int: okay.
283: Resp: then I just put the dry dressing on but sometimes my sister ... three times she asked the lady across there by heractually come around here now on a Tuesday and supposedly on a Friday.
284: Int: Uhmm-uhmm.
285: Resp: but my sister went to go and tell them my mom's going to physio every Friday and then they stopped coming again on a Friday.
286: Int: but that isn't so. She doesn't go every Friday?
287: Resp: no.
288: Int: oh.
289: Resp: I was going to take her but because of the transport problem I've got I said no.
290: Int: but the wound is fine. You're quite happy and everybody's happy with the wound. So ...uhmm ... pain?
291: Resp: pain now and then, but not the pain she had, like, before, it's, like, more cramps she's saying. And it's not painful really at times she says whenever they do the dressing she says it's, like, burning. But they put on the saline water and stuff and she says it's slightly burning but not for long. It's fine.
292: Int: oh.
293: Resp: the only other thing is she's ... she don't want to listen when I tell her she's supposed to lay on her stomach a couple of minutes everyday or second day or so, and she don't want to do that. But when I take her for physio then she do it there. Yesso
294: Int: ... you having a problem with her physio. She's not ... is she moving that leg at all, the stump?
295: Resp: ja, she's moving it.
296: Int: she moves it. Does she move herself on the bed around or or or...
297: Resp: I found out since the second amputation above the knee it's getting a bit of a problem for her, but she still moves. She moves from the bed onto the commode and back. Ja, but that's about it. She's a bit scared, like, to stand up. She feels more unbalanced.
298: Int: uhmm.
299: Resp: whereas with the other part she still stood up, like, but...uhmm...when we come to the hospital for, like, physio then she gets, like, excited. She enjoys it there because she sees more people that's the same, then she'll tell me, "See, that man's got no legs."
300: Int: and mental ... emotional, how is that? Is she coping with the fact that ... her leg?
301: Resp: she is ... she'll tell people straight, she open up the leg and show it to them and stuff like that. But I feel at times and especially when she's alone ... I saw at times her eyes is closed and when she's slightly sleeping, she's not sleeping then she like crying and sometimes. Ja.

302: Int: you lost a part of your body so you have to mourn for that, the person you were. Depressed...

303: Resp: the only problem is a family problem getting to her.

304: Int: It's getting to her.

305: Resp: ja, I actually left her with my sister, they came to fetch her one Saturday, only for the day. But then they kept her there and they came to fetch her pyjamas. On the Sunday when I went to go fetch her they said no, I can fetch her. So she said, "Come tomorrow, I'll stay here a bit." And my sister kept her there for the week.

306: Int: Uhmm.

307: Resp: but then I got a message from my father... it's almost like she's putting my mom on a dressing table and inviting everybody, "my mom's here" because people don't like going there actually.

308: Int: uhmm.

309: Resp: but now when my mom's there she knows that the people wants to see my mom now they must come there and because she's got a problem with my other sister staying around the corner. She knows my sister's not going to come ... even my father sent me a message to say it's better if she stays here with me....

310: Int: Uhm

311: Resp: or pay her, because he usually paid her to look after my mom. When I used to work he'll like, tell her to come during the day, he don't like it... when we all had a meeting she also said ... "I'll look after mommy but I can't do it for free"

312: Int: so the family dynamics are causing your mother a bit of unhappiness?

313: Resp: uhmm.

314: Int: Uhmm.

315: Resp: we weren't even there for an hour and she let him call me back to see if I'm at home because she don't want to ... Because I found out when she was, like, by my sister, whenever she says she wants to come home... they'll tell her I'm not at home, they can't get hold me and I've got a cellphone. At times when I must go out and I ask her to finish my business now... It's causing me problems for me at the moment.

316: Int: so since I was here last there's been no improvement in your caring?

317: Resp: no, I thought they were going to do it but my brother, even my brother, ja.

318: Int: you had said you hoped.

319: Resp: and I told him about what my sister said about she went to go tell everybody my mom got sick and ended up in hospital because she fell. I left my mom here the Friday night and they couldn't get hold of me and it wasn't even a Friday night, it was four o' clock, quarter past four and jana. It's not nice.

320: Int: and how did you feel about that ... did it upset you?

321: Resp: I felt about... before?

322: Int: ja.

323: Resp: I ... I felt like guilty at the hospital they told me it's bound to happen but they going to try and help themselves in they're going to fall and some people are very stubborn.

324: Int: Uhmm.

325: Resp: and they told me don't feel guilty, you know? It's like, your mom needs care but you mustn't treat her like an invalid, like, do everything for her. At the end of the day she's just going to lay there and she wants everything and she's not going to try and stand up for anything like that.

326: Int: ja, it must be hard for you. But you say she's not really standing so she's not moving...

327: Resp: she's ... she's now ... she's been very tired lately if she stands up, like, she gets dizzy and sits down again.

328: Int: Ummm.

329: Resp: but ...uhmm...jana.

330: Int: so basically, she's from the bed to the wheelchair...

331: Resp: Ja.

332: Int: to the toilet when she needs to go so that if...

333: Resp: she'll sit wherever. I'll try and take her out at times, but whenever we put her in the car, like, we'll drive about ten minutes then she'll say, oh, she's not feeling or, I'll tell her "come we go down, come with me to the supermarket, I'm going to push mommy in the chair," then she'll say, "No, but the people is gonna look at me and say..." she's open about it and she accepts it but at times she's she feels like she don't want to see too many people.

334: Int: ja.

335: Resp: if she sees somebody she hasn't seen for a long time then she starts crying. "See here, I got no more leg".

336: Int: but if you must say that ... how are things actually, did you expect it to be the way they are, or...

337: Resp: I'll say unfortunately I kind of had the feeling it's gonna end up where my family's concerned, either for some time now. Where that is concerned, I'm disappointed but it's not something new for me.

338: Int: you weren't surprised.

339: Resp: ja, concerning my mom, when I thought they were going to be there for her, but that is not true.

340: Int: Ummm.

341: Resp: I don't even mind leaving my mom with my sister just because of the way she is and she'll sit inside next to my mom ... anybody comes an visit my mother, they start straight away talking about... then my mom will, like, go in a state, just stare one way and she'll get cross. They must stop it now ...but then she'll just continue. That's why I can't leave my mom with her.

342: Int: ja. So ...uhmm... otherwise if you feel that you'd be able to cope and manage on your own but it's but your personal life, has that been put on hold now?

343: Resp: definitely. My son's mom, when I asked her, like, to get married and stuff like that, she's now thinking I'm doing it because my mom... but at the same time the way she's talking it's like she's... I'm the only one looking after my mom. And when we must go out or we want to go somewhere then mom is home alone then I'm okay, then I say... but I can't leave you at home. Stuff like that. I can run to the shop quickly, I'll go with the car to the shop but I can't leave you.

344: Int: putting strain on that relationship?

345: Resp: uhhh.

346: Int: ja. So what ... what are you planning to do about?

347: Resp: that's a very important thing. It's been keeping me awake. A couple of times I would just leave my mom with my sister. I think it must be because we've never been, like, separated with my mom since when I was born. Uhhh...after my sisters got married, I mean, they never took, like, they never said, like, we're the eldest my sister's the oldest and the other they never, like, said, "Okay, mommy can come and stay with us." When my mom got sick, all of them said, "No, we want mommy to come and stay with us." Phoned my father and he said, but he can't say anything, it's up to my mother. Don't see what's the reason... because she's with me all the time, here with me. When the time came nobody really said now, "Okay, mommy come stay with us." And the one who wants to take her is, like, doing it for all the wrong reasons.

348: Int: Uhhh. And causing your mother unhappiness.

349: Resp: Ja. And it's putting me on the spot and...I felt at one stage I felt my son's mom should accept it more, like, whenever we want to go out I can get somebody to look after her, or she'll get somebody

350: Int: so do you manage to ... to go out sometimes. You do manage sometimes?

351: Resp: yes. But not... it's not...

352: Int: not as often as you'd like.

353: Resp: as often, or especially when somebody tells me, "oh, we must be there tonight." Then it's kind of a problem. They must, like, tell me the morning, or the night before so that I can see if I can but otherwise it's okay.

354: Int: Ummm.

355: Resp: it's causing me a lot of problems.

356: Int: Ummm.

357: Resp: but I think I will feel guilty if I leave her in somebody's hands that's not gonna look after her.

358: Int: so, in effect, your life your life is on hold.

359: Resp: ummm.

360: Int: and you don't see any way in the foreseeable way in the future of changing that.

361: Resp: I've been thinking of going to work but I can't go back to my father. Because for the wages he gave me I should get somebody to look after my mother.

362: Int: an assistant.

363: Resp: I'll be working for nothing and it's, like, better for me to stay at home at the moment.

364: Int: financially, are you coping with the ...

365: Resp: it helps me at times but whenever something comes up, like I have to pay a R200 fine... I needed go to Grassy Park, to my son's mom's mommy.... and we go there with the company car... Thursdays and Friday's ...something like that two days a week about. And for years now I've been going ... not every week, but I know the roads there, it's like a hundred K's and suddenly eighty and then suddenly sixty. And I've never... one night we came from the hospital few days after that and she was in a hurry to get to her mother's place and I don't know, but I look at the speed limit and she tells me, "But I don't drive like that." And it just slipped, I went from a hundred to eighty and I never went from there again.

366: Int: Really

367: Resp: Ja.

368: Int: ja, that camera there by that robot.

369: Resp: sure....

370: Int: two hundred rand.

371: Resp: ... two hundred rand

372: Int: and that, I mean, that R200 has a place to go.

373: Resp: Ja.

374: Int: so it's a bit tight.

375: Resp: it's a bit tight, ja. But I survive, I'm, like, never without anything in the house.

376: Int: and your brother helped ... I mean, does he help sometimes?

377: Resp: not really, no.

378: Int: not really.

379: Resp: because, I mean, the other day he came and he asked my mom when's pension again? Get your money, you can go buy yourself a nice dress because you the one dress or the other dress. But they never say, "Okay, we'll buy you here, we bought this for you."

380: Int: they don't bring little bits of things food and that sometimes?

381: Resp: they'll bring fruit now and then but not ...

382: Int: not now with the fast they don't bring. ..

383: Resp: They supposed to...

384: Int: the sister's don't send a plate of food around at night?

385: Resp: my mom was there at my sister for a weekend. The one night when I got there ... I'll go around whenever I have time, in the night or the morning. If my mommy.... I saw the ... there was no toilet rolls but she sends her children to the shop to buy this and that, and she said, "okay, use this paper, this towel paper and paper towels," and the next evening I thought she would buy... and then my mommy told me, "She's leaving" so I went to go and buy toilet roll, late at night.

386: Int: okay. Besides the family that's not being much of a help. Other friends and that, last time we spoke about that couple who came here that day that sometimes supporting and other friends?

387: Resp: they come lots yes. Uhhh...I used my mom's cousin actually, but it's, like, more, like, my cousin the way we going out together. And at one stage now when my mom had the amputation it kind of causes small problems because like.. my girlfriend, because she's she went with me... with them, like, but they go, like, to the casino but we not into gambling we go for the fun, we go... and we don't play game ... games and stuff. But when my mom , like, had the amputation she, like, at times, especially on a Wednesday, she'll look for an argument then she'll disappear then, you know, then she went with them, she gave them a lift, like, to the casino. Or on the weekend, she'll, like, go there and because they come home late then she sleeps over there, she won't come around here. And it causes a problem and I soma told them, "I nogal don't think it's a nice idea you taking her..." She's running away from me and okay, it's personal, but we're talking now.

388: Int: Uhhh.

389: Resp: she's not, like, somebody won't pay her fine, she had like R500 left this week and then she'll go again and tomorrow morning when I get her, or she comes home she'll have no money. And I told her, "No."

390: Int: shame, you're having a hard time with this. Ah, no.

391: Resp: I told her, "I can't tell you what to do with your money," but I don't think...

392: Int: ja, but I think you...you getting some satisfaction and you're doing your duty and your responsibilities.

393: Resp: at times I feel guilty also... then I'm then I'm supposed to, like, buy something and that's the only money that's left of mine then I use it.

394: Int: and that's to buy...

395: Resp: I have to but whenever I need to buy stuff for her I'll do it. And if I take her to the hospital I pay cash. You know, I don't want another bill to come because another bill to pay also that's why I

396: Int: well, I mean, you're doing your duty and I know...a person sometimes doesn't...

397: Resp: Ja.

398: Int: , no but I'm so glad that you coping with everything. .. taking part in our research.

399: Resp: I feel guilty if I'm giving out my personal family business but...

400: Int: no, but you see that's...

401: Resp: I speak to nobody about it and it's, like, when we went to the physio and the amputation clinic, the physiotherapist came up to.... to my mom ...where's my sister, "where's your daughter, like? Is she okay?" and my mom said, Asa, she said "Yes", because why, she spoke to me the last time we were waiting in the hospital... for about

an hour and she was crying. And she was, like, crying and she had a sad stories and stuff and I told her to go and speak to a social worker.

402: Int: Ummm.

403: Resp: and I said, "Shame, I really think my sister's ...".

404: Int: no, but you see, that's one of the reasons why we do this, because when people have problems, when there's an illness in the home, the whole family is involved you know, affected and ...uhmm... how do people cope, that's just one of those things. Don't feel guilty about talking about it. Talking about it helps a bit then welcome to. Thanks again hey?

405: Resp: gamdrula.(Thank you)

406: Int: good, good. And N looking well after you?

407: Resp: yes, he's my son. He must look after me because I will look after him.

408: Int: because you did look after him. You did look after him, otherwise he wouldn't be as big as he is now and able to look after you.

409: Elderly: and how are you?

410: Int: no, I'm well, thank you. I'm fine.

411: Elderly: not tired of the people.

412: Int: no, not at all. No but I'm glad to see you looking well and he said that your leg is okay?

413: Elderly: yes.

414: Int: the leg is feeling okay? No pain there? No, no pain. That's good.

415: Elderly: no pains. Just a little bit short... I just wanted it to grow a little.

416: Int: agh, Mrs H. No but I'm glad that you're getting on okay. No but as I ...

417: Elderly: sit, man.

418: Int: no, no I really must go. But thanks very much for allowing me to come. For allowing me to come and to see you people. I really appreciate it.

419: Elderly: no, I appreciate you too.

420: Int: okay, thank you Mrs H.

421:

[1] Internal DB: Parents divorced. Mother helped him rear his son. Brother got married and moved out of the house. So he and his son were living with his mother.

The interviewer continues by asking a few leading questions - some of the information she obtained prior to audio-taping the interviews.

[2] Internal DB: He had problems transporting his mother to the Day-hospital to have her dressings done. So he asked for information at the day-hospital and they allowed him to do the dressings at home.

This information was shared with the interviewer before the recording started.

[3] Internal DB: The staff at the clinic showed him how to do the dressings. He was not shown the dressing technique prior to the discharge of his mother. Because he had transport problems he asked the staff at the clinic whether he could do the dressings at home.

Information obtained prior to the tape-recording of the interview.

[4] Internal DB: He got the commode from a friend.
Information shared prior to tape-recording

[5] Document: PARTICIPANT 09 - Memo

[6] Internal DB: Elderly was sent home unannounced

[7] Internal DB: He worked for his father. He gave up his work when his mother started developing a diabetic foot.

[8] Internal DB: The name of the Day-hospital

[9] Internal DB: Moslem faith to fast during the month of Ramahdaan

[10] Internal DB: The grandmother was ordering her grandson around and as a result of this she fell. This left the primary carer guilt-ridden as he delegated the caring to his son for the forty minutes that he went to the shop.

[11] Internal DB: Cell phone message



Project: Informal Home-based Care User: Administrator Date: 2006/02/25 - 07:41:46 AM

DOCUMENT TEXT REPORT

Document: PARTICIPANT 11
Created: 2004/10/03 - 01:47:49 PM
Modified: 2005/06/13 - 10:58:37 AM
Description:
PARTICIPANT 11

Document Text:

1: PARTICIPANT 11. 03/02/04[[1]

2:

3: Int: Mrs A I want to say thank you for allowing me to have the interview I just want to ask you a few questions about your mother and you can speak freely... and if one of your children or your mother needs your help in between then just say so... OK, so how did you feel when your mother went to the hospital...why did she go and what was the cause and how did you feel?

4:

5: Resp: To tell you the truth I did not know my mother had a stroke, only heard at the hospital that she had a stroke, my perception of a stroke was ... you know, because we don't have a full time maid... because my husband is not working...I did not know that she had a stroke and my hands are very full and I feel the stroke is going make me ... I don't work well with money, I have three children ... and I have a brother who is my responsibility...who is not always the same.... I only just hoped that is not going to be a bedridden situation...or something like that, I don't get any help from the family

6:

7: Int: when your mother was in the hospital and you saw that she will need help, how did that effect you

8:

9: Resp: not, no I did not really think about it, I was actually thinking of going to look for work, that is why I had myself sterilized the beginning of this year...I felt that I have to find work...I have to ...I cannot cope...financial wise I am going to find myself a job...I gave in my name to do a course, and I do voluntary work...during the time that I was at home I stressed a lot...I stress a lot here at home...I just felt that I was at home for too long periods of time...my mother was ill before this stroke....she was sick...so I went to join rape crisis, so I did voluntary work to get out of the house for a bit...because I became depressed ...and then my mother became ill...I made my own plans to find a job and to have somebody come in now and again... and so forth... to help my mother...but now I cannot do anything...because my mother became sick...and I cannot get somebody to help because financially I am not capable to do that and ...my brother and sister are not help financially ...I mean the expenses of my mother I have to carry all the costs

10:

11: Int: You said that you are one of seven children... and do they live near by

12:

13: Resp: yes. My one sister and my brother... They all work...

14:

15: Int: ...they all work ...but they are not contributing?

16:
17: Resp: No... absolutely not.
18:
19: Int: when your mother was discharged you knew that the responsibility will be on your shoulder
20:
21: Resp: Yes, yes
22:
23: Int: and heavy on your shoulders
24:
25: Resp: Yes....
26:
27: Int: So before you mother was discharged did you get anything additional in the house for her ...a wheelchair ?
28:
29: Resp: No I did have...I did have the walking frame but I had to get a bedpan, because she wets herself, on the bed...so I got the pan...on her way to the toilet it drips
30:
31: Int: Does it help now that you have bed pan
32:
33: Resp: yes it does help, now my father can help her during the night or if I'm busy with my baby then my father helps her
34:
35: Int: OK so you have little help from your dad, that's good that's good
36:
37: Resp: But he...he is 73 and he also tries
38:
39: Int: OK now that your mother is at home... what things do you have to do for your mother, I know your life is very full, take for example yesterday, yesterday was a very full day because when I phoned you, you said that you were pressurized, just explain...yesterday...what happened from the time you got up, tell me what did you have to do during a day? With your mother and so on
40:
41: Resp: Do I have to explain from the time that I got up until I went to bed...basically a day that passes ...OK , I got up at twenty past five, I help my husband I put in bread for the day then and when he is done then I get the children ready for school and then I take the small one to school, he is now in grade A ...then I take him to school...and when I come back then my day really begins, then I must see that my mother gets her bread ...her breakfast for the morning and the my mother takes her tablets and the I see to my baby
42:
43: Int: OK can I stop you just here ...your mother's tablets, what tablets does she take, for the heart...heart tablets
44:
45: Resp: Two types of tablets for her heart ...for her blood... and the cholesterol tablets... and tablets for sugar, two types of sugar tablets... it is a lot of tablets
46:
47: Int: it is a lot of tablets, so you give her tablets with her breakfast
48:
49: Resp: after she has finished her meal I give it ... or my father sees to it that she takes her tabletsI cannot be with my mother full time, I have this six-month old baby

50:

51: Int: Yes one can understand...

52:

53: Resp: ...You see I have this baby and I must see that everybody gets something to eat...my father and my brother...then I must see to it that my baby is washed and...I must feed my baby and that the house must be cleaned and the washing must be done...and all those things... then at 12 o'clock I must fetch my kid from school and I have two children ...both of them wet their beds and this gives even more work ...more washing. And my mother wets her bed.

54:

55: Int: OK and when do you wash your mother in the day or at night?

56:

57: Resp: sometimes in the morning and some times in the evening ...if she wets herself.

58:

59: Int: But mostly you do the bedbath in the morning before you dress her. Ok ... so you have done the washing ...fetched your child from school

60:

61: Resp: then I must make food for them.... and the people in the house ...and then I have to see that evening meal is prepared ...put on the stove...

62:

63: Int: and in the meantime you have to put your mother on the bed pan and so forth...

64:

65: Resp: ...and the baby

66:

67: Int: ...and the baby

68:

69: Resp: and the I still have the one in the house ...he is schizophrenic

70:

71: Int: your brother

72:

73: Resp: yes, he has a mental problem and he is some days he is very difficult

74:

75: Int : so you have lot on your plate at the moment

76:

77: Resp: yes specially with the children that make a noise and carry on.... I must watch the children ...they called me yesterday about the course that I planned to do... Open Xhosa...Now I don't know what to do...I may have to rather leave it...

78:

79: Int: So who will look after children if you do the course?

80:

81: Resp: my daughter is in standard 6 now and she can look after the small one, ...in any case I would not have had a problem ...it is just because my mother is sick ...I will have to leave it all ...to tell you the truth... I am not complaining... I am not complaining but...I feel that my life is on hold...if my husband pays, then I must buy diet food, I really...it has become a strain...I cannot say that it has become a strain on my marriage ...but ... I had my own home... but my mother...my parents asked me to give up my house and come and live with them come and live here... and my family...they all asked me to do this ...so we agreed to come and live here...but it is taking It's toll on me.

82:

83: Int: You knew ...before your mom was discharged that it would be your responsibility to take care of your mother... did'nt your sisters and brothers come forward when your mom was in hospital

84:

85: Resp: they visited her every evening...they were there every night I did'nt...could not go because of the baby, they went ...no they went to her...and they come to visit here... and that's all

86:

87: Int: they come to visit ...and you must make the tea...

88:

89: Resp: they come and visit... yes, yes

90:

91: Int: so they actually make more work for you when they visit

92:

93: Resp: like...last night my sister was here... I just laid there because of the sterilization...she carried on about a cup of tea ...Laughs...for a cup of tea...so I asked the girl to make some tea...

94:

95: Int: ai jite you have a lot of problems apart from thisit's your own circumstances...it is really a lot ...so you don't really get any support from the rest of the family....do you have other people...do you have friends that support you?

96:

97: Resp: No...people avoid ...people avoid coming here because my brother is mental...yes...if they do come it is only for ten-twenty minutes and then they go..

98:

99: Int: so your life is actually on hold at this moment ...OK Mrs A can we just come back to your mother's condition...let us talk about that...you said she wets the bed if she is not lifted on to the bedpan soon enough...is the urine strong, is it normal...does it smell or is it alright?

100:

101: Resp: it is not always the same...sometimes it smells and at other times it does'nt smell

102:

103: Int: not a bad odour ...just a...

104:

105: Resp: Uhm, uhm...sometimes...sometimes..

106:

107: Int: because your mommy is on a lot of medicine and that can also be why her urine smells... does she drink enough fluids

108:

109: Resp: o yes

110:

111: Int: What is her appetite like...she is a diabetic ...so you have to make special foods for her

112:

113: Resp: She does not want to eat the food

114:

115: Int: she does'nt want to eat the food... the diet food..?

116:

117: Resp: not always, she wants the food that we have... the appetite is good but some times she says that she is not going to eat the boiledup stuff...Laughs....

118:

119: Int: OK, she moves around a bit... she sits a little bit...she gets up...she walks with the walking frame...with help...

120:

121: Resp: it is just the getting up that is a bit difficult, but she walks Ok from here to the sitting room ...but if I have to move out then I borrow a wheelchair... if she has to visit the hospital then I borrow a wheel-chair ...

122:

123: Int: OK she has no bed sores because she is on the go...her body is OK ...and then her bowels how is that?

124:

125: Resp: Oh I don't know

126:

127: Int : does she go to the toilet by herself ...and she goes regularly...

128:

129: Resp: Uhm (Yes)

130:

131: Int: I mean she does not have a problem with constipation...

132:

133: Resp: Uhm...Hm (No)

134:

135: Int: so she eats fruit? ...

136:

137: Resp: Yes ...a lot of fruit...very fond of fruit?

138:

139: Int: OK so we must summarise things are a bit difficult at the moment ...you intended to go and work, but now that your mother is sick you can't go and you do everything on your own

140:

141: Resp: the hospital did give a letter to me...there was a suggestion that my mother go for rehabilitation at Conradie...they spoke to the family...my father...but at the end of the day nothing happened...they changed their minds because she won't ... Sister W...W ... everything was filled in and then they stopped the process...they said that she would'nt qualify

142:

143: Int: did they stop it...but the family was willing

144:

145: Resp: and my mother was willing to go...because I explained it to her.

146:

147: Int: well Mrs A I am so pleased and thankful for your time and hope to see you in a months time

148:

149: WEEK 4

150:

151: Int: : Good afternoon Mrs. A I am glad you have time to chat to me again, oh, now I remember we spoke Afrikaans the last time, we can continue in Afrikaans ... no problems. Mrs A how are things here with your mommy and all the things that were problematic the last time I was here

152:

153: Resp: no...my mother fell ill again after the last time ...I was in a state of stress...you remember

154:

155: §3 Int: has your wound healed?

156:

157: Resp: yes...yes...that is fine... she got sick again, a little time thereafter ...so I took her to the hospital... she looked like someone who was going into a coma ... a stroke again... but we, I did not know then ... so I took her to the Emergency Department of the Day Hospital ... so they told me that the sugar was on 1 ...1.2

158:

159: Int: Oh... her sugar was low

160:

161: Resp: Yes...she was nearly in a coma, but they did not keep her there, they only put her on a drip and sent her home again...that evening

162:

163: Int: you mentioned the last time that she did not want to...did not have an appetite... her appetite was so poor ... that is why her sugar...

164:

165: Resp: that is why...and then the following day it happened again, so it looked a bit worse ... because the froth was coming out her mouth and she was completely lame, lame ... and then I took her again and they just did the same as the previous time ... they put her on the drip again...but at that time she appeared to be very weak

166:

167: Int ... did they tell you to decrease the tablets or something

168:

169: Resp: no I had to stop the tablets ...

170:

171: Int: Oh you stopped it....

172:

173: Resp: I stopped the sugar tablets ...the sugar tablets...and I put some sugar in her tea ... and a week later she went for a check-up again and they told me to continue with the sugar... but she now she is much weaker ...

174:

175: Int: much weaker

176:

177: Resp: much weaker...not so very much, but she is weaker than before... and this morning... this morning she could not even sit up straight ... I had such a laugh this morning when I was feeding her...and I tried to lift her up...when I lifted her...she slid to the other side, almost off the bed ... Laughs

178:

179: Int: ... but you can't manage her on your own ...

180:

181: Resp: Laughs... so I asked her...Mamma where are you going to...I forgot that she could no longer sit up straight...she is very weak now and we cannot...we cannot... my father helped me a little especially in the mornings ...with washing, but his arm is starting to bother him because we have to lift her ...

182:

183: Int: Uhm...so it a bit difficult now,

184:

185: Resp: a bit difficult now ...

186:

187: Int: because you said the last time, it was more than a month ago...you said that your father had to assist your mother during the night... now that your mother has

become weaker, could your father still help her in during the night if she wanted to go to toilet?

188:

189: Resp: No, we are now using kimbies

190:

191: Int: how does your mother feel about it?

192:

193: Resp: No she does not worry about it...she calls me to put it on because she knows that she wets the bed ...because she cannot lift herself.

194:

195: Int: But that is much more expensive

196:

197: Resp: It is yes...but I did not buy an[2]y this week...so I don't know what I will do if these are finished...because there is two days that she will have to go with out it... until Friday

198:

199: Int: so things are tough at this time ...

200:

201: Resp: my Father said this morning ...if there is not a hospital...If we cannot take her to a hospital...but I think that it is useless to take her back to the hospital ... they will ... you know they will take her for an hour or two... and then they will send her back again ...but I can really not...I can really not handle her, she is a bit too heavy to lift ... earlier I felt that I wanted to put on a kimby but it is a job to do it during the day, in the long run she will become completely lazy...and then she will not want to move at all ...This morning she looked weak again...so I gave her sweets...

202:

203: Int: and did it help?

204:

205: Resp: Uhm

206:

207: Int: Do you take her to the day hospital ...and you haven't contacted Groote Schuur again...do you think it would help if you talked to Sister W again ...Have you still got her number?

208:

209: Resp: but what can she do for me?

210:

211: Int: she can you advise, you said it is now so difficult to handle your mother and that you have the problem with your back ...maybe she can help her to send her to a place where she can be assisted regarding her rehabilitation what did they say about that the last time?

212:

213: Resp: That was the case the last time.... all the forms were completed and so on, but they later decided that no...they are not going to send her because they thought her to be too old...

214:

215: Int: Oh...was that the reason...

216:

217: Resp: she is too old...they didn't think that she would improve...but as I see it...the one day she is OK and the next day she is not...

218:

219: Int: So tell me what about your sisters...and your...

220:

221: Resp: I think that she has had another stroke...I think that with the sugar ...

222: (Calls her father)...Dad must get the pan...(Moves away)

223:

224: Resp's Father: I have a polio leg...I cannot...

225:

226: Resp: (Comes back)...she wet the bed...I am going to...

227:

228: Int: so this is how your day passes...up and down...and up and down...Your sisters...You said that you think that she has had another stroke...because she is weaker...Did you talk to your sisters to ask them whether they could come and help you?

229:

230: Resp: the day that I... took my mother to the hospital, then my aunt phoned my sister ...anyhow so my sister came to the hospital and then I went home...so I left her there ...because I have the baby ...and the house...that day my baby was very difficult...and my father is weak...so she helped me for that week ...when she took leave...they help me in their own way, she was here for a few days and then she washed my mother and then she sommer ... she goes and lays next to her...I carry on with ...the house and the washing...you know... they help, but don't really help, that is always the case ...and the kimbies if I don't have the money... I will ask my sisters but...

231:

232: Int: so it does not come from their side, and your brother...what about you brother

233:

234: Resp: no he did not want to take his pills ... He was overbearing he became so bad that he interfered with the people that walked passed him and he grabbed at the girls who passed by... so I had to send him back to Valkenberg

235:

236: Int: so when did you put him in Valkenberg

237:

238: Resp: Last week...he went last Wednesday ...the previous week

239:

240: Int: so it is a bit easier ... you don't have that problem also so it's ...it looks if you are walking very poorly today (speaks to the father)

241:

242: Resp's father: yes the leg is giving me a lot of problems

243:

244: Int: so every thing rests on you at this stage

245:

246: Resp: by the time that I get up ...then he has helped her to wash ...I think they also get frustrated because I want wash her myself ... if my father helps her then she washes and I can't wait for her because I have to finish so that I can see to my child and so on

247:

248: Int: you do not give her a chance to become independent ...you are too rushed

249:

250: Resp: now... before I get up in morning then he already has the wash basin with water and he would say come help me...but this morning she is very weak, and then I had to help

251:

252: Int: yes... and if you hurt yourself and your back what then?

253:

254: Resp: what will help us a lot is if we could place my mother at such a rehabilitation.... for a week or two ...you know...I don't know if I'm doing enough

255:

256: Int: you can only do as much as you can...you do as much as you are capable to do... but you must also look after yourself ... and your sister-in-law how is things...so your live is on hold...

257:

258: Resp: I go for counselling on a Wednesday ...and I must ask one of my sister's children to come and look after the babyalso to look after my mom... you see it is too much for me... but when out of the house I am a different person, I don't like friends and visiting friends.... it is a bit hectic...but, I feel good about theyou know what I'm saying

259:

260: Int: and I think it is important that you get out of the house and that you break away ...so the counselling is good for you ...

261:

262: Resp: I went for counselling for myself, because I can feel things are becoming too much for me...it is not just my mother, it is my brother and my dad and so on...you know

263:

264: Int: it has an impact on your marriage

265:

266: Resp: yes there is also a strain there ... I did not know that it was going to be like this ...

267:

268: Int: but it is not your fault, it just happened and I am very pleased that you are doing this course and it is something good that you undertook and it can only just help you

269:

270: Resp: my problem is just the baby ... the baby needs a nanny ...Laughs...

271:

272: Int: you are the nanny ...mommy...you are the nanny

273:

274: Resp: They asked me to go away to Wolesley for a weekend, so I said... how can I go to Wolesley for a weekend ... everything is so uncertain...it is this and that...if I have to go away from the house

275:

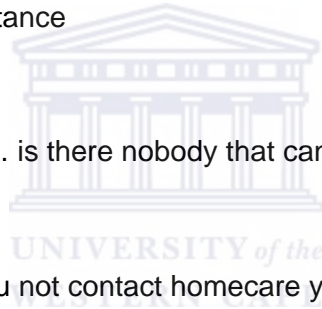
276: Int: I think you must just take it day by day, your problem at the moment is that you have nobody that can help and support you ... and your sister will she not come and stay here for a few days?

277:

278: Resp ... Yes ... two weeks ago they came to my mother ... it was only the family you know ...and so on and served cookies ... like on a Sunday ... but I did not even know that they organised something ...it was to cheer my mother up a bit ... they said I don't have to do anything we will bring everything...and when the people got here ...they were sitting and stuffing themselves ...and I had to... I washed up three times...so I said ...what is the use if you come and exhaust me more ...no... so my husband also said that I must tell them that the next time they must do it at their own houses... and they can come and fetch my mother...and my mother became sick...because they had cake and other things ...and who will look past it if it's placed in front of you...and I have a problem with her and diarrhoea...

279:

280: Int: Oh ...
281:
282: Resp: yes I don't know why she gets diarrhoea so often
283:
284: Int: and then you can't get her onto bedpan ...or get her to the toilet in time ... tell me ...she does not have any bed sores?
285:
286: Resp: No ... now I must go on there ... that is what I am talking about... if I had to take care of her on the one side and the baby ... you know, it makes me confused
287:
288: Int: at least tomorrow is Wednesday ...so you say that the family is not really of much help ... and the community ... and friends ...
289:
290: Resp: no they just come to hold a service and bring Holy Communion and so on
291:
292: Int: But they would not come and sit here for a half day, a day or a few hours with your mother while you are doing something
293:
294: Resp: No...not help... not to help her...my aunty comes to sit here... and they pray...have services and so on, but that is as far as it goes
295:
296: Int: But not physical assistance
297:
298: Resp: Hm...hm No...
299:
300: Int: and the Day hospital... is there nobody that can come in and do something
301:
302: Resp: No
303:
304: Int: and homecare, did you not contact homecare yet
305:
306: Resp: No...Because I know that home care does dressings. But I do not know if there....
307:
308: Int: the homecare is nothing, but if I contact somebody for such a service then I still have to pay the person ...you know...
309:
310: Int: and that is another story
311:
312: Resp: People don't want to do come and help for the day ...because of my brother...because he carries on in the house, and I also don't want to ask anybody because he shunts everybody around " Make me some tea...bring me some food"...you know
313:
314: Int: I hope he does not hold you responsible for putting him there...
315:
316: Resp: He did he threatened me with the hell... Laughs... he said that he was going to send me to hell...and my children...Laughs
317:
318: Int: " Shame...It is good that at least do not have to care for him now...
319:



320: Resp: Yes...but it is not going to be long because he is forcing them to send him home

321:

322: Int: ... Yes but if they give his injection before he is discharged

323:

324: Resp: They did, but stillhe refuses to take the injection there ... the doctor called me to inform me that he refuses to take the injection...so I said ...well You just have to threaten him...and so forth... but on Sunday...he took the injection but he just wants to do what he wants to do...he wants to drink the tablets that he wants to drink and not what they give him to drink ... so he is still confused...he is no better, in fact he seems as if he is a bit worse ... and so I am also panic-stricken that he can come home anytime ... but in any case

325:

326: Int: Mrs. Adams at the moment things do not look to well , it seems difficult and not as if there is any light, but there is light at the end of the tunnel ...

[1] Document: PARTICIPANT 11 - Memo
[2] Internal DB: Kimbies - adult nappies



APPENDIX 9: EXAMPLE OF CODE REPORT

NVivo revision 2.0.163 Licensee: Default

Project: Informal Home-based Care User: Administrator Date: 2006/02/25 - 09:55:12 AM

NODE CODING REPORT

Node: /Carer describes elderly

Treenode address: (2)

Created: 2004/10/09 - 05:03:31 PM

Modified: 2005/06/13 - 12:58:33 PM

Documents in Set: All Documents

Document 1 of 31 PARTICIPANT 01

Passage 1 of 9 Section 0, Para 23, 55 chars.

23: she hides the things so that we cannot find it. Laughs...

Passage 2 of 9 Section 0, Para 39, 129 chars.

39: Sister, you know they are just like small children, now they are all right and a few moments later they have a fever or something

Passage 3 of 9 Section 0, Para 39, 115 chars.

39: she would say " You don't have time for me! ... Just like a small child...Laughs...That true, I have to give her attention

Passage 4 of 9 Section 0, Para 43, 240 chars.

43: The day that I...if I don't...then I have to go back...because I cannot...those things bother her...little things...then that woman is so mad ...It seems as if ...she does'nt want to..." Go away, I don't want your food".... that is how she carries on...Laughs...

Passage 5 of 9 Section 0, Para 111, 304 chars.

111: Resp: Laughs... she does not want to hear that ... she does not want to hear that ...she did not want to go to the one nearby[2]... down the road, near us, and she knew that if she is not going to stay with me, they are going to sent her there ... they will put her in one of these homes, and that she don't want

112:

[2] Internal DB: Refers to a home for the Aged
Passage 6 of 9 Section 0, Para 115, 380 chars.

115: Resp: ...then I said don't worry I will not put grandma in a home ... but if for instance if she gets a stroke, I can't take care of grandma ... if Grandma becomes bedridden... I have to complete these forms... and when I hand it in, then her name will come on the waiting list, but that is not to say, that she must go in immediately ...

grandma is not going like tomorrow ... It takes years
116:

Passage 7 of 9 Section 0, Para 119, 550 chars.

119: Resp: I have told her, but she said someone told her that I am going to put her in the old-age home, and I said no... I am not going to put grandma there yet and I told her about the forms ... and then when she saw the forms, she said "Do you think I am going to sign that forms? I don't want to go to the Old Age home, it is you that want to put me there"... Laughs...she does not want to go, out of her own she will never go there ... she said ...you can do what you want to do, but I will stay here until I die and then they can take me ... with my feet first

120:

Passage 8 of 9 Section 0, Para 128, 104 chars.

128: the next thing... she put baby talcum powder in her ears...Laughs.....So I told her grandma must'nt do that...

Passage 9 of 9 Section 0, Para 132, 271 chars.

132: Yes sometimes she scolds me scolds me terribly...and then I just keep quiet...sometimes I feel bad about it...and then I walk away... and then I will find out if she needs anything like water ...but then she does'nt want anything and fetches the water by herself from the bathroom

Document 2 of 31 PARTICIPANT 02
Passage 1 of 4 Section 0, Para 6, 65 chars.

6: She always said she feels safe ...hm... when I take her to the toilet.

Passage 2 of 4 Section 0, Para 10, 122 chars.

10: Resp: She walked with me even though she leans on me...but I hold her on her hips and ensure that she feels safe in my arms.

11:

Passage 3 of 4 Section 0, Para 39, 66 chars.

39: Look they are old people... they are just like babies at this moment

Passage 4 of 4 Section 0, Para 134 to 138, 114 chars.

134: mamma isn't a difficulty person...

135:

136: Int: Uh is that so?

137:

138: Resp: ...not with me. But with others she is a bit difficulty.

139:

Document 3 of 31 PARTICIPANT 06
Passage 1 of 6 Section 0, Para 33, 66 chars.

33: He didn't just lie there as though this was the end of the world.

Passage 2 of 6 Section 0, Para 214, 48 chars.

214: RESP: Yes, he tries very hard to be independent.

Passage 3 of 6 Section 0, Para 222, 57 chars.

222: he is like a child again. It's not so easy to explain it.

Passage 4 of 6 Section 0, Para 222, 77 chars.

222: I can see the fear in his eyes, he wants to get up...but ... he knows he can't.

Passage 5 of 6 Section 0, Para 254, 128 chars.

254: My father was always a very strong person, and now he is paralysed. Suddenly...
So it's a big change... everything is ... topsy-turvy

Passage 6 of 6 Section 0, Para 326, 315 chars.

326: RESP; It's just the hours that are a bit awkward. I mean, he wakes up at four
o'clock in the morning, then he wants to eat. Then he buggers Rita or my mother around,
then he must eat, and she must wipe him down and so forth. So that by seven, eight in
the morning, then she is finished ...(poop). She has no breath...

Document 4 of 31 PARTICIPANT 07
Passage 1 of 1 Section 0, Paras 161 to 167, 261 chars.

161: RESP: We don't know... but he always tell me that he is going to die when he is
ninety-three.

162:

163: INT: Ohhh. How do you know that, sir?

164:

165: PATIENT: I don't know, I just feel like that

166:

167: INT: You just feel like that. Okay , so still have a number of years, good years

168:

Document 5 of 31 PARTICIPANT 08
Passage 1 of 3 Section 0, Para 89, 50 chars.

89: He is independent, a man who looks after himself ...

Passage 2 of 3 Section 1, Para 207, 99 chars.

207: he was always an independent person ... and didn't bother with us, I suppose this is what he wants.

208:

Passage 3 of 3 Section 1, Para 211, 51 chars.

211: He is not a person who will just go and lie down.

212:

Document 6 of 31 PARTICIPANT 09
Passage 1 of 4 Section 1.1, Para 134, 724 chars.

134: Resp: Uhhh, the only problem I have is at times, it's not really a problem for me because I understand if she's got, like, a slight Alzheimer's problems she forgets very quickly. She'll remember the olden days, she will remember a lot of stuff that we can talk about when she was young, and in her days. But at times, now say for instance somebody will come and visit her now and give her something, ten minutes later she will forget who was here, like, and then say, "When was this person ... when last was this person here?" Something like that. Even before she went to hospital, she'd, like, leave her pension money somewhere and then she'll forget where it is and then I have to look through all the cupboards and stuff.

Passage 2 of 4 Section 2, Para 299, 194 chars.

299: when we come to the hospital for, like, physio then she gets, like, excited. She enjoys it there because she sees more people that's the same, then she'll tell me, "See, that man's got no legs."

Passage 3 of 4 Section 2, Para 301, 290 chars.

301: Resp: she is ... she'll tell people straight, she open up the leg and show it to them and stuff like that. But I feel at times and especially when she's alone ... I saw at times her eyes is closed and when she's slightly sleeping, she's not sleeping then she like crying and sometimes. Ja.

Passage 4 of 4 Section 2, Para 335, 114 chars.

335: Resp: if she sees somebody she hasn't seen for a long time then she starts crying. "See here, I got no more leg".

Document 7 of 31 PARTICIPANT 12
Passage 1 of 1 Section 0, Para 9, 149 chars.

9: and once more it was better that she came home, because the first thing that she said after the leg had been amputated was whether she could go home?

Document 8 of 31 PARTICIPANT 13

Passage 1 of 3 Section 0, Para 34, 226 chars.

34: Resp: I would'nt say so...I think he was longing to see us...because when we got there he would look extremely sick...and then the children would say...mamma, but dadda looks very sick...but if we are there for a while he brightens up...

35:

Passage 2 of 3 Section 0, Para 86, 109 chars.

86: Resp: Yes he becomes mad because he was used to...he was a very active person...you know. So he becomes mad at me

Passage 3 of 3 Section 0, Para 322, 57 chars.

322: he will not like that...very impatient and very independent

Document 9 of 31 PARTICIPANT 3
Passage 1 of 2 Section 3, Para 21, 229 chars.

21: I just felt to calm her down....as she was upset because of the fact that I had to fly to my husband .to Tanzania and she has now fallen and the hip has been..... the doctor confirmed this with x-rays that the hip has been brokened[7].

[7] Internal DB: Carers role conflict re. care of her mother and responsibility towards her husband

Passage 2 of 2 Section 3, Paras 307 to 309, 117 chars.

307: I nt.: And her, her uhm emotional state through the whole of this process?

308:

309: Resp.: Do you know... very positive!

This Node codes no other documents in this set.