Cape Peninsula
University of Technology

THE INFORMATION NEEDS OF INFORMAL CAREGIVERS IN RURAL SOUTH AFRICA

by

AMNA ALI ABDULSALAM ASHOUR

Thesis submitted in fulfilment of the requirements for the degree

Magister Technologiae: Information Technology

in the Faculty of Informatics and Design

at the Cape Peninsula University of Technology

Supervisor: Prof AC De La Harpe

Cape Town Campus
January 2019

DECLARATION

I, **Amna Ali Abdulsalam Ashour**, declare that the contents of this thesis represent my own unaided work, and that the thesis has not previously been submitted for academic examination towards any qualification. Furthermore, it represents my own opinions and not necessarily those of the Cape Peninsula University of Technology.

January 2019

Signed **Date**

ABSTRACT

Care provision presents physical, psychological, and social challenges to caregivers during the course of their duties. These challenges are directly linked to the availability and accessibility of information to the caregivers. Although information is easily accessible to caregivers by means of the Internet and health care professionals, caregivers often need more information during the course of their activities. In South Africa, the information needs of caregivers are largely unclear and remain unidentified in different contexts. The aim of the study was to explore the unmet information needs of caregivers in their work activities in order to identify and address the information need challenges during the course of performing their duty.

The study employed one primary research question (PRQ), namely: “What are the unmet information needs of caregivers in South Africa?” Four sub-research questions guided the PRQ: i) “What are the work practices of caregivers and their related information needs in Cape Town, South Africa?” ii) “What are the factors affecting unmet information needs of caregivers in Cape Town, South Africa?” iii) “How are information resources made available to caregivers in Cape Town, South Africa?” iv) “How do caregivers obtain/access alternative sources of information necessary for their care activities in Cape Town, South Africa?”

In order to answer these questions, the present study was conducted at two institutions and with three private caregivers who provide comprehensive care to different types of care recipients in the City of Cape Town, South Africa. An interpretivist epistemological stance was adopted, and an inductive research approach was followed. The research strategy was a multiple-case study. Data for this study were gathered during interviews (21 in total) using semi-structured questionnaires. The data collected were transcribed, summarised, and categorised to provide a clear understanding of the data.

The study produced nineteen (19) findings, from which five themes were derived. The themes are: i) Caregiver work practices; ii) Caregiver challenges; iii) Unmet information needs; iv) Caregiver information resources; and v) Information sharing. Results from the study show a major misalignment between the information required by caregivers during the course of their work activities and the care services required from them. Measures such as more comprehensive training programmes by training institutions to caregivers are recommended in order to prepare caregivers adequately for care practices.

Keywords: Caregivers, information needs, South Africa, information sharing

ACKNOWLEDGEMENTS

I would like to thank God, the Almighty, for providing me this opportunity and granting me the capability to proceed successfully.

I further wish to extend my sincere gratitude to the following persons:

- Dr AC De La Harpe and Mr A Afolayan for their supervision, and critical and invaluable inputs – your guidance has taught me so much
- All University staff, especially the IT Department
- My research respondents, without whom this study would not have been possible
- My friends and everyone who encouraged me with the words, “You will make it!”
- My parents, brothers and sisters whom I was separated from
- My brother Muhsen who stayed with me in South Africa and who was always there for me – I am especially grateful to you
- My friend, Whafieka Martin, for offering me advice and support during my study

TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

GLOSSARY

Abbreviations/Acronyms	**Full Word/Term**
ADHD	Attention Deficit Hypertension Disorder
ADLs	Activities of Daily Living
CHBC	Home-Based Caregivers
COP	Community of Practice
CP	Cerebral Palsy
CPS	Collaborative Problem Solving
DS	Down’s Syndrome
HBC	Home-Based Care
HHAs	Home Health Aides
KM	Knowledge Management
LPNs	Licensed Practical Nurses
MSWs	Medical Social Workers
NGOs	Non-Governmental Organisations
NHD	National Health Department
NPO	Non-Profit Organisations
OTs	Occupational Therapists
PTs	Physical Therapists
QoL	Quality of Life
RNs	Registered Nurses
SADAG	South African Depression and Anxiety Group
SLPs	Speech Language Pathologists

CHAPTER ONE: INTRODUCTION

1.1 Introduction

Caregivers are key figures in the provision of care through providing emotional and physical support to patients. They play a major role in clinical decision-making, with more people relying on the services of caregivers; a pertinent need for caregiving services has increased globally (Lambert, Bellamy et al., 2018; Millenaar et al., 2018; Selman et al., 2018; Wingham et al., 2017). In England and Wales, it is estimated that approximately 10% of the population are caregivers, and over 60% of the population expected to become caregivers at some point in their lives (Wendlandt, et al., 2018). In the USA, the estimated number of people who are caregivers is 4.3 million, a number that has contributed to the steady increase in numbers globally (Wingham et al., 2017). The growing numbers gave rise to an increased burden and workload placed on caregivers, hence they are often faced with challenges relating to support structures and information needs (Wendlandt et al., 2018). It is therefore important to identify caregivers' support structure and information needs systematically in order to develop interventions that will address these needs globally (Denham et al., 2018).

In South Africa, the high prevalence of the HIV epidemic formed major part of the shift in roles of caregivers from generalist to specialist (Masuku et al., 2018). Before the advent of the HIV epidemic, the roles of caregivers were relatively limited, dealing with health conditions related to poverty, social inequality and migrant lifestyles (Masuku et al., 2018). However, with the rapid progression of the HIV epidemic and other chronic diseases, these roles shifted from providing basic physical care and support to providing specialist care to a variety of care recipients living with different and often complex conditions (Denham et al., 2018). Specialist care exceeds basic home-based care and includes care provided to the elderly, those suffering from debilitating diseases, and children with special conditions (Pinquart, 2018). Recently, the National Department of Health (NHD) of South Africa developed policies that shifted the role of the general "community worker" appropriating general care, support and treatment to categories that define caregivers in specialist roles (Morton et al., 2018). These caregiving roles incorporate conditions such as HIV/AIDS, dementia, Alzheimer's disease, tuberculosis (TB), cancer, and mental illness in addition to many other conditions. Unavoidably, the new integration of caregiving roles places a demand on caregivers to equip themselves with the necessary information and knowledge in order to support a broad range of care activities (Lambert, Bellamy et al., 2018; Lambert & Girgis, 2017).

The required information and support needs are often unmet, which directly affects the performance and wellbeing of the caregiver, and consequently also the care recipient (Selman et al., 2018; Werner et al., 2017). Particularly, some studies highlighted information needs to include disease-specific knowledge, basic medical care knowledge, knowhow on chronic medication administration, and knowledge of dietary needs (Morton et al., 2018; Lim et al., 2017). Furthermore, inaccessibility and unavailability of information resources on accredited Internet platforms, workshops, and training were also highlighted as contributing factors to caregiver information needs.

Therefore, further research is needed to identify the unmet needs of caregivers in order to inform intervention development and the prioritisation of resources in specific contexts. The purpose of this study was to identify and explore the information needs of caregivers within the South African context. Findings from this study were expected to provide new insights into the unmet information needs of caregivers. Knowledge about the unmet needs of carers can inform the development and refinement of interventions and services in order to address the supportive and information needs of caregivers in South Africa.

This study was based in the City of Cape Town and focused on three case studies, situated in the Western Cape Province of South Africa. The first group comprised caregivers who had home-based care (HBC) training. They provide frail care to the elderly at an old age home to those suffering from debilitating diseases such as dementia, Alzheimer’s, and advanced cancer. This group of caregivers had basic informal on-site training at the facility, which included washing, grooming and lifting patients, taking blood pressure and urine samples, and basic massage. The second group of caregivers had both basic formal and informal on-site training at the facility. Care recipients in these facilities include special needs children who suffer from mental and physical disabilities. The training received at this facility was guided by the Western Cape Provincial Education Department (WCED) forum and focused on the development of fine motor skills and basic physiotherapy. The third group comprised private caregivers recruited from different communities in the Cape Town region. These caregivers possess formal qualifications as professional nurses and caregivers and their care recipients vary from post-trauma patients to the elderly.

1.2 Background to research problem

South Africa has a large community of caregivers who provide care to members of the community that are too ill or unable to care for themselves (Litzelman et al., 2018). Challenges faced by diverse care recipients require the care, assistance and support of someone who is well equipped to help them get through menial daily tasks such as bathing, eating, completing medical regimes and treatments (Millenaar et al., 2018). Lambert, Hulbert-Williams et al. (2018) opine that the physical and psychological demands of caregiving often exceed the social and economic capacities of caregivers, given the taxing nature of their work. The nature and importance of caregiving activities thus require the availability of adequate support and resources, which caregivers often lack in terms of accessible and timeous information (McIlfatrick et al., 2018). Morton et al. (2018) as well as Sandy et al. (2013) describe the critical support needs of caregivers as financial, emotional, and practical support, availability of information, and further training for caregivers extremely important.

It has been revealed that the lack of information and guidance from the family members or supervisors in terms of the type of care services needed, caused caregivers to suffer from feelings of hopelessness, inadequacy and stress (Morton et al., 2018). Caregivers also reported challenges relating to accessible resources, inadequate training on how to access information resources from the health care system, limited exposure to disease-specific knowledge, and further training as constraints in performing their activities (Tatangelo et al., 2018). Black et al. (2018) argue that caregivers need to be adequately empowered in terms of the required skills and knowledge to provide proper care to their recipients.

Tatangelo et al. (2018) and Lim et al. (2017) report that the most frequently reported unmet needs of caregivers are related to health system and information, followed by psychological patient care and support, and physical daily living. Care recipients often differ in their care needs; these recipients include the elderly or those who suffer from some or other form of debilitating disease such as dementia, cancer or HIV, which prevents them from functioning normally throughout the day (Galvin et al., 2018; Lambert, Bellamy et al., 2018; Millenaar et al., 2018). However, many caregivers lack specific knowledge on how to handle different care situations they are tasked with, unwittingly subjecting the care recipients to risks. Furthermore, an unmet information need exposes caregivers to high levels of stress, as they are unable to complete their tasks efficiently. Other consequences of unmet information needs include increased caregiver burden, stigmatisation, exposure to liability, and feelings of incapability and inadequacy due to a lack of the necessary resources and information to carry out their duties adequately (Chironda & Bhengu, 2018). Nevertheless, Zwingmann et al. (2019) argue that the effects of unmet caregiving information and its experience can be mitigated if caregivers have prompt access to information required to execute their duties optimally.

To address the unmet information needs of caregivers, McIlfatrick et al. (2018) posit that knowledge-based interventions are required to address the limited knowledge on information and skills requirements of caregivers in various contexts. Zwingmann et al. (2019) argue that although many studies have been conducted on the general needs of caregivers, more focus should be placed on the information needs of caregivers specifically, as caregiving is information dependent and experience-based. Although studies have been conducted focusing on the challenges of caregivers, the underlying issues and reasons of challenges relating to information needs have not yet been identified and addressed adequately (McIlfatrick et al. 2018; Zwingmann et al., 2019).

1.3 Problem statement

The information needs and challenges relating to a lack of information available to caregivers are considerably unclear and unidentified in different contexts. It is therefore important to identify the information needs of caregivers in South Africa in order to improve their work conditions and the services they provide.

1.4 Research questions (RQs)

One primary research question and four sub-research questions have been formulated to address the research problem.

1.4.1 Primary research question (PRQ)

PRQ: What are the unmet information needs of caregivers in South Africa?

1.4.2 Sub-research questions (SRQs)

SRQ 1.1: What are the work practices of caregivers and their related information needs in Cape Town, South Africa?

SRQ 1.2: What are the factors affecting unmet information needs of caregivers in Cape Town, South Africa?

SRQ 1.3: How are information resources made available to caregivers in Cape Town, South Africa?

SRQ 1.4: How do caregivers obtain/access alternative sources of information necessary for their care activities in Cape Town, South Africa?

1.5 Research aim and objectives

1.5.1 Aim

The study aimed to explore the unmet information needs of caregivers in their work activities in order to identify and address the information need challenges during the course of performing their duties.

1.5.2 Objectives

The objectives formulated to accomplish the aim of the study are:

- To determine the work practices of caregivers in South Africa and related information requirements
- To determine the factors affecting unmet information needs of caregivers during the course of their duty
- To examine the information resources available to caregivers, and existing mediums through which information resources are made available to caregivers in South Africa

Table 1.1 denotes the research questions and the complimentary method of investigation to achieve the objectives.

Table 1.1: Research problem, PRQ, SRQs, research methods, and objectives

Research Problem	The information needs and challenges relating to a lack of information available to caregivers are considerably unclear and unidentified in different contexts. It is therefore important to identify the information needs of caregivers in South Africa in order to improve their work conditions and the services they provide.	
Primary research question (PRQ)	What are the unmet information needs of caregivers in South Africa?	
Sub-research questions (SRQs)	**Research methods**	**Objectives**
SRQ 1.1: What are the work practices of caregivers and their related information needs in Cape Town, South Africa?	Literature / Interviews using semi-structured questionnaires	To determine the work practices of caregivers in South Africa and related information requirements
SRQ 1.2: What are the factors affecting unmet information needs of caregivers in Cape Town, South Africa?	Literature / Interviews using semi-structured questionnaires	To determine the factors affecting unmet information needs of caregivers during the course of their duty

Sub-research questions (SRQs)	**Research methods**	**Objectives**
SRQ 1.3: How are information resources made available to caregivers in Cape Town, South Africa?	Literature / Interviews using semi-structured questionnaires	To examine the information resources available to caregivers, and existing mediums through which information resources are made available to caregivers in South Africa
SRQ 1.4: How do caregivers obtain/access alternative sources of information necessary for their care activities in Cape Town, South Africa?	Interviews using semi-structured questionnaires	To determine how caregivers obtain/ access alternative sources of information necessary for care activities in Cape Town, South Africa

1.6 Research methodology

Research methodology is the process of investigating a phenomenon using scientific methods, underpinned by philosophies, paradigms and techniques carried out to unravel information that describes the nature of the phenomenon. Research philosophies are an important aspect of research, as they guide the research focus and choice of methods to obtain the truth and true state of the phenomenon, based on the beliefs and assumptions of the researcher.

1.6.1 Research philosophy

The subjectivist ontology is based on the inter-subjective perception of reality (Allan & Randy, 2005). In this, reality infers that meaning is gained through understandings based on social and experiential levels, which is illustrated in the agreement of different minds and consciences on a particular set of meanings (Allan & Randy, 2005), while the objectivist ontology assumes that reality is independent of social assumptions, constructs, and social interpretations. In this study, the subjectivist view that relies on the analysis and interpretation of reality was adopted (Ormston et al., 2014). The adopted view allowed for subjective interpretation of divergent factors affecting the information needs of caregivers according to the opinion of the subjects (Ormston et al., 2014).

1.6.2 Interpretivist research paradigm

Due to the subjective nature of the study, an interpretivist stance was adopted, focusing on the extraction of meaning from the sample population that reflects different aspects of the subject matter. The research followed a naturalistic approach of data collection where the development and interpretation of meanings occurred towards the end of the research process (Ormston et al., 2014).

The study adopted the interpretivist paradigm, which relies on data collection methods such as small samples, in depth investigations and qualitative data (Onwuegbuzie & Frels, 2013).

1.6.3 Research approach

In social research, an inductive or deductive approach is commonly used (Saunders et al., 2009). The inductive approach is founded on the development and generation of meanings from the collected data to identify patterns and relationships for constructing either a new theory or inferring an existing one. The emergent theory can be used to address the research question, identify emerging patterns, resemblances and regularities in the data in order to reach a conclusion (Saunders et al., 2009; Bryman, 2015). The study adopted the inductive approach to investigate the information needs of caregivers in order to gain deeper insights into the factors affecting the information needs of caregivers, based on their perceptions and experiences of patient care.

1.6.4 Exploratory research design

Exploratory research provides a better and deeper understanding of the problem and remedial actions emerge towards the end of the research process (Yin, 2017). In addition, exploratory research also offers new knowledge on a topic that has not been addressed previously (Saunders et al., 2009). The study's research design was exploratory in nature as it focused on exploring all aspects of the research subject matter. However, the intention was not to offer final solutions or conclusions to the existing problem, hence, the motivation to employ exploratory research design, as literature concerning the information needs of caregivers in the South African context appears to be limited and not fully explored.

An exploratory case study design was used to investigate the phenomenon within the boundary and context of caregiving activities in South Africa. The exploratory study utilised qualitative methods. Purposive sampling was adopted, as it is widely used in qualitative research for the identification and selection of information-rich cases related to the phenomenon being studied (Palinkas et al., 2015). Qualitative studies employs data instruments such as observations, experiments, interviews, focus group discussions, and open-ended questions in questionnaires (Eriksson & Kovalainen, 2015). Semi-structured interviews were conducted with the caregivers selected by means of purposive sampling. Data were analysed using the qualitative thematic analysis technique.

1.6.5 Research strategy

1.6.5.1 Case study

A case study research method is described as an empirical study that explores a present-day, real phenomenon of which the evidence is obtained from multiple sources, and where there are no clear boundaries between the phenomenon and the context (Tsang, 2017). In a case study, the information is explored and mined in order to examine the given phenomenon with insight. Generally, a case study is more exploratory than confirmatory (Anderson, 2018). In case studies, the researcher normally seeks to identify themes or categories of behaviour and events rather than prove relationships or test hypotheses. Case study methods are especially prominent in community-based problems such as drug addiction, poverty and unemployment (Anderson, 2018).

A research study can adopt either a single-case or a multiple-case design depending on the issue being studied. Common categories of case studies are exploratory, descriptive, and explanatory (Yin, 2017). Exploratory case studies focus on the exploration of the phenomenon in the data, whereas descriptive case studies set to describe the natural phenomena that occur and describe the data as it emerges (Yin, 2017). On the other hand, explanatory case studies take a closer look at the data in order to explain the phenomena in the data (Hancock & Algozzine, 2016). While interpretive case studies focus on the interpretation and development of conceptual categories that either support or challenge the assumptions surrounding them, evaluative case studies add the personal judgement of the researcher to the phenomenon found in the data (Hancock & Algozzine, 2016).

Based on the exploratory aim of the research, the research employed an exploratory multiple-case study as the research strategy.

1.6.5.2 The cases

Three cases were selected for the study, with an overall total of 21 participants. The three cases are: i) the Sherwood Park Special Care Centre (SPSCC); ii) the ATKV Zonnebloem Old Age Home (ATKV OAH); and iii) three private caregivers with no formal affiliation to any one organisation. These cases were selected based on the non-random sampling method. Purposive sampling was further carried out to identify appropriate participants with knowledge of the subject matter within the organisation. In total, 21 caregivers were interviewed (Chapter Three, Chapter Four, section 4.3). The cases included two non-governmental organisations (NGOs), employing caregivers for provide care to different categories of care recipients. Although five NGOs were approached, only two NGOs were willing to participate in the research. The third case involved private caregivers who work independently and who are not affiliated to any organisation.

1.6.6 Data collection

Neuman and Robson (2014) identify several methods to collect data, including the analysis of existing documents, observations, interviews, and questionnaires. One of the most common methods of data collection in qualitative research is the individual interview (Gill et al., 2008). Data collection was done by means of semi-structured interviews using an interview guide (Appendix A). The interview was based on an in-depth semi-structured style, following specific questions designed for the study. The semi-structured interviews were conducted with 21 participants. The interview questions were guided by the research questions and objectives, which focused on participants’ experiences, challenges, tasks, and feelings of caregiving. The units of observation were identified as the caregivers and the unit of analysis as the caregiving organisations.

1.6.7 Data analysis

Data were analysed using qualitative data analysis techniques. On completion of the data collection process, a thematic analysis technique was applied (Smith & Firth, 2015). The thematic analysis process includes the development of codes, categorisation, and the identification of themes and patterns (Robson & McCartan, 2016; Saunders et al., 2009). From the transcribed data, extracted keywords and phrases were categorised, themed, and interpreted. Lastly, patterns and relationships were identified, summarised and the findings were linked to the research questions and the objectives of the research (Saunders et al., 2009).

1.7 Delineation of study

The researcher understands that the data generated from the study and the information needs that have been established by the selected population are not an overall representation of the information needs of all caregivers in South Africa.

1.8 Research assumption

The researcher assumed that the caregivers were able to identify their information needs and challenges faced during their care activities accurately and effectively. The researcher furthermore assumed that there could be a difference in the information needs of the private caregivers, frail-care caregivers, those caring for special needs children, which was evident in the findings.

1.9 Significance/contribution of the research

The research is particularly important due the limited availability of literature and interventions that cover the information needs of caregivers in South Africa. This research provided valuable insight into the information needs of caregivers and the current ICT resources available to them, thus recommending ways for government, NGOs, higher learning institutions, and policy-makers to develop and provide further interventions, adequate resources, upskilling, and training programmes for caregivers.

1.10 Ethics statement

Adherence to ethical principles: An ethical principle refers to the obligation of the researcher to respect each participant as a person capable of making an informed decision regarding participation and access to findings (Smith & Firth, 2015). All ethical principles were strictly adhered to in the study. The aims and objectives of the study were explained in depth to all participants who volunteered and consented to participate in the study. The researcher obtained a consent form (Appendix C) from all participants prior to conducting the interviews, and informed them of their right to withdraw at any point. Furthermore, the anonymity and confidentiality of all participants were assured by the researcher.

Confidentiality and integrity of data: Data collected were not fabricated or falsified. The confidentiality and integrity of the collected data were upheld, none of the participant responses was divulged to anyone in the organisation. Participants were also informed that the collected data would not be published without their consent. The researcher further assured all participants that data would only be accessible to CPUT to advance further research and knowledge. All relevant research documents will be safeguarded and accessed only by authorised people involved in the research study. Furthermore, the information needs of the caregivers did not include any of the individuals' personal health records.

1.11 Headline findings

Nineteen (19) findings are presented in Chapter Four, based on the analysis of interview answers collected during the research process. From these nineteen (19) findings, five headline findings were identified.

1.11.1 Headline finding 1: Caregiver work practices

The tasks of caregivers in this study included: i) grooming of the client; ii) tasks related to medication; iii) domestic related tasks; and iv) educational tasks. This study found a misalignment between the training caregivers received in terms of home-based care courses and the type of care services required by the recipient.

1.11.2 Headline finding 2: Caregiver challenges

Caregivers work very hard, often much longer hours than conventional jobs, which may lead to burnout. Thus, caregiving is a physically and emotionally taxing task and caregivers face physical, psychological, emotional, and financial challenges. Some caregivers have expressed feelings of discouragement, a general sense of hopelessness, and in some cases, depression. The physical challenges include being physically unable to do some tasks and those related to feeling overburdened with too many duties, such as cooking and domestic work. Other challenges include the inability to communicate with clients due to aggressive behaviour.

1.11.3 Headline finding 3: Unmet information needs

The study showed that the biggest challenge reported by caregivers is related to the unmet information and training needs. Unmet information needs impede caregivers from adequately completing their caregiving tasks and require more attention, as training does not prepare them to for the task of caregiving.

1.11.4 Headline finding 4: Caregiver information resources

Caregivers have access to resources in the form of health professionals, the Internet, and material resources. Findings show that caregivers prefer interactive and practical information obtained from medical staff, while some rely on their personal experience they have gained over the years. In terms of ICT information resources, caregivers reported difficulties with accessibility at institutions. Caregivers reported that accessing information from the Internet is challenging, as they are required to be on duty all the time. Caregivers in this study also reported a need for protective equipment such as gloves, aprons, and masks, which are necessary to perform caregiving tasks. Some caregivers expressed a need for material resources such as books, learning aids and devices for childcare recipients.

1.11.5 Headline finding 5: Information sharing

Caregivers in this study admitted to engaging in peer education practices and reported sharing knowledge with their peers, colleagues, managers, and supervisors. The study confirmed a community of practice between caregivers.

1.12 Conclusion

Even though there are many attempts to improve the knowledge base of caregivers, there is still a need to for more information. Caregivers are under pressure to assist the people that need attention in a professional way but their work environment makes this very difficult to achieve. Caregivers lack emotional support, but they also need physical equipment to do their work.

1.13 Organisation of the thesis

This thesis comprises six chapters.

Chapter One provides the introduction and background of the study. This chapter is introductory and contextualises the research topic and research problem. It also outlines the research questions, objectives, and aim of the study. The chapter concludes with the delineation, significance of the research, and the ethics statement.

Chapter Two provides the literature review with a special focus on the information needs of caregivers. The discussion includes caregiving in South Africa, caregivers, caregiver challenges, caregiver needs, community of practice (COP), health care knowledge, and knowledge management.

Chapter Three outlines the research methodology adopted for the study. A broad overview covers the research philosophy, research approach, research strategy, data collection techniques and data analysis methods used for the study. A discussion of the interpretivist epistemology is provided, based on a multiple-case study using a non-random purposive sample totalling 21 caregivers. The unit of analysis and unit observation are identified. A full discussion of the data collection procedure is provided along with the construct of the semi-structured interview. Further details of the data analysis procedures used in the study are also provided. The chapter concludes with a discussion on ethics that were considered throughout the research process.

Chapter Four provides a detailed description of the context and participants involved. Analysis of data was done systematically, with a corresponding report of qualitative data relating to the objectives of the research. The chapter concludes with a summary of all the findings and the themes derived.

Chapter Five presents a discussion of the research findings in relation to the research questions. Literature is synthesised with the findings, and the practical implication and the significance of the findings is indicated.

Chapter Six provides conclusions drawn from the study and outlines recommendations for policy-makers and caregiving interventions. Future research is highlighted, with the focus on how to understand the subject matter better in future.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

Caregiving has become a necessary and complex endeavour in today’s society, with the number of people who need the services of caregivers rising per annum (Black et al., 2018). Furthermore, the physical and psychological demands of caregiving have led to higher rates of health problems for caregivers. South Africa especially faces a real problem with the rising number of people with HIV and AIDS (PLWHA) (Chironda & Bhengu, 2019). Besides facing the daily challenges of caregiving, caregivers of PLWHA face compounded physical, emotional, social, and psychological challenges. Thus, there exists a great need for community-based, home-based and hospice institutions. In general, caregivers assist the care recipient with improving their quality of life (QoL) and play a vital role in the provision of palliative care (Conrad et al., 2018).

These challenges cannot be addressed without first examining the causes, which may be best understood by determining the needs of the caregivers. The needs may be tangible and/or intangible. The tangible needs refer to physical resources whereas as the intangible needs refer to emotional, support and information needs. Because the information needs of caregivers have not yet been properly identified, understood and addressed, the problem of unmet caregivers’ needs persists (Black et al., 2018; Galvin et al., 2018; Farrant et al., 2017).

This chapter provides the literature review for the study, guided by the aim and problem statement. For ease of reference, the aim and problem statement are listed below.

The aim of the study was to explore the unmet information needs of caregivers during their work activities in order to identify and address the challenges of information needs during the course of performing their duty.

Problem statement: The information needs and challenges relating to a lack of information available to caregivers are considerably unclear and unidentified in different contexts. It is therefore important to identify the information needs of caregivers in South Africa in order to improve their work conditions and the services they provide.

The literature review is based on the keywords identified from the title, problem statement, research questions, and aim of study. The keywords used to examine the literature were found in the online databases of the library of CPUT. These databases include Google Scholar, Emerald, EBSCOhost, and ProQuest. The literature review is presented in the following format: i) caregiving in South Africa, ii) caregiver, iii) caregiver challenges, iv) caregiver needs, v) community of practice (COP), vi) health care knowledge; and vii) knowledge management (KM).

2.2 Caregiving in South Africa

Studies have proven the demand for voluntary caregivers in South Africa (Millenaar, et al., 2018; Morton et al., 2018; Lambert & Girgis, 2017; Chironda & Bhengu, 2018, 2019). As such, the demand for home-based care (HBC) is an attempt to address the escalating numbers of patients requiring caregiving (Li et al., 2017). To meet this growing demand, the South African government encourages volunteer-based programmes, provide stipends, and assist caregivers to formalise their work (Millenaar et al., 2018). However, South African caregivers find themselves in difficult conditions in the face of a broad range of challenges, such as lack of patient information, basic resources, inadequate training, and insufficient knowledge (Morton et al., 2018). Numerous South African health care non-governmental organisations (NGOs) are recruiting home-based caregivers who have been inadequately trained and equipped for meeting patient demands (Dageid et al., 2016). Despite the highly significant role that caregivers play in South Africa, many have received minimal or no training (Morton et al., 2018).

In sub-Saharan Africa, caregiving is a vital part of HIV/AIDS care and their care work extends from an individual and community based-level to terminally ill patients with TB, HIV/AIDS, and other chronic illnesses (Morton et al., 2018). Care services are in high demand in Africa and South Africa in particular, with some of the highest levels of HIV/AIDS prevalence rates reported in the world. According to the World Health Organisation (WHO), South Africa has the highest number of people living with HIV/AIDS in the world (O'Neil, et al., 2018). The high prevalence of AIDS infected persons therefore require and seek health care from the public health system, which consequently places a huge strain on the system. The public health system has thus come to rely on the voluntary services of caregivers. However, the reality is that many community health workers (CHWs) and caregivers are under resourced, under-trained, and ill equipped in terms of providing proper care to recipients (Pinquart, 2018). Furthermore, caregivers are often taken from communities wherein AIDS is prevalent and trained by non-governmental home-based care (HBC) organisations. Most of these organisations are faith-based and often the only source of support to them (Tatangelo et al., 2018).

2.3 Caregiver

The term caregiver refers to “anyone who delivers assistance to someone else who is, to some extent, debilitated or incapacitated and in need of help” (Longacre, 2013:50). Informal caregiver is defined as “persons without formal health care education who are caring for, or helping a person with functional disabilities, prolonged psychiatric or physical illness, or age-related problems” (Lethin et al., 2016:32). The caregiver may operate as full-time or part-time, secondary or primary, or may live with the patient on a full-time basis or separately. Informal caregivers include family, neighbours, and friends (Longacre et al., 2014). Non-medical home care is paid for by the individual or family. These services enable the client to stay at home rather than living in a facility (Werner et al., 2017). The term “private-duty” refers to the private pay nature of these relationships (Comfort Keepers, 2017). Non-medical home-based care is usually funded privately as opposed to home health care, which is task-based and requires government or insurance funding.

The type of caregiver investigated in this study is a formal employed caregiver. The caregivers have achieved an element of education or training in the field. In this research, the focus is on the experiences that employed caregivers have while working at the institutions and a private home setting, and not on the amount of training they received.

2.3.1 Care recipients

Care recipients refer to people who receive care (Tatangelo et al., 2018). Care recipients include people who suffered strokes and heart attacks, those with a specific disease such as Parkinson’s or Alzheimer’s, people living with HIV and AIDS (PLWHA), individuals who have been exposed to traumatic injury and in need of rehabilitation, or a child who suffers from a mental or physical disability (Mansfield et al., 2017; Masuku et al., 2018). Home health services provided by caregivers is primarily to assist children, adults, and senior citizens who are recuperating after treatment, needs a day care stay, or additional special care at home to avoid further hospitalisation (Galvin et al., 2018; Denham et al., 2018).

2.3.2 Caregiving services

Services provided to patients vary and are specific to the needs of the patient. For example, patients who are terminally ill such as cancer patients may be provided with hospice care in addition to the home care, whereas patients recuperating from major surgery or illness may be provided with rehabilitative therapies (Heckel et al., 2018).

2.3.3 Types of care work

The duties of caregivers often go beyond basic medical care and include household chores, counselling, child-care services to sick parents, organising material support and food for affected families, arranging funerals, and helping patients and their relatives to access social grants (Werner et al., 2017). The type of care work varies according to different populations and includes tasks such as caring for the young, elderly, sick or underprivileged. Children may require care services due to health needs or abandonment whereas frail-care refers to the care and protection of the elderly (Werner et al., 2017; Yamaoka et al., 2015). Some caregivers provide disease-specific care, such as dementia, cancer and AIDS (Zwingmann et al., 2019).

Caregivers primarily provide home-based care (HBC), which is also known as social care. It is supportive care where assistance is provided to the patients in the comfort of their own home (McIlfatrick et al., 2018). This type of care is provided by health care professionals to children, adults and senior citizens to meet the specific care and medical needs of the patients, and is especially focused on activities of daily living (ADLs), ensuring that patients live a quality life (Lambert, Hulbert-Williams et al., 2018). Caregivers also do short-term nursing, rehabilitative and therapeutic treatments, and general home health care, sometimes guided and supported by registered nurses (RNs), licensed practical nurses (LPNs), physical therapists (PTs), occupational therapists (OTs), speech language pathologists (SLPs), home health aides (HHAs) and medical social workers (MSWs) (Kumar & Das, 2017).

In addition to providing medical care and supportive services, caregivers also provide non-medical assistance when patients are not capable of performing the non-medical activities independently. Tasks include grooming, bathing, toileting, dressing, positioning, exercise, medication reminders and feeding; other duties include light household tasks such as meal preparation, some housekeeping, laundry, shopping, pet care, and errands as needed (Jukic et al., 2017).

2.4 Caregiver challenges

South Africa has a huge human resource deficit in the health care sector. Health care providers and caregivers are placed under considerable strain to meet demands and have reported major needs and challenges that they face in their daily tasks (Rogerson, 2018). Furthermore, many caregivers work in underserved and under-resourced areas such as rural communities (Wang et al., 2018). These communities do not have the necessary resources to alleviate the challenges of caregivers. One of the biggest challenges faced by caregivers is caregiver burden.

Masuku et al. (2018) conducted a study in rural South Africa and highlighted the many challenges faced by informal caregivers. The study established that barriers to proper home-based care included poverty, poor access to basic health care, limited information, and the limited capacity within impoverished rural communities to deal with HIV infection. Informal care of PLWHA places a huge physical and financial burden on caregivers. Caregivers also expressed basic needs, which include assistance with daily living, palliative care, and assistance to obtain social security benefits (Masuku et al., 2018).

2.4.1 Caregiver burden

Caregiver burden is used to describe the load carried by caregivers because of assuming the caregiving role (Wang et al., 2018). Objective caregiver burden refers to the physical cost of caring for the recipient whereas subjective burden describes the caregiver's perception of their responsibility in terms of caring for the patient (Reblin et al., 2018). Objective and subjective caregiver burden are emotionally and physically demanding on the caregiver, with numerous implications for the somatic and psychological health of the caregiver (Reblin et al., 2018; Akbari et al., 2018).

According to the South African Health Review (Gray & Vawda, 2017), the estimated HIV prevalence rate is approximately 13.1% among the South African population, which represents an increase of 12.9% from the 2017 figure. The total number of people living with HIV in 2018 is estimated at about 7.52 million (Gray & Vawda, 2017). Many caregivers are unable to cope with the physical and emotional demands of caring for PLWHA and often suffer from occupational stress and burnout (Akbari et al., 2018).

Reblin et al. (2018) researched the perceived stress and burnout among volunteer caregivers working in AIDS care in South Africa. The authors confirm that caregivers are left with feeling an intense sense of despair and hopelessness, overwhelmed by the task of caregiving. The study describes experiences, feelings and perceptions of South African caregivers within different settings such as health care, teaching, and counselling in the HIV/AIDS field (Reblin et al., 2018). Results indicate that caregivers furthermore struggle with bereavement issues, they experience constant fear of being exposed to HIV, and they are unable to deal with the stigmatisation issues experienced by patients (Reblin et al., 2018). According to Gray and Vawda (2017), caregivers reported a lack of information regarding management methods for TB. In terms of psychological distress, many caregivers reported feeling anxious and depressed, struggling to function properly.

O'Neil et al. (2018) examined the experiences of caregivers of TB in Botswana and its effects on their psychological distress levels. Findings indicate a lack of adequate caregivers’ skills such as the handling and disposal of clinical waste. Similarly, Reblin et al. (2018) posit that comprehensive caregiver training is needed to increase caregivers’ coping strategies of caregiver burden.

Romero et al. (2018) investigated the burden, social stigma, and willingness of caregivers to continue caregiving based on the support they receive. The study confirms that caregivers experience high levels of personal discrimination and stigma because of caring for HIV patients. According to Kolanowski et al. (2018), caregivers reportedly agree on a lack of support structures from family members and the church, but good support is received from other caregivers and nurses alike. Findings show that caregivers who reported lesser degrees of stress and burden because of discrimination are more willing to continue with caregiving as opposed to those who reported severe levels of stress. The study was based in South Africa, where 358 caregivers were recruited from KwaZulu-Natal. Results confirm that over 13% of informal and formal caregivers personally face discrimination because of caring for PLHA (Singh et al., 2011).

Meyer-Weitz et al. (2018) report on caregiver burden among adults caring for orphaned children in rural South Africa and suggest that caregivers with economic vulnerability and those struggling with their own AIDS-related illness feel the most overburdened. The study recommends programmes that foster economic security in order to alleviate caregiver burden and the co-ordination of services with home-based care programmes serving the chronically ill.

2.4.2 Stigma

Caregivers of PLWHA reportedly experience personal discrimination and stigmatisation as result of caring for PLWHA. They are in need of support programmes to help them cope with discrimination and stigmatisation (Lambert, Bellamy et al., 2018). Similarly, Akintola et al. (2013) and Kiyange (2018) reported on palliative care in semi-rural communities in South Africa. The participants were caregivers who all expressed moderate to high levels of occupational stress. Most of the causal factors for their stress levels include lack of support from the public health systems and government, which exacerbates the burden of providing care for PLWHA (Kiyange, 2018). Perceived stigma attached to caring for PLWHA as well as a lack of training and information about the illness are indicated as predictors of burnout (Kolanowski et al., 2018).

2.5 Caregiver needs

2.5.1 Support needs

Lambert, Hulbert-Williams et al. (2018) conducted a study on the unmet needs of individuals with advanced cancer and their caregivers. A lack of support was reported by caregivers who provide care services that greatly affected their stress levels and ability to provide adequate care. The study also recognises and identifies the dire support needs for informal caregivers, which include financial, emotional, and practical support. Werner et al. (2017) researched the supportive care needs, anxiety, and depression among informal caregivers of patients with cancer and cancer survivors. The authors report that caregivers face financial difficulties, social isolation, and limited support from the wider community. The study recommends that the somatic, psychological, and socio-economic needs of the care providers be addressed through the planning and provision of rehabilitative interventions and better support programmes.

Darkwah et al. (2018) explored the experiences of caregivers of people living with serious mental disorders in Ghana. The study shows that the caregivers of people living with serious illnesses are exposed to stigma and discrimination, and they find themselves isolated from sources of support. In addition, poverty, the lack of support from others, diminished social relationships, depression, emotional trauma, and poor or interrupted sleep are the reported consequences of caregiving (Darkwah et al., 2018).

Most caregivers receive inadequate support from the patient’s provider in managing dementia related problems; they feel strained and have a low confidence in terms of managing caregiving. New models of care are needed to address the complex care needs of patients with dementia and equip their caregivers (Hanrahan, 2018). Caregivers of patients referred by geriatricians more often report having a health care professional to help work through dementia care problems than those referred by internists, family physicians, or other specialists, but self-efficacy remains the same (Litzelman et al., 2018). Low caregiver self-efficacy is associated with higher caregiver strain, more caregiver depressive symptoms, and caring for a patient with more severe behavioural symptoms (McIlfatrick et al., 2018).

Litzelman et al. (2018) also confirm the need for caregivers of the elderly, and points out that research conducted on how such care impacts the overall well-being and somatic health of the elderly caregivers, is limited. The authors also indicate that the lives of these caregivers are drastically affected by factors such as long periods of absence from home and the lack of coping mechanisms available to deal with the daily tasks of caregiving.

Masuku et al. (2018) report on a study where participants all agreed that a lack of support structures seriously affect their ability to provide proper care. The study confirms the dire need that exists for decision and policy makers to develop and fund HBC models. This can be achieved through the reduction of workload placed on caregivers, the provision of continual psychosocial support, and recruiting professional nurses to assist volunteer caregivers in terms of training (Lim et al., 2017).

While caregiving can be a very stressful situation for many caregivers, studies also show that there are beneficial effects, including feeling positive about being able to help a disabled spouse, feeling appreciated by the care recipient, and feeling that their relationship with the care recipient has improved (Hanrahan, 2018). Often caregivers are depressed due to the increased demands placed on them, and they are unaware of the variety of support services available to them. Seventy-five percent (75%) of caregivers of Alzheimer's patients indicate a lack in meeting the needs of the patients, and they admit to not knowing how to access support services (Selman et al., 2018).

2.5.2 Training needs, skills and information

Lundberg et al. (2016) investigated experiences of caregivers of PLWHA in Vietnam and reported a lack of training programmes for caregivers. The study shows that caregivers express a need for programmes that provide information on infection control, as they fear exposure to infection.

Conrad et al. (2018) conducted a study on the care programmes and training of caregivers at McCord Hospital (Durban, South Africa), Mseleni Hospital (KwaZulu-Natal, South Africa), and the Tshedisa Institute in Gaborone (Botswana). The study recognises an urgent need for the development of HIV/AIDS care/treatment programmes for caregivers, integrated with other treatment services and tuberculosis (TB) programmes (Conrad et al., 2018).

Sklenarova et al. (2015) researched the social, psychological, economic, and physical needs of caregivers. The study established that caregivers need more resources and training, which is not available to them. A study by Majumdar and Mazaleni (2010) sought to examine the daily experiences and needs of caregivers of PLWHA in rural Eastern Cape, South Africa. The aim of the study was to develop and apply a model of home-based care and address some of these needs. The participants were informal caregivers from underserved South African villages of whom the majority expressed some major challenges. Some of these challenges include the inability of caregivers to cope with the symptoms of HIV and AIDS due to a lack of knowledge about the disease. Caregivers also indicated a lack of training on how to care for the recipient, and pointed out that in the dire socio-economic conditions of the underserved community, they were not provided with the necessary resources. The study thus confirms that caregivers need medical and physical assistance to cope with illness, and that a lack of community resources available to them is a reality (Majumdar & Mazaleni, 2010).

James et al. (2018) researched community home-based caregivers (CHBCs) of PLWHA. The study indicates that caregivers often operate in dire circumstances, that they are socially isolated and exposed to stigmatisation, and that they generally complain about the lack of basic caregiving training. Matsea et al. (2018) report on the views of caregivers regarding the support they receive from the families of care recipients in rural South Africa. The study recommends that caregivers receive regular training and support in order to understand mental illness and improve their caregiving services. Nurses should be recruited as primary sources of training by providing clinic-based engagement and home visits to address this need Matsea et al., 2018).

2.5.3 Resource needs

Caregiver strain and low self-efficacy for managing dementia related problems are common among those caring for patients with dementia, but the level of unmet needs and relation to provider type has not been well characterised. O'Neil et al. (2018) report that caregivers do not have access to basic resources, including wound dressings, toiletries, linen, cotton, wool, and sheets. Many caregivers also point to a lack of protective equipment such as masks, gloves, and aprons. The study recommends that caregivers be provided with information on infection control and basic medical care in addition to counselling (O'Neil et al., 2018). The authors conclude by stating that properly trained caregivers will play a positive role in the improvement of medical care for PLWHA. Proper training will also alleviate caregiver burden and associated health issues such as occupational stress (O'Neil et al., 2018). The study encourages increased communication and coordination between the public health care facilities and the community in order to facilitate service utilisation for the caregivers.

Williamson et al. (2018) recommend and encourage health and social care decision-makers to design strategies that address the needs of caregivers of PLWHA. Their study also indicates the limited resources required to support caregivers.

2.5.4 Information needs

This section focuses on literature regarding the knowledge and information needs of caregivers. Morton et al. (2018) opine that the scope of caregiver information needs is broad and varies according to the disease type, the ethnicity of recipient and their cultural and religious backgrounds. These barriers to care will have to be addressed uniquely in order to achieve all-inclusive palliative care. Furthermore, the socio-economic conditions of underserved communities affect the information needs of caregivers; it should therefore be taken into consideration when caregiver information needs are addressed (Morton et al., 2018).

Werner et al. (2017) focus on identifying barriers to information needs of caregivers in the management of dementia related behavioural symptoms. A qualitative study by Whitlatch and Orsulic-Jeras (2018) on the information needs and sources of caregivers of people living with dementia (PLD) confirmed the need for information on dementia and first aid practices. The study also established that food and nutrition information is a priority to caregivers, and that caregivers indeed lack information in this regard.

Chen et al. (2016) researched the unmet supportive care needs of caregivers of lung cancer patients. Findings show that the primary caregivers of patients with lung cancer reported information needs and health care service needs. The study recommends that health care providers evaluate the caregivers’ care needs and emotional states so that appropriate and adequate medical information and services can be provided on time (Chen et al., 2016).

2.5.5 Skills needs

Skills are defined as “goal-directed, well-organised behaviour that is acquired through practice and performed with an economy of effort”. Farran and colleagues define caregiver skill as “something that caregivers do” using “goal-directed behaviours based on knowledge, experience, or personality style” (Farran et al., 2007). The necessary skills enable caregivers to receive guidance, counselling, and direction from health professionals and practice what they learn. Given, Given and Sherwood (2015:131) outline the skills of the caregivers and mention “monitoring, interpreting, making decisions, taking action, adjusting to changing needs, comforting with hands-on care (direct care), accessing resources, working with the ill person, and negotiating the health care system".

Park and Schumacher (2014:142) describe family caregiving skills as the "ability to engage effectively and smoothly" in nine care processes, requiring psychomotor, cognitive, and psychological skills. Special skills include and consider factors such as the patient's personality type, the level of progression of the illness, and the physical, cognitive, social, organisational, and psychological knowledge and skills of the caregivers (Given et al., 2015).

Nurses and social workers should firstly do an assessment of the care situation and assist family caregivers in the development of the skills they need, which will lead to lowered feelings of burden, stress, and distress (Park & Schumacher, 2014). Education interventions are thus necessary for caregivers' tasks or the knowledge and skills they require, and are of vital importance for planning and implementing interventions. Mastery of skills, preparedness, and competence are essential mechanisms to facilitate effective decision making and problem solving by caregivers. However, currently the formal care systems and institutions are not providing caregivers with the required skills.

Abdelmoneium and Alharahsheh (2016) researched the challenges of caregivers who care for old persons in the Arab region. The study found that the main challenges were linked to a lack of social skills and the inability to communicate with the recipients. Caregivers need to be equipped with social and problem solving skills in order to provide care competently. Baudry et al. (2018) report on the supportive care needs, anxiety, and depression of caregivers of patients with cancer and cancer survivors. The study shows that caregivers need skills to cope with activities of daily living (ADLs) in order to manage symptoms, provide emotional support to care recipients, and co-ordinate care services; they also require skills for information seeking.

The following section provides the discussion on the conceptual framework for the study.

2.6 Community of Practice (COP)

A community of practice (COP) refers to "a group of people having a common identity, professional interests and that undertake to share, participate, and establish a fellowship" (Ataman et al., 2015:83). Wenger (2011:3) defines COP as "a group of people, along with their shared resources and dynamic relationships, who gather to practice and utilise shared knowledge, in order to enhance learning and create a shared value for the group".

The term 'community' implies that these groups are not inhibited by geographic or functional boundaries but share common responsibilities and duties, contexts, and interests (Paulin & Suneson, 2015). The word 'practice' infers knowledge in action, indicating how individuals actually go about doing their jobs on a daily basis (Wenger, 2011). The concept of a community of practice (COP) as a knowledge-sharing community within organisational settings originated with Lave and Wenger (Wenger, 2011). It is thus a perspective that locates learning, not in the head or outside it, but in the relationship between the person and the world, which for human beings is a social person in a social world (Toomey, 2011). A community of practice is not merely a community of interest, i.e. people who like for instance certain kinds of movies (Rowley & Hartley, 2017). Members of a COP are practitioners. They develop a shared repertoire (collection) of resources – experiences, stories, tools, ways of addressing recurring problems, in short, a shared practice (Rowley & Hartley, 2017). This takes time and sustained interaction.

An example of a COP is a group of nurses who meet regularly for lunch in a hospital cafeteria. They may not realise that their lunch discussions are one of their main sources of knowledge about how to care for patients. Still, in the course of all these conversations, they have developed a set of stories and cases that have become a shared repertoire for their practice (Janasz & Janasz, 2018).

2.6.1 Types of COP

While COPs all contain the three elements of a domain, a community, and a practice, these communities are found in a variety of forms. Some are quite small, while others are huge, often with a core group and many peripheral members. Some COPs some are local and some cover the globe; some meet mainly face-to-face while some meet mostly online; some are within an organisation and some include members from various organisations; some are formally recognised, often supported with a budget, while others are completely informal or even invisible (Bloor, et al., 2018).

Even though health care delivery practices are dynamic and constantly developing, there is still a gap in knowledge for formal and informal health care professionals and caregivers in the community (Slaboda et al., 2018). Caregivers are often confronted with medical problems and treatments that are not adequately represented in medical literature. As a result, they are unable to make decisions based on clinical evidence (Fauer et al., 2018). It is also highly unlikely that a health care professional will possess an abundance of personal experience of a particular illness in conjunction with all its likely syndromes, symptoms and conditions, which are needed in order to make the right decision (Fauer et al., 2018).

There will thus always be a gap in knowledge and how much is known about an illness or a disease. In order to address this gap in experiential knowledge, literature suggests that the unexploited tacit bank of health care knowledge of caregivers and the clinical practices and intuitive problem-solving strategies vested with health care professionals, be combined to become actionable health care knowledge (Sanders et al., 2018).

The tacit knowledge shared among formal and informal caregivers in communities and the practical insights with regard to finding solutions to various health problems may provide useful (Sanders et al., 2018). Therefore, caregivers are in need of tacit and explicit health care knowledge in order to provide better care services and alleviate burdens and challenges (Nour et al., 2018).

2.7 Health care knowledge

Traditionally tacit health care knowledge is not strictly “evidence-based” and is acknowledged as valid, valuable, and essential to health care practice (Nour et al., 2018). Manogaran et al. (2017:134) refers to tacit health care knowledge as an “undercapitalised resource” and opines that it plays a vital role in improving the quality and delivery of health care. The “overcapitalised explicit (published) health care knowledge” is located in abundant sources such as structured reviews, journal articles, and clinical practice guidelines Manogaran et al. (2017:134). However, the tacit knowledge of formal and informal health care professionals such as caregivers is not always documented.

2.7.1 Tacit and explicit knowledge

The tacit knowledge embedded within health care professionals and caregivers should be considered an important source of experiential knowledge (Manogaran et al., 2017). However, due to some technical and operational reasons, this specific type of health care knowledge has not yet been fully harnessed and not made available to caregivers. Caregivers often complain about the paucity of health care knowledge. In the traditional sense, such knowledge would be accessed via published best evidence, which may not necessarily provide solutions to challenges faced by caregivers in the day-to-day caregiving activities. Caregivers need to be able to access a tacit knowledge base, drawn from personal experiences, intuitions and perspectives of other formal and informal caregivers and health care professionals who face similar challenges and problems (Janasz & Janasz, 2018).

In addition, caregivers also require and should have access to actionable knowledge such as the development of new treatments, guidelines in caregiving, procedures, and delivery practices as opposed to mere service quality and outcome measurement treatments (Imran et al. 2019). Strategies to acquire the tacit knowledge of health care professionals and caregivers should be developed in order to improve and achieve a better quality of life for the care recipient.

In this regard, the development of communities of caregiving practitioners may be considered a viable strategy, as it allows caregivers to share their experiences, exchange new information, and build on their current bank of information. Ginter et al. (2018) suggest that the acquisition of the tacit knowledge possessed by health care professionals is of vital importance for the development and sustainability of COP caregivers. Imran et al. (2019) researched tacit knowledge sharing from the perspectives and experiences of physicians and argue that health care knowledge should be formulated and presented in a computational format that enables easy access by caregivers, and that their tacit knowledge should be crystallised and validated by health care professionals.

2.7.2 Collaborative Problem Solving (CPS)

Collaborative problem solving refers to groups of people working together to find solutions to real problems. These groups comprise members that share a common concern. Stoeffler et al. (2018) opine that social and collective communication can be found in the collaborative problem solving (CPS) strategy along with educational discussions by COP caregiver members. Thus, the manner in which a community of caregiving practitioners communicate, may lead to the development of a network of expert knowledge. CPS is a necessary and critical skill not restricted by the confines of individual problem solving. CPS looks at the collective efforts, in this instance, of a community of caregivers who join their perspectives and work together to solve a particular problem or challenge (Stoeffler et al., 2018).

The advantages of CPS are numerous, and besides facilitating the effective division of service in a particular community, it further provides a basis for the effective incorporation of tacit and explicit knowledge from multiple sources, experiences and perspectives (Graesser et al., 2018). In addition, a community of caregiving practitioners may develop much more creative solutions to their specific problems, leading to a better quality of service to the care recipients, initially stimulated by the ideas of other group members.

However, the articulation, description, and distribution of tacit knowledge embedded in the formal and informal caregiving community is a challenging task, and to operationalise such knowledge is just as hard. Knowledge management should therefore focus on the recognition, appreciation, attainment, distribution, and application of actionable health care knowledge embedded within formal and informal caregivers and other health care professionals (Selman et al., 2018).

In South Africa, there appears to be a lack of structure between the caregivers and the formal health system (Manogaran et al., 2017). Non-profit organisations (NPOs) and non-governmental organisations (NGOs) have in the past, depended on the individual efforts of staff in facilities and organisations. Because of the lack of complimentary collaboration efforts between the informal caregiving sector with other communities of caregiving, as well as with the formal health care services and professionals, the National Health Department (NHD) has attempted to address this shortfall of policy guidelines (Horwood et al., 2018).

The NHD is in the process of proposing new arrangements that will focus on formulating the work of informal community care workers (caregivers) through the integration of their work into the formal health facilities of the communities they work in (Horwood et al., 2018). In addition, it has also been proposed that NPO-based community caregiver programmes continue to operate alongside the outreach teams in such communities, thereby exposing informal caregivers to a range of training and informational workshops. This may address the many challenges faced by informal caregivers in communities and lead to the consolidation of relationships between formal and informal care workers (Van Pletzen & MacGregor, 2013; Aantjes et al., 2014).

2.7.3 Outreach programmes proposed by the NHD in South Africa

South Africa has an abundant source of health care experience and expertise in providing community based care, especially with non-formal NPO-led programmes (Naidoo et al., 2018). It is vital that this is not lost and that it is used effectively to address the critical shortage of trained health care professionals and informal caregivers in the country (Walsh & Van Rooyen, 2015). With the rising numbers of HIV and AIDS infected persons and an increased need for home care, it has become necessary for the National Health Department to recognise and consider the experience of seasoned community caregivers alongside those of professional nurses who may be able to fulfil supervisory roles to informal caregiving communities. Tsolekile et al. (2014) investigated the roles of community health workers in the management of non-communicable diseases in an urban township and report that communities of caregivers in South Africa may, with the assistance of professional nurses, become supervisors of “community health workers” in outreach teams in order to address the many challenges faced by caregivers.

Community caregivers are important sources of expertise and act as liaisons between community members and medical care providers (Naidoo et al., 2018). However, the growing reliance of health care systems worldwide on home caregivers has exceeded research on their praxis. In other words, the communities of caregiving practitioners, particularly in the informal sense, have not yet been provided with the tools or the appropriate forums to combine and integrate their indigenous (tacit) knowledge with technical knowledge of caregiving practices. This integration is essential in order to alleviate caregiving problems, which will ultimately have an impact on patient outcomes.

2.7.4 Assistive applications

Janse (2018) focused their study on Care-Net which is an interactive Web-based system intended to support informal caregivers through an effective interactive environment in order to address caregivers’ information needs. Caregiver needs could be addressed by providing a forum were caregivers obtain information and guidance, and where efficient and fast communication and collaboration with professional health care workers and other caregivers is facilitated (Cacchione, 2018). In this manner, caregivers will have access to advice, emotional and psychological support, health care information, and physical resources to enhance and ensure proper care. The platform should facilitate the documentation of personal observations, experiences, perspectives, interventions and insights, which will be harnessed as a future knowledge resource for other caregivers (Cacchione, 2018).

CAREGIVERSPRO-MMD (CMMD) is an application that specifically targets caregivers of people living with dementia (PLWD) and incorporates the live-in family caregiver into the system (Barrué et al., 2017). The aim of CMMD is to provide a support platform that promotes the quality of life (QoL), wellbeing, and medication compliance of PLWD and caregivers in the community at the point of care. The application will be accessed via smartphones and tablets using Web browser and SMS text messaging with an interface designed for users who have low IT familiarity. The application is specifically aimed at the collection and processing of data concerning health for specific and legitimate purposes (Barrué et al., 2017).

2.8 Knowledge Management (KM)

Knowledge management is “the deliberate and systematic coordination of an organisation’s people, technology, processes, and organisational structure in order to add value through reuse and innovation” (Hislop et al., 2018:26). This co-ordination is achieved through creating, sharing, and applying knowledge as well as through feeding the valuable lessons learned and best practices into corporate memory in order to foster continued organisational learning. Nikolai et al. (2015:4) refer to KM as “a multidisciplinary approach to achieving organisational objectives by making the best use of knowledge”.

KM focuses on identifying and retaining valuable knowledge and identifying intellectual assets, ensuring that materials are produced from that knowledge and subsequently stored in a manner that allows for easy retrieval and access at all times (Hislop, 2013). The products produced by KM will be exchanged by individuals, between members of a COP, and then back to the organisation itself (Hislop et al., 2018). This knowledge exchange may be in the form of personal experiences, lessons learned, best practices and corporate memory (Castaneda et al., 2018).

The aim of KM is to achieve the objectives of an organisation such as competitive advantage, innovation, integration, improvement and continual performance of the organisation by encouraging knowledge sharing (Castaneda et al., 2018).

2.8.1 Benefits of KM

KM offers a range of benefits to individual employees, COPs, and the central organisation (Castaneda et al., 2018). In terms of the individual, for example a caregiver, KM provides assistance to them in performing their jobs and simultaneously saving time through better and faster decision making and problem solving (Ghimire et al., 2018). In addition, KM contributes to creating a sense of community bonds among informal caregivers and facilitates constant learning by helping them to stay informed and abreast of current and new developments in home care. KM also provides a platform for caregivers to share their experiences, challenges, and solutions with their counterparts and provides opportunities to contribute to the existing network (Ghimire et al., 2018).

2.8.2 KM and COP

For the COP, KM contributes to the development of professional skills, promotion of peer-to-peer mentoring, facilitation of operative networking and collaboration, and the development of a professional code of ethics that members can follow (Migdadi et al., 2018). As for the organisation, KM assists in developing and executing strategies, facilitating quick problem solving, disseminating best practices to workers, advancing knowledge entrenched in products and services, encouraging and increasing opportunities for innovation, providing organisations with a competitive advantage, and growing organisational memory (Migdadi et al., 2018).

Seeking knowledge and finding information is an integral part and function of individuals working in any organisation or for themselves. Sources of information span from digital technologies to the World Wide Web, databases, knowledge management systems and other individuals in the organisation. Janse (2018) established that individuals still turned to people first in order to find information, solve problems, and make decisions. When knowledge is sought and shared among a group or community of people, a COP is developed. Thus, COPs have been around since humans have been learning together, where members of the COP may be core or just below the surface, and are found everywhere (Janse, 2018). They are linked together by what is familiar and common, which is ultimately what draws the individual to the community in the first place. COP allows individuals to look beyond formal settings such as classrooms or institutions, and enhances learning and perspectives though engagement in practice and participation in informal learning.

Shapiro and Varian (2013) conducted a study with a large aviation company in the United States and focused on how workers sought and found information. The study reports that workers prefer to contact other people in order to find, recover, and utilise information and that it is in fact, established to be the most successful strategy to employ with information acquisition (Shapiro et al., 2013). Thus, the best way to acquire knowledge is through people. Learning is therefore essentially a social event and occurs predominantly in an informal spontaneous manner. More recently, technology such as e-mail groups and virtual chats also gained momentum in providing a novel medium for workers who have common professional interests, problems and responsibilities, thereby enabling knowledge acquisition and sharing.

2.8.3 KM and Information Management (IM)

Knowledge and information are very different, although the terms are at times used interchangeably. Similarly, information management and knowledge management are often used synonymously (Barley et al., 2018). However, knowledge is not as sharply defined as information and has a certain unique human quality attached to it. Whereas information can be easily understood, categorised, shared, and measured, knowledge is intangible and inimitable and resides within the human mind. Furthermore, knowledge is disseminated without the assistance of external factors such as machines or technology (Barley et al., 2018). In contrast, the definition of information is much more rigid, simplistic, and uniform than that of knowledge (Janich et al., 2018).

Definitions of information usually include *organised data* and *interpreted data* (Janich et al., 2018), but it also includes human participation in the focused organising of raw data. Information management (IM) focuses on the manner in which people learn and look at ideas such as the creation, validation, codification, and sharing of knowledge and decision-making based on this information. IM primarily focuses on the manipulation of data and information (Rowley & Hartley, 2017).

Paulin and Suneson (2015:73) define knowledge as "a mix of fluid experiences, values, contextual information and intuition that provides a structure to evaluate and incorporate new experiences and information". Knowledge originates from the human mind and it is applied in the minds of people, and therefore the human element from a KM perspective is much more obvious than from an IM perspective.

Knowledge is governed by the role of humans who create, carry, transfer, apply, or translate it into action, whereas information might include the same functions, but could occur externally to the direct influence of humans.

2.8.4 Categories of knowledge

Often companies, institutions, and organisations overlook the importance and wealth of intangible knowledge possessed by its employees, for example their values, insights, perspectives, images, metaphors, gut feelings, hunches, and intuition (Janasz & Janasz, 2018).

Tacit knowledge involves experiential learning with subjective and cognitive domains whereas explicit knowledge relies on the rational, objective, and technical domains. In palliative care and generally home-based care, the needs of caregivers may relate to both tacit and explicit knowledge (Hislop et al., 2018). For example, explicit knowledge such as data, policies, procedures, and documents may be accessed by caregivers via databases or through training from health care professionals and institutions, whereas tacit knowledge such as intuition may be gained from other caregivers who became skilled through experiential learning (Hislop et al., 2018). The integration of explicit and tacit knowledge may be the solution that allows organisations and COPs of caregivers to meet the information needs of caregivers. Furthermore, addressing the information needs of caregivers improves the care services of the caregivers and care receivers.

2.9 Conclusion

The chapter set out to review current literature on the information needs of caregivers globally and in South Africa. The literature review is guided by the main and sub-research questions of the study, which sought to establish the information needs of caregivers in South Africa. Using the problem statement as a guideline, this chapter provided a detailed background of caregivers, types of caregivers, caregiver work, care services, and activities. The literature highlights that caregivers provide care to children, adults and the elderly in order to meet specific daily care and medical needs. Services provided to care recipients include hospice care and rehabilitative therapies.

The chapter also provides insight into some of the challenges faced by caregivers. Caregiver burden is reported as one of these challenges. Physical challenges include exposure to sickness and disease as well as sustaining physical strain due to care activities. Psychological challenges include psychological stress, stigma, and personal discrimination because of an association with certain care recipients.

In respect of caregiver needs, the literature indicates that caregivers have information, training, support, and skillset needs. The information required to meet the needs of the care recipients is lacking, and this is a major concern for caregivers. A secondary issue include the lack of training programmes that provide disease-specific information to caregivers. Literature also highlights that caregivers of PLWHA lack basic health information and generally have poor access to basic health care. In terms of resources, a lack of community resources and physical resources are also highlighted as needs.

The chapter concludes with a discussion of COP and KM. The COP model was selected for this study, as it is widely practiced among health care professionals, and strategies such as collaborative problem solving are adopted. In terms of KM, the chapter provides a discussion on how information and knowledge sharing may be harnessed to integrate the tacit knowledge of caregivers with the explicit knowledge of health care professionals.

The combination of COP and KM may provide useful guidelines to address the information and knowledge challenges and needs of caregivers.

The next chapter (Three) discusses the research methodology used in this study, and includes the research philosophy, research approach, research strategy, data collection techniques, and data analysis.

3. CHAPTER THREE: RESEARCH METHODS

3.1 Introduction

This chapter provides the outline for the research, philosophy, paradigm, approach, design, strategy, methods, unit of analysis and sampling techniques. This is followed by a description of data collection, ethical considerations, and the summary.

According to Walliman (2011:7), research is defined as “an activity that involves finding out, in a more or less systematic way, things you did not know”. Brown (2006) describes research methodology as the foundation on which the research is built or the philosophical framework within which the research is done. There are two major criteria making up research methodology: firstly, methodology should have the ability to attain the objectives of the research successfully, and secondly, it should be applicable to similar research studies (Allan & Randy, 2005).

Research is initiated with defining the research problem, followed by the formulation of research questions and objectives to select the best possible methodology that will address the questions and reach the aim. Allan and Randy (2005) posit that the following two criteria should be met when conducting a research methodology: i) the methodology should be the most suited to address and achieve the objectives of the research; and ii) replication of the methodology with similar research should be possible. The research design describes the general plan used to answer the research questions by connecting the data to the conclusion (Saunders et al., 2009).

This research employed a qualitative design. Research design can be divided into two groups – exploratory and conclusive. Exploratory research, according to its name, merely aims to explore specific aspects of the research area and does not aim to provide final and conclusive answers to research questions (Walliman, 2011). This study adopted exploratory research.

Research design is the blueprint or action plan for the research process from the start to the end and is employed to answer the research question (Saunders et al., 2012). In this study, the research questions comprise one primary research question and four sub-research questions, formulated to address the research problem.

The primary research question is stated as follows:

PRQ: What are the unmet information needs of caregivers in South Africa?

The sub-research questions are stated as follows:

SRQ 1.1: What are the work practices of caregivers and their related information needs in Cape Town, South Africa?

SRQ 1.2: What are the factors affecting unmet information needs of caregivers in Cape Town, South Africa?

SRQ 1.3: How are information resources made available to caregivers in Cape Town, South Africa?

SRQ 1.4: How do caregivers obtain/access alternative sources of information necessary for their care activities in Cape Town, South Africa?

The aim of the study was to explore the unmet information needs of caregivers in their work activities in order to identify and address the information need challenges during the course of performing their duty.

The following is discussed below: i) the research philosophy; ii) research approach; iii) research design; iv) research strategy; v) data collection techniques; and vi) how the data were analysed. The chapter ends with the ethics considered throughout the research process.

3.2 Research philosophy

It is important to understand the choice of philosophy as it reflects the researcher's assumptions, which serve as the basis for the research strategy. Different philosophical views are a reflection of paradigms that support objectivity and subjectivity. Research philosophy as stated by Collis and Hussey (2014) relates to the source, nature, and development of knowledge. The researcher has to consider the practical implications of the study, as there are important philosophical differences between quantitative and qualitative studies, giving rise to a further choice between the positivist and interpretivist approach (Mackey & Gass, 2016). However, recently pragmatism has gained popularity. In order to understand the different paradigms underlying objectivity and subjectivity, it is important to mention two major philosophies: epistemology and ontology (Saunders et al., 2012).

3.2.1 Epistemology

Epistemology is specifically concerned with the nature, sources, possibilities and limitations of knowledge (Mackey & Gass, 2016). It can be further explained as the study of the criteria of what constitutes knowledge, in terms of our understanding of knowledge, how it was obtained, and how much value is ascribed to it.

Punch (2013) observes that knowledge is obtained through the bottom-up approach, which means that themes and patterns are developed from observations of the world. The process involves the collection of information and evidence, followed by the development of themes based on this evidence. The second means of knowledge acquisition is known as the top-down or deductive approach (Neuman & Robson, 2014). With the deductive approach, hypotheses and logically derived propositions are tested against empirical observations. This approach starts with a conclusion and uses the evidence to confirm or reject the conclusion whereas the inductive approach uses the evidence to formulate the conclusion. The study adopted the inductive approach.

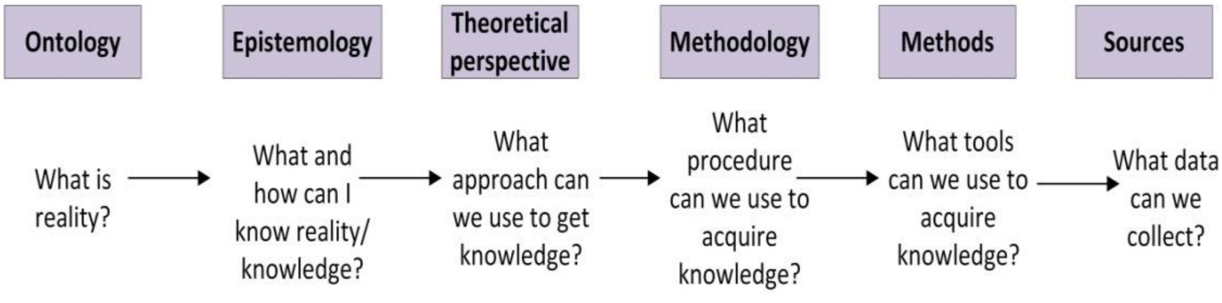
There are two major philosophical views in research, namely objectivism and subjectivism (Allan & Randy, 2005; Saunders et al., 2009). The subjectivist ontology is based on the inter-subjective perception of reality, which infers that meaning is gained through understanding based on social and experiential levels and is illustrated in the agreement of different minds and consciences regarding a particular set of meanings (Allan & Randy, 2005). Subjectivist epistemology appreciates that people and the knowledge they carry are inseparable, and advocates the human connection of the researcher to the subject of research. Thus, it has been argued that the human element cannot be removed from the research process (Chan et al., 2013). The objectivist ontology utilises the use of quantitative and mathematical methods, while subjectivism relies on experiences and consensus (Allan & Randy, 2005). In this research study, the subjectivist view that relies on the analysis an interpretation of reality has been adopted.

3.2.2 Ontology

Ontology is the philosophical study of the nature of being and a systematic account of existence (Punch, 2013). It has also been defined as the examination of what is meant by the word “thing”. Central to ontology is the concept of whether social reality may exist independent of the views and perspectives of social actors, that is, the interpretations and conceptions of humans, and whether a shared view of reality exists within a particular context (Blaikie, 2010). Thus, this view advocates that the social world can only be understood through human minds and the meanings constructed by them, and that reality does not exist independently of these social constructs. Ontology therefore refers to what constitutes reality and how this existence is understood. Ontology refers to the science or study of ‘being’ (Blaikie, 2010) and focuses on the nature of reality. Ontology is based on an interpretation of an individual about what constitutes a fact and is concerned with whether individuals and social entities should be considered as objective or subjective. Ontology has two major aspects, objectivism (or positivism) and subjectivism (Blaikie, 2010). Objectivism asserts that social phenomena and meanings ascribed to them exist independent of social actors, whereas subjectivism (also known as constructionism or interpretivism) views that they are developed from observations, perceptions and the actions of social actors (Monette et al., 2013). This study used the interpretivism paradigm, which focuses on the created worldview of the individual concerning their reality. The research employed this paradigm, as it allowed for exploration and deeper understanding of the needs of caregivers in rural South Africa.

3.3 Research paradigm

Research is based on an underlying assumption of what constitutes valid knowledge (Neuman & Robson, 2014). It is thus important to understand how knowledge has been obtained in order to evaluate the validity thereof. Epistemology is concerned with the assumptions of knowledge and the way it can be obtained, and consists of three categories: positivist, interpretivist, and critical realist (Allan & Randy, 2005). The research paradigm is defined as “the set of common beliefs and agreements shared between scientists about how problems should be understood and addressed” (Allan & Randy, 2005)



Adapted from Hay (2002) pg. 64 and Crotty (1998)

Figure 3.1: Research paradigm
(Source: Hay, 2002:64)

Research paradigm deals with the source, nature, and development of knowledge and can be categorised into pragmatism, positivism, realism, and interpretivism. The research paradigm consists of ontology, epistemology, methodology, and methods as illustrated in Figure 3.1. Different paradigms have differing ontological and epistemological perspectives, and therefore result in variant assumptions of reality and knowledge for each approach, which include positivism, interpretivism and critical realism (Neuman & Robson, 2014).

3.3.1 Positivism

Positivism is a philosophy based on the view that ‘factual’ knowledge is obtained through observation (the senses), including measurement, and can be described from an objective point of view, independent from the phenomena being studied (Babbie, 2015). The role of the positivist researcher is restricted to data collection and objective interpretation of the data only. The phenomena should therefore be isolated and observations are repeatable and the research findings are usually observable and quantifiable (Punch, 2013). Positivism depends on quantifiable observations that guide the researcher towards statistical analysis. It has been noted that as a philosophy, positivism is congruent with the empiricism, which states that knowledge originates from human experience, and that it has observable and distinct components and events working together in a noticeable, specific, and regular manner (Babbie, 2015). Furthermore, the positivist approach does not leave room for human interest and usually adopts a deductive approach. Studies based on the positivist paradigm are purely founded on facts, and the world is considered as objective and external (Punch, 2013). This study did not adopt the positivism approach as the research design is qualitative, which requires a deeper interaction with the data collection and analysis.

3.3.2 Interpretivism

In social sciences, interpretivism is the opposite of positivism, drawing its roots from the philosophical position of idealism that seeks to collect diverse approaches such as phenomenology, social constructivism, and hermeneutics (Moon & Blackman, 2014). Thus, interpretivism incorporates human interest and the conscious element into the study and views that reality does not exist independently (Saunders et al., 2012). The interpretivist approach is broadly based on a relativist ontology and subjectivist epistemology (Ormston et al., 2014). Interpretivism is also known as the interpretive philosophy, and it includes elements of interpretation done by the researcher (Onwuegbuzie & Frels, 2013).

Interpretive research is based on the assumption that reality may be accessed through social constructs such as language, consciousness, shared meanings, and instruments (Saunders et al., 2009). In an interpretive approach, the researcher appreciates variant perspectives among different people; meaning is derived and extracted dependent on human consciousness, and scientists cannot be completely independent from the phenomena being studied (Moon & Blackman, 2014).

Therefore, this study followed an interpretivist approach focused on the extraction of meaning from the sample population to reflect different aspects of the subject matter. The research followed a naturalistic approach of data collection where the development of meanings occurred towards the end of the research process (Ormston, et al., 2014). The study adopted the interpretivist paradigm, which relies on data collection methods such as small samples, in-depth investigations, and qualitative data (Onwuegbuzie & Frels, 2013).

3.3.3 Critical realism

Critical realism views the world as consisting of objects that are capable of generating events. These objects or structures exist in the social and natural world, and do not always produce regular measurable patterns of events (Myers & Klein, 2011). Social science therefore has to be critical of the social objects (Zachariadis et al., 2013). Critical realism is based on a series of philosophical positions; it includes ontology, structure, causation, persons, and forms of explanation and interpretation (Zachariadis et al., 2013). It presents as an alternative paradigm to science-based positivism, which involves regularities and the development of law-like forms; it also lends itself as an alternative to the interpretivist approach, which favours interpretation over explanation and description over causation. Instead, critical realism advocates that there is not one singular framework, methodology or set of beliefs explaining reality, but that the social world is a heterogeneous collection of elements drawn from a relatively common pool (Archer et al., 2013). Archer et al. (2013) explain critical realism as comprising of three layers: empirical data; theories and interpretation we draw upon to explain our empirical data; and philosophies and theories underpinning our theories, known as meta-theories.

3.4 Research approach

With the qualitative research approach, the most important aspect for the researcher is gaining a complex and rich understanding of the human experience and the socially constructed nature of reality (Archer et al., 2013). This study was based on a qualitative approach, concerned with the recording, analysis and uncovering of the deeper meaning and significance of human behaviour and experiences within the selected population (Babbie, 2015). This qualitative study was therefore guided by inductive reasoning as the research approach.

3.4.1 Inductive approach

According to Neumann (2003), Neuman and Robson (2014) and Saunders et al. (2009), the inductive approach draws its insights from observations and only proposes theories towards the end of the research process. Inductive research “involves the search for patterns from observation and the development of explanations – theories – for those patterns through series of hypotheses” (Bernard, 2011:7). Hypotheses and theories are not applied at the onset of inductive studies, thus allowing the researcher freedom in terms of developing or altering the direction of the study (Bryman, 2015). However, inductive research is not void of theories when objectives and research questions are formulated (Bryman, 2015). The inductive approach is founded on the development and generation of meanings from the collected data, in order to identify patterns and relationships for the construction of either a new theory or an already existing one (Saunders et al., 2012). The emergent theory can be used to address the research question by identifying emerging patterns, resemblances and regularities in the data in order to reach a conclusion (Bryman, 2015).

This research adopted the inductive approach to gain deeper insights into the information needs of caregivers based on their perspectives and experiences when dealing with patient care. As illustrated in Figure 3.2, the study utilised the bottom-up approach, where theory is developed at the end (Ormston et al., 2014).

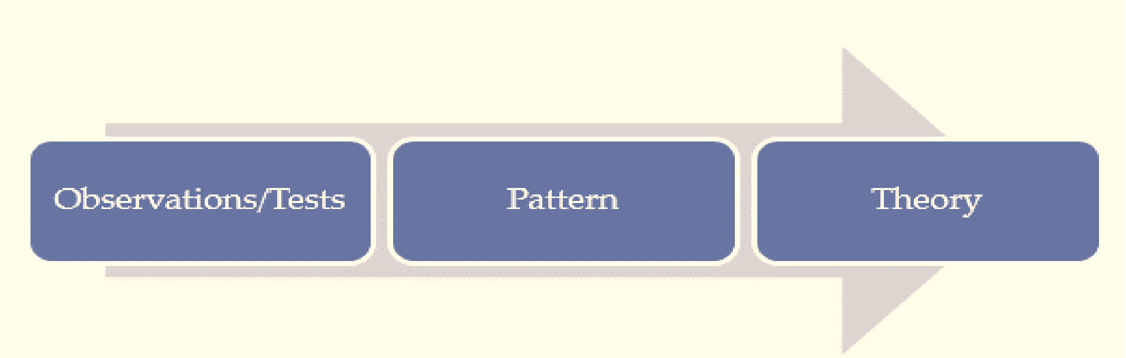


Figure 3.2: Inductive Approach
(Source: Ormston et al., 2014:52)

3.4.2 Deductive approach

The deductive approach is the opposite of the inductive approach and involves the development of hypothesis based on an existing theory, followed by the design of a research strategy to prove or disprove the theory (Bryman, 2015). It is best explained as starting with the conclusion and then using the evidence to support or reject the predetermined conclusion. Ormston et al. (2014) posit that deductive is reasoning from the *particular* to the *general*, and starts with an expected pattern that is tested against observations, as opposed to induction, which begins with observations and evidence, and then attempts to identify a pattern. A schematic representation of the deductive approach is illustrated below (Figure 3.3).

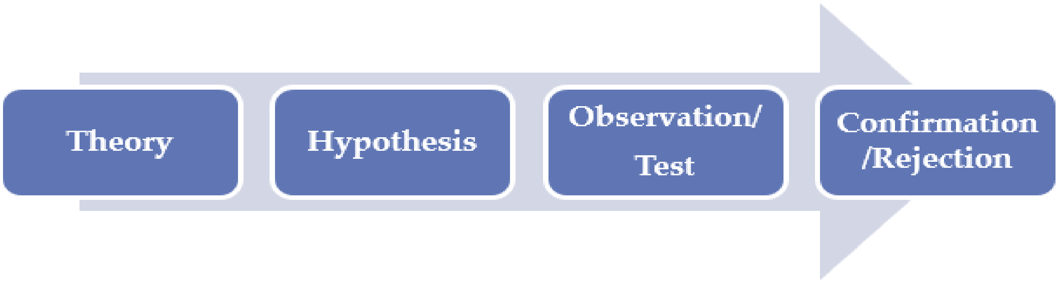


Figure 3.3: Deductive approach
(Source: Ormston et al. 2014:52)

3.4.3 Abductive approach

The abductive approach or reasoning sets out to address weaknesses of the inductive and deductive approaches and is based on a pragmatic perspective, that is, a mixed method approach (Monette et al., 2013). It is founded on the view that deductive reasoning lacks clarity in terms of selecting the theory to be tested through formulating hypotheses, and criticises inductive reasoning on the basis that empirical data are not completely sufficient for theory-building (Babbie, 2015).

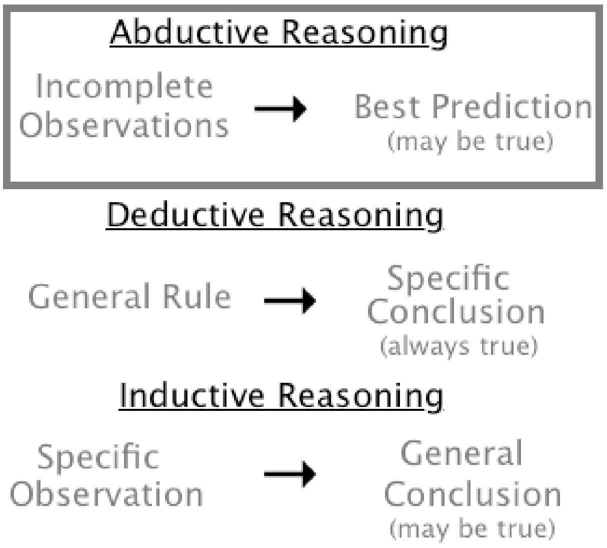


Figure 3.4: Abductive, deductive, and inductive reasoning
(Source: Monette et al., 2013)

However, abductive reasoning does share similarities with the deductive and inductive approaches, in that its application involves logical inferences and the construction of theories. The research process is initiated with unexplained ‘surprising facts’ or ‘puzzles’, and dedicated to the explanation of these puzzles. The abductive approach selects the best explanation after careful analysis of all existing alternatives, through the combination of both mathematical and cognitive reasoning (Monette et al., 2013).

3.5 Research design

Research design refers to the logical sequence that links the data to the research question. There are four categories of research design, namely explanatory, exploratory, descriptive, and conclusive. This study adopted a multiple-case study within an exploratory qualitative study, as it aimed is to explore the unmet information needs of caregivers during their work activities in order to identify and address the challenges of information needs during the course of performing their duty.

3.5.1 Qualitative research

Qualitative research is essentially a form of exploratory research, used to gain an understanding of underlying reasons, opinions, and motivations. Qualitative studies are based on perceptions, words, and feelings as opposed to quantitative research, which is based on numerical and mathematical data (Saunders et al., 2012). Qualitative data instruments include observations, experiments, interviews, focus group discussions and open ended questions in questionnaires (Eriksson & Kovalainen, 2015). This study employed formal qualitative techniques using in-depth interviews. A review of the current literature and available information on the topic was employed as the secondary data source.

3.5.2 Exploratory research

Exploratory research relies on primary and secondary research techniques, which may include qualitative approaches or formal qualitative techniques (Eriksson & Kovalainen, 2015). The research design used in this study is exploratory in nature as it focuses on exploring all aspect of the research subject matter, but it does not intend to offer final solutions or conclusions to the existing problem. Exploratory research provides a better and deeper understanding of the problem and proposed remedial actions will only emerge towards the end of the research process. In addition, exploratory research may also offer new knowledge on a topic that has not been addressed previously (Saunders et al., 2012).

This particular research design is motivated by the fact that literature concerning the information needs of caregivers in the South African context appears to be limited and not fully explored. Therefore, this study explored the information needs of a selection of caregivers in the Western Cape, South Africa.

3.5.3 Explanatory research

Explanatory research aims to explain the extent and nature of cause-and-effect relationships, and it is conducted to assess effects and impacts of certain changes on various processes and existing norms (Ormston et al., 2014). The most popular data collection method is the experiment and usually focuses on the explanation of patterns of relationships and causal links between variables (Collis & Hussey, 2014).

3.5.4 Descriptive research

Descriptive research is not strictly qualified as either quantitative or qualitative, but instead employs elements of both and often within the same study (Mackey & Gass, 2016). The term ‘descriptive research’ refers to the type of research question, design, and data analysis applied to a given topic. Survey research is commonly included in this type of measurement, but often goes beyond the descriptive statistics in order to draw inferences (Babbie, 2015). In descriptive research, the researcher aims to determine, describe, or identify *what is*, whereas analytical research attempts to establish *why it is* that way or *how* it came to be (Mackey & Gass 2016). The aim of descriptive research is to shed light on current issues or challenges through a data collection process that allows the description of the situation in more detail (Mackey & Gass, 2016).

3.5.5 Conclusive research

Conclusive research design aims to generate findings that will facilitate decision making and conclusions (Monette et al., 2013). Most popular methods of conclusive research include quantitative methods of data collection and data analysis, and are usually deductive in nature. Conclusive research design is further categorised into causal research and descriptive research.

3.6 Research strategy

Research strategy refers to the method that guides the researcher to investigate the research issue. It is a general design that aids the researcher in addressing and answering the research questions in a methodical way, and stipulates why a certain research strategy has been selected (Saunders et al., 2012). The research strategy guides the study in terms of collecting relevant background information and using appropriate data analysis techniques to arrive at a conclusion. Research strategies include literature review analyses, interviews, case study analyses, experiments, and surveys.

For this research, a qualitative survey strategy using interviews was selected for the collection of qualitative data and information.

3.6.1 Qualitative strategy

Interviews enable the collection of reliable and valid data necessary to achieve the objectives and aims of the research (Saunders et al., 2012). For this study, two non-governmental organisations (NGOs) using caregivers to assist with the care of patients were identified. These two NGOs were randomly selected by ‘cold’ calling them. Five NGOs recommended by people in the industry were approached, and only two NGOs were willing to participate in the research.

The participants included caregivers with similar characteristics who shared the same concerns and performed the same duties. Even though the participants might have had different backgrounds and experiences, the interviews were focused only on their caregiving experiences.

3.6.2 Sampling techniques

3.6.2.1 Population

A population is a set of entities in which all the measurements of interest to the practitioner or researcher are presented (Denscombe, 2014). A sample is defined “as a subset of the population” and must be representative of the population being studied in terms of size and bias (Goddard & Melville, 2001:34).

The population of this study was drawn from a selection of caregivers from two local NGOs, namely: i) Sherwood Park Special Care Centre (SPSCC); and ii) the ATKV Zonnebloem Old Age Home (ATKV OAH). Three private caregivers with no affiliation were also selected. The NGOs and the private caregivers were located in the Western Cape Province, South Africa, at the time of the study. The caregivers offered a range of care services such as frail-care, home-based care, and general care.

3.6.2.2 Sampling

Sampling refers to the process of selecting a representation of a population to collect data from (Levy & Lemeshow, 2013). Sampling refers to a particular principle employed in order to select members of a population that are to be included in the study (Fraley & Hudson, 2013). Because it is challenging to use an entire population for a particular study, techniques of statistical sampling were developed to acquire samples from the broader population.

The advantages of sampling include the following: i) it facilitates easier accessibility and manageability of the research; ii) it saves costs; III) it results in a higher rate of accuracy in the research findings; iv) it speeds up the data collection process; v) and it enables faster processing of the information (Levy & Lemeshow, 2013).

Sampling methods are categorised into probability and non-probability sampling (Saunders et al., 2012). With probability sampling, every member of the population has a fair chance of taking part in the research, and it includes stratified, systematic, simple, cluster and multistage sampling methods (Fraley & Hudson, 2013). Non-probability sampling means that members are selected in a non-random manner, thereby eliminating the chance of each member of the population to participate. Sampling methods included in non-probability are quota, purposive, snowball, and convenience sampling methods (Explorable.com, 2019). The target population represents a particular segment within the broader population.

3.6.2.3 Non-probability purposive sampling

Judgmental sampling is a non-probability sampling technique also known as purposive and authoritative sampling (Fellows & Liu, 2015). The advantage of purposive sampling is that a more representative sample can be selected to elicit more accurate results (Saunders et al., 2012). The implication of using non-probability sampling lies in the limitation of the generalisability of the study (Saunders et al., 2012). However, non-probability sampling allows the researcher to target people with the required information and relevant data are collected. The process involves the selection of specific individuals from the population based on their knowledge and judgment of the subject matter (Allison et al., 2016).

Non-probability purposive sampling was selected for this study. This sampling method produces a sample that is more representative of the population. The criteria for the selection were limited to caregivers who provide care services and who have experience in caregiving. The sampling frame was accessed via the two organisations, and the sampling size for this study was set to be anything from 15 to 21 caregivers.

3.6.3 Unit of analysis

The unit of analysis was subject to the non-probability sampling approach. The unit of analysis refers to the major entity under analysis in a study; the ‘what’ or ‘who’ being studied (Ritchie et al., 2013). Monette et al. (2013) state that the unit of analysis used in social research includes individuals, groups, social organisations, artefacts, and programmes. For this study, the unit of analysis was the caregiving services and the unit of observation was the selected group of caregivers from the SPSCC, ATKV OAH, and the three private caregivers. The caregivers were selected on the assumption that they were providing care services to a range of recipients, and that they might have experienced certain challenges in terms of information needs.

3.6.4 Unit of observation

The unit of observation was the 21 selected caregivers who provided care services to recipients.

3.7 Data collection

Data collection is the integral part of the research process and forms the basis on which a study is founded. Data collection methods include surveys, interviews, observations, documents, interviews, and participant research (Saunders et al., 2012). This study employed the individual interview as the primary data collection instrument (Appendix A).

3.7.1 Individual interview

One of the most common methods of data collection in qualitative research is the face-to-face individual interview (Saunders et al., 2009, 2012). Interviews enable the respondent to speak of himself or herself without the pre-allocation of responses by the researcher. This method of data collection was selected, as it is flexible and interactive. Furthermore, the repetitive process of gathering information, conducting the analysis, and testing the data draws the researcher closer to the phenomena being studied (Robson & McCartan, 2016).

The interview was based on an in-depth semi-structured style, and followed specific questions designed to answer the research questions of the study. Semi-structured questions were favoured over structured ones, as it allowed the researcher further probing and extracting of information (Galletta, 2013). Semi-structured interviews with open-ended questions offer respondents the opportunity to elaborate on the answers and provide more insight into the subject of research.

The interviews ranged between 20 and 30 minutes and were audio recorded by the researcher and assistants using a smartphone or audio recorder. Thereafter, the audio files were transcribed into MSWord format by the researcher. The assistants were informed of the aims of the study prior to data collection, and they were made aware of the importance of adherence to ethical principles.

3.7.2 Data collection process

The data collection process entailed the following steps: Permission was obtained from the management of SPSCC and ATKV OAH, as well as from the individual private caregivers to conduct research at the organisations (Appendix E; Appendix F). Once approval was received from Management, the participants were contacted by the manager/supervisor of the organisation to inform them of the study and determine their willingness to participate. After permission was obtained from the caregivers, the managers/supervisors of the organisations contacted the researcher to set up a date for conduct the interviews. Most of the caregivers agreed to participate; a few declined for personal reasons. The interviews were conducted on the premises of the organisations in a private room.

The private caregivers were contacted through a community worker in the Bo-Kaap area, who had a database for caregivers in the area. The researcher personally contacted private caregivers via telephone and explained the purpose of the study. Three private caregivers consented to participate in the study. After the caregivers agreed to participate in the study, a meeting was set up to conduct the interviews. The interviews were conducted at their homes. All participants were made aware of the ethics as indicated on the individual consent form, which was signed by each participant before commencement of the interviews (Appendix C). All participants were asked if they were comfortable with being recorded during the interview (data collection) process and all 21 participants affirmed positively.

The interviews were conducted using semi-structured questionnaires. The questions focused on the information needs of caregivers, caregiving practices, challenges faced on a daily basis, and the availability of resources and information resources to them. Issues pertaining to specific information services and collaboration with formal health professionals such as nurses and doctors were also highlighted.

This study used this method of data collection as it enabled the interpretation of the first-hand experiences of the caregivers (Saunders et al., 2012). Once the data collection process was completed, the researcher started the process of data analysis.

3.8 Data analysis

3.8.1 Qualitative data analysis

Qualitative data analysis relies on the analytical and critical thinking skills of the researcher; therefore, the generated results of a qualitative study cannot be repeated to produce the same results (Robson & McCartan, 2016). As mentioned, the data collected during the interviews were recorded via smartphone or audio recorder. Thereafter the audio files were transcribed into text format and kept in raw format. All data collected were then summarised, organised, and categorised to provide the researcher with a better understanding of the data and the development of themes. Qualitative data analysis was employed in this study by following three stages (Robson & McCartan, 2016).

The first stage comprised developing and applying codes. Coding has been defined as the organisation of data, where a code refers to a short phrase or word representing a particular idea or theme. Thereafter, meaningful titles were ascribed to each code. The second stage involved the identification of themes, patterns and relationships based on coding (Saunders et al., 2012). The final stage in the qualitative analysis process involved summarising the data. During this stage, the researcher attempted to link the findings of the study to the aims and objectives of the research (Smith & Firth, 2015). To support coding and thematic development, quotations from the transcriptions were used to highlight major themes that emerged from the findings.

3.9 Ethics

Ethics is defined as the “norms of conduct that distinguish between acceptable and unacceptable behaviour” (Resnik, 2015:1). The ethical principles comprise honesty, plagiarism, informed consent, and permission to publish (Myers & Klein, 2011). Researchers have to be diligent in the application of these ethical principles during the research process and ensure that the rights of individuals and institutions are preserved (Eriksson & Kovalainen, 2015). The ethical principle refers to the obligation of the researcher to respect each participant as a person capable of making an informed decision regarding participation and access to findings.

The aim and objectives of the study were explained in-depth to all caregivers who volunteered to participate in the study. Participants were provided with all necessary information to ensure a full understanding of the purpose of the study and their voluntary participation in the study.

Consent: Participants signed a consent form in which they agreed to participate in the study. They were informed of their right to withdraw from the study at any point (Appendix C).

Anonymity: Participants were assured of their anonymity in the study and that their personal details would be kept anonymous.

Confidentiality: In order to maintain the integrity of the data, all relevant research documents were safeguarded and accessed only by the researcher and supervisors involved in this study (Saunders et al., 2012). The information needs of the caregivers did not include any individual’s personal health records, and thus no personal health information was requested. Participants were also assured that their responses were confidential, would not be shared with other participants or the management of the organisation, and that data were stored electronically in password-protected files.

Honesty: The researchers adhered to honesty when they reported findings; no data were fabricated.

Integrity: The researchers adhered to all promises made to participants.

For this study, various ethical principles were considered. Consent was obtained from the management of SPSCC, ATKV OAH, as well as the private caregivers (Appendix E; Appendix F). Although the researcher obtained consent from the organisations and individuals, no data will be published without their permission.

3.10 Summary

This chapter provided a broad overview of the research methods adopted, including the research philosophy, research approach, research strategy, data collection techniques and data analysis method used for the study. For this study, an interpretivist epistemology was adopted, as there were multiple ways of looking at the phenomena under investigation. This study adopted the interpretivist paradigm, which relies on data collection methods such as small samples, in depth investigations and qualitative data.

An inductive approach was followed and a multiple-case study based on a non-random, purposive sample was employed. The sample consisted of twenty-one (21) caregivers in total, with eighteen (18) caregivers from the SPSCC and ATKV OAH, and three (3) private caregivers. The unit of analysis was identified as caregiving services and the unit of observation as the caregivers. Prior to the data collection process, permission was obtained from the management of the SPSCC, ATKV OAH, and private caregivers. Research was conducted at the premises of the organisations and at the homes of the private caregivers.

Data were collected using interviews with a semi-structured style. On completion of the data collection, which included audio recording, the interviews were transcribed and analysed. Data were then summarised, organised, and categorised to provide the researcher with a better understanding of the data and the development of themes.

The chapter ended with a discussion on ethics. The researcher ensured all participants of their anonymity in the study and confirmed that their responses were confidential. They were also assured of their right to withdraw from the study at any point.

The next chapter (Four) provides more information of the cases used for the research. The analysis of the interviews conducted during the research process is elaborated on, and the resultant findings and themes based on the analysis of the interviews are presented.

4. CHAPTER FOUR: ANALYSIS AND FINDINGS

4.1 Introduction

In this chapter, profiles of data sources, the data analysis process, and interpretation of findings are presented. The chapter provides the analysis of the interviews conducted with participants, and findings are formulated based on the responses of the 21 participants. For ease of reference, the problem statement, research questions, and aim of the study are again provided below. The chapters are divided into sections that discuss the case studies, present representative narratives of responses and corresponding findings, as well as related themes drawn from the analysis of the dataset. The chapter concludes with a summary of the findings. Related sub-research questions and the themes developed from the findings are also presented.

Research problem statement: The information needs and challenges relating to a lack of information available to caregivers are considerably unclear and unidentified in different contexts. It is therefore important to identify the information needs of caregivers in South Africa in order to improve their work conditions and the services they provide.

Aim of the study: The study aimed to explore the unmet information needs of caregivers in their work activities in order to identify and address the information need challenges during the course of performing their duties.

Primary research question:

PRQ: What are the unmet information needs of caregivers in South Africa?

Sub-research questions (SRQs):

SRQ 1.1: What are the work practices of caregivers and their related information needs in Cape Town, South Africa?

SRQ 1.2: What are the factors affecting unmet information needs of caregivers in Cape Town, South Africa?

SRQ 1.3: How are information resources made available to caregivers in Cape Town, South Africa?

SRQ 1.4: How do caregivers obtain/access alternative sources of information necessary for their care activities in Cape Town, South Africa?

4.2 The cases for this study

The cases studies include two Non-Governmental Organisations (NGOs) that employ caregivers to assist with the care of patients. These two NGOs were among five NGOs non-randomly selected in the industry, from which only two NGOs were willing to participate in the research study. The participating NGOs were: i) The Sherwood Park Special Care Cente; and ii) The ATKV Zonnebloem Old Age Home. The third case included three private caregivers with no affiliation.

4.2.1 Case A: Sherwood Park Special Care Centre (SPSCC)

Sherwood Park Special Care Centre (SPSCC) is situated in Sherwod Park, Western Cape and provides special care services to mentally handicapped children. The organisation has been established in 1984 and has been running from a residential property in Sherwood Park for the past 30 years. The SPSCC offers a pick-up and drop-off sevice to its clients with mini-buses specially equipped for the transportation of special needs children. The school caters for childen suffering from Attention Deficit Hypertension Disorder (ADHD), Cerebral Palsy (CP), and Down Syndrome (DC).

Caregivers at the organisaton have been specially trained to perform tasks such as cleaning and feeding the children, providing comfort as well as special activtities for the children. The organisation is administered by a committee and the caregivers receive training from the WCED who provide them with guidelines and tasks. Currently, SPSCC has four classrooms and a total of 40 children. Staff includes (eight) caregivers, (3) drivers, (1) caretaker and a manager. The participants from this case are referred to as Sherwood participants (SP) in this study.

4.2.2 Case B: The ATKV Zonnebloem Old Age Home (ATKV OAH)

The Afrikaanse Taal en Kultuur Vereeniging Zonnebloem Old Age Home (ATKV OAH) is situated in Zonnebloem area, Cape Town in the Western Cape and specialises in frail-care for the elderly. Currently, it is overseen by a supervisor, a committee and staff consisting of professional nurses, enrolled nursing assistants, (ENA) and caregivers.

Residents include frail-care patients, patients that suffer from dementia, cancer, age-related illnesses and those who are able to still take care of themselves, Services provided by the organisation include bathing, grooming, recreational activities, feeding, religious activiities, physiotherapy and general care services. The participants from this case are referred to as Zonnebloem Participants (ZP) in this study**.**

4.2.3 Case C: Private caregivers

The private caregivers who particiapated in this study include professional nurses who worked at hospitals and provide private care to patients. Their duties include the administration of medication, grooming and feeding clients, as well as doing basic household chores to make the care recipients more comfortable. The participants from this case are referred to as Private Participants (PP) in this study.

4.3 The study participants

In order to provide clear answers to the research questions, 21 participants were interviewed. The interviews were guided using an Interview guide (Appendix A). All the participants are caregivers, working with care recipients such as the elderly, sick and children with certain conditions. Five (5) SPSCC caregivers for mentally challenged children were categorised as the participants for Case A. Thirteen (13) ATKV OAH participants focusing on frail-care formed Case B. Three (3) private caregivers responsible for medication, feeding and grooming of their clients were collectively grouped as Case C.

Table 4.1 provides a detailed description of the participants in this study, including their years of experience, training, and duties.

Table 4.1: Descriptions of participants, including years of experience, training and duties

Participant	Experience	Training	Responsibilities/Duties
SP1	27 years	Certificate for mental health, special-care needs, caregiving courses and training	Administration and overseeing of all activities; co-ordinator of tasks for caregivers
SP2	5 years	Workshops for behaviour patterns, and in-house training at the centre	Performing basic activities in daily programme; feeding and cleaning (diaper changes) of children
SP3	4 months	Early Childhood Development (ECD) thee-year course	Plans programmes for children and daily activities for caregivers; feeding and cleaning of children
SP4	4-6 years	No formal training; attended workshops on the role of caregivers and how to deal with Cerebral Palsy and Down Syndrome children, in-house training	Cleaning (diaper changing) and feeding children and implementing daily activities
SP5	5 years	Underwent a frail-care course in Strandfontein; home-based care experience; completed courses in basic care-giving	Cleaning (diaper changing) and feeding children and implementing daily activities

Participant	Experience	Training	Responsibilities/Duties
ZP1	7 years	Basic care-giving course	Taking care of residents; feeding, washing, dressing and grooming residents; additional tasks include cleaning rooms, making beds, packing cupboards, giving medication
ZP2	5 months	Cape Learning Course (three months), covering how to bed wash, give medication, shower and feed patients; providing students with a basic overview of some illnesses (Alzheimer's, diabetes, and dementia)	Taking care of residents; feeding, dressing, washing and grooming residents; additional tasks include cleaning rooms, making beds, packing cupboards, giving medication, doing laundry and dressing wounds
ZP3	2 months	Cape Care Nursing Foundation for home-based care course (four months), covering home-based care only and wound cleaning and dressing; no extra workshops or training completed since	Taking care of residents; feeding, washing, dressing and grooming residents; additional tasks include cleaning rooms, making beds, packing cupboards, giving medication and dressing wounds
ZP4	4 years	Cape Care Learning Foundation caregiver course	Taking care of residents; feeding, washing, dressing and grooming residents; additional tasks include cleaning rooms, making beds, packing cupboards, giving medication and dressing wounds
ZP5	16 years	Wynberg Medical Centre carer course	Taking care of residents; feeding, washing, dressing and grooming residents; additional tasks include cleaning rooms, making beds, packing cupboards, giving medication, dressing wound and lifting patients
ZP6	5 years	Cape Learning Foundation	Taking care of residents; feeding, washing, dressing and grooming residents; additional tasks include cleaning rooms, making beds, packing cupboards, giving medication, dressing wounds and lifting patients
ZP7	2.5 years	Basic carer course (institution not mentioned)	Taking care of residents; feeding, washing, dressing and grooming residents; additional tasks include cleaning rooms, making beds, packing cupboards, giving medication, dressing wounds and lifting patients
ZP8	10 years	Bellville College for Homecare (caring for AIDS patients and babies); Kaylen Care; Monte Rosa (five years as caregiver)	Taking care of residents; feeding, dressing, washing and grooming residents; additional tasks include cleaning rooms, making beds, packing cupboards, giving medication, dressing wounds and lifting patients

Participant	Experience	Training	Responsibilities/Duties
ZP9	2 years	Basic Caregiving course	Taking care of residents; feeding, dressing, washing, grooming residents; additional tasks include cleaning rooms, making beds, packing cupboards, giving medication, dressing wounds and lifting patients
ZP10	7 years	Basic Caregiver course Tourism Management course	Taking care of residents; feeding, dressing, washing, grooming residents; additional tasks include cleaning rooms, making beds, packing cupboards, giving medication, dressing wounds and lifting patients
ZP11	15 years	Morrison Hospital, nursing course	Taking care of residents; feeding, dressing, washing, grooming residents; additional tasks include cleaning rooms, making beds, packing cupboards, giving medication, dressing wounds, lifting patients, taking blood pressure
ZP12	1.5 years	Cape Town Community College basic care course	Taking care of residents; feeding, dressing, washing, grooming residents; additional tasks include learning rooms, making beds, packing cupboards, giving medication, dressing wounds, lifting patients
ZP13	Not mentioned	Carer course in Parrow	Taking care of residents; feeding, dressing, washing, grooming residents; additional tasks include learning rooms, making beds, packing cupboards, giving medication, dressing wounds, lifting patient
PP1	+20 years	Professional nurse	Counsellor and co-ordinator of a NGO caregiver association; recruiting caregivers to jobs in the community; attends workshops and trains caregivers
PP2	7 years	Training	Domestic chores, cooking, cleaning, taking care of patients, feeding, showering, giving medication
PP3	9 years / 8 years	Queen Elizabeth Central Hospital (six months), nursing course / Private caregiver	Blood work, assistant in theatre; taking care of residents; feeding, dressing, washing and grooming residents; additional tasks include cleaning rooms, making beds, packing cupboards, giving medication, dressing wounds and lifting patients

4.4 Data collection process

The interview appointments were made via phone calls and confirmed on email in order to set out available time for the interview process. Once the venue, date and time were ascertained, the researcher arrived at the venue on time. Prior to the interview process, the researcher provided a basic overview and introduction of the study to the participants. The interview process was explained to participants in advance in a relaxed environment, which took place inside private rooms at the two participating organisations.

The interviews for the private caregivers took place at their respective homes. This arrangement allowed for free flowing interaction between the interviewer and interviewees. The participants were assured of their right to provide consent before the interview started, and they were informed of their right to withdraw from the study at any given time.

Before commencement of the interview process, a consent form was signed by the participants. Permission to audio record the interview was also sought before commencement and was noted and acknowledged with a verbal consent. As soon as permission was granted, participants were asked to introduce themselves and provide some background information on their training and years of experience.

Participants were generally eager to provide information and no difficulties were experienced during this process. Main questions were specifically developed for the interview, and in some cases follow-up questions were required during the interview process to facilitate further probing to obtain useful information relevant to the study.

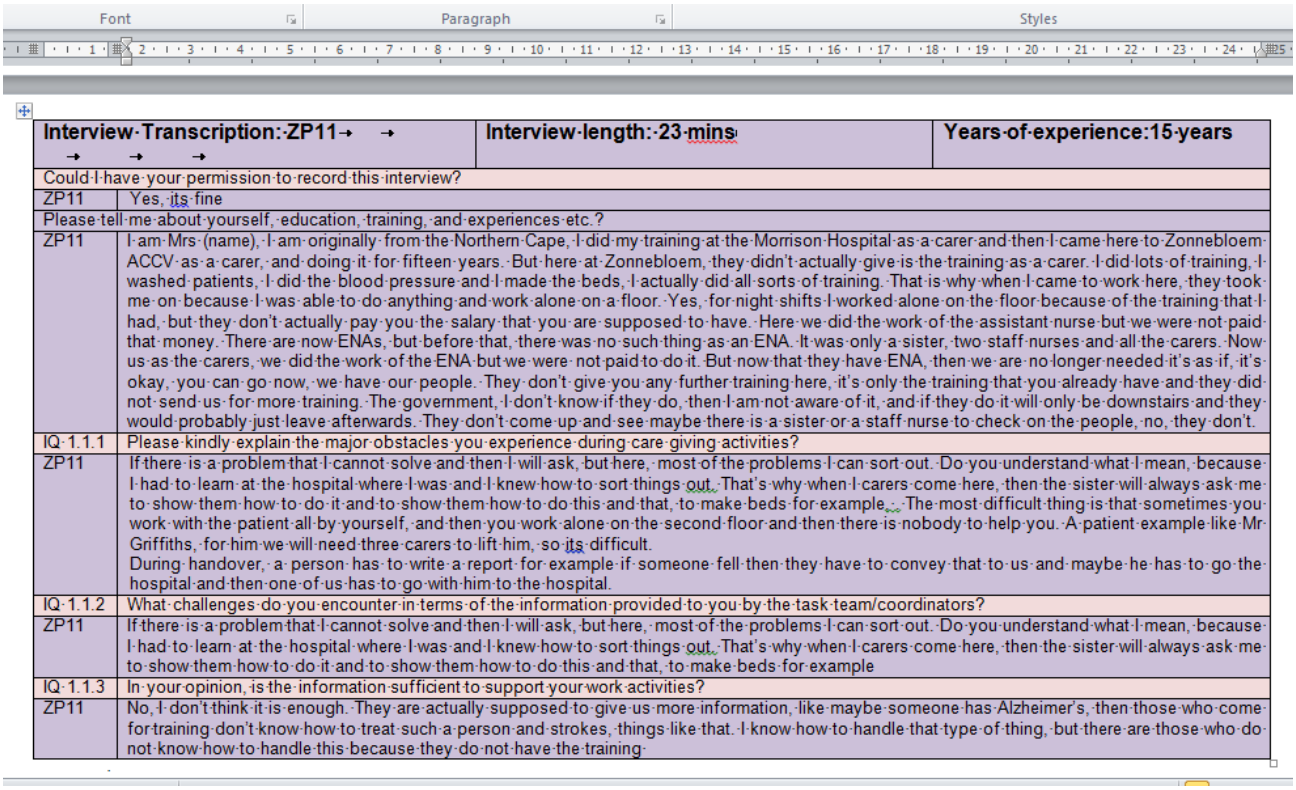
The researcher stipulated a timeframe of 30 minutes per interview, but some interviews lasted for over 60 minutes. The average time per interview was 25 minutes. At the end of the interviewing process, participants were assured of their anonymity in the study report and their participation was duly acknowledged. All interview conversations were saved and uploaded on a laptop that is password protected, and saved on the personal computer of the researcher.

4.5 Data analysis process

4.5.1 Transcription process

A verbatim transcription was carried out on the interview data. In order to ensure accurate transcription of wording in the interviews, audio tracks were replayed several times and listened to carefully.

A sample of a transcription is given in Figure 4.1.



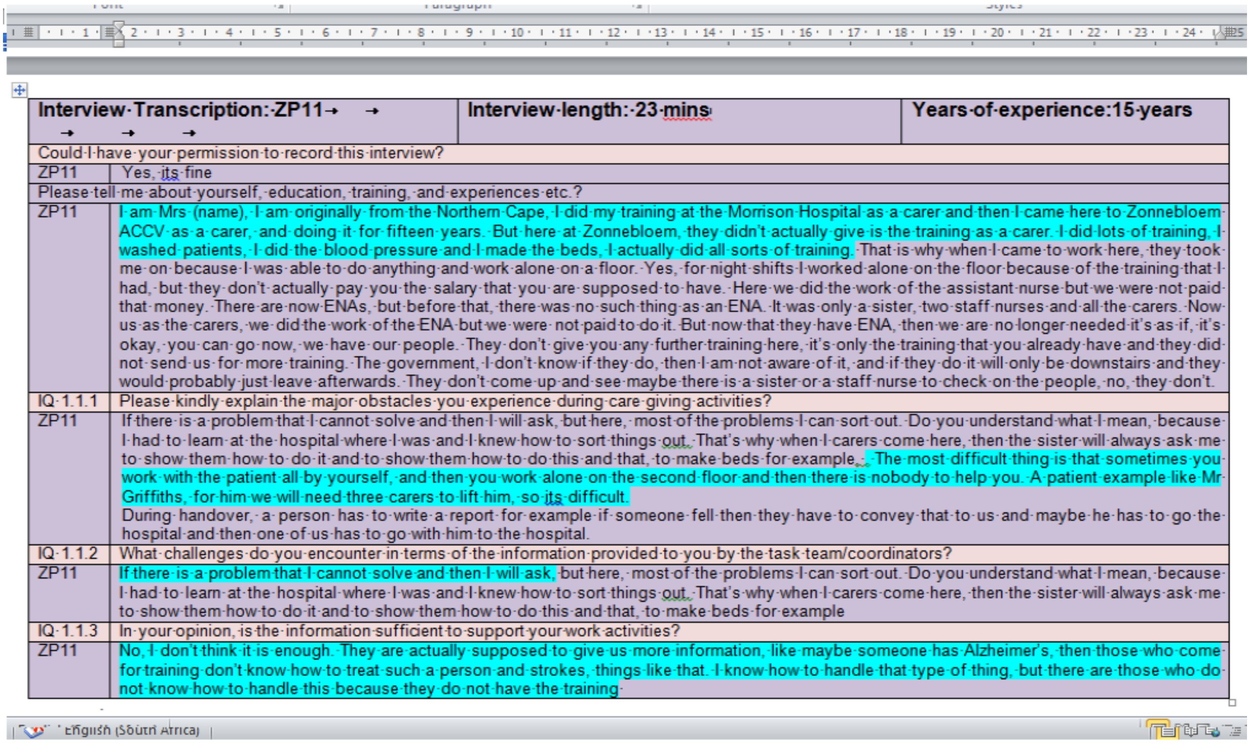
Interview Transcription: ZP11	Interview length: 23 mins	Years of experience:15 years
Could I have your permission to record this interview?		
ZP11	Yes, its fine	
Please tell me about yourself, education, training, and experiences etc.?		
ZP11	I am Mrs (name), I am originally from the Northern Cape, I did my training at the Morrison Hospital as a carer and then I came here to Zonnebloem ACCV as a carer, and doing it for fifteen years. But here at Zonnebloem, they didn't actually give is the training as a carer. I did lots of training, I washed patients, I did the blood pressure and I made the beds, I actually did all sorts of training. That is why when I came to work here, they took me on because I was able to do anything and work alone on a floor. Yes, for night shifts I worked alone on the floor because of the training that I had, but they don't actually pay you the salary that you are supposed to have. Here we did the work of the assistant nurse but we were not paid that money. There are now ENAs, but before that, there was no such thing as an ENA. It was only a sister, two staff nurses and all the carers. Now us as the carers, we did the work of the ENA but we were not paid to do it. But now that they have ENA, then we are no longer needed it's as if, it's okay, you can go now, we have our people. They don't give you any further training here, it's only the training that you already have and they did not send us for more training. The government, I don't know if they do, then I am not aware of it, and if they do it will only be downstairs and they would probably just leave afterwards. They don't come up and see maybe there is a sister or a staff nurse to check on the people, no, they don't.	
IQ 1.1.1	Please kindly explain the major obstacles you experience during care giving activities?	
ZP11	If there is a problem that I cannot solve and then I will ask, but here, most of the problems I can sort out. Do you understand what I mean, because I had to learn at the hospital where I was and I knew how to sort things out. That's why when I carers come here, then the sister will always ask me to show them how to do it and to show them how to do this and that, to make beds for example. The most difficult thing is that sometimes you work with the patient all by yourself, and then you work alone on the second floor and then there is nobody to help you. A patient example like Mr Griffiths, for him we will need three carers to lift him, so its difficult. During handover, a person has to write a report for example if someone fell then they have to convey that to us and maybe he has to go the hospital and then one of us has to go with him to the hospital.	
IQ 1.1.2	What challenges do you encounter in terms of the information provided to you by the task team/coordinators?	
ZP11	If there is a problem that I cannot solve and then I will ask, but here, most of the problems I can sort out. Do you understand what I mean, because I had to learn at the hospital where I was and I knew how to sort things out. That's why when I carers come here, then the sister will always ask me to show them how to do it and to show them how to do this and that, to make beds for example	
IQ 1.1.3	In your opinion, is the information sufficient to support your work activities?	
ZP11	No, I don't think it is enough. They are actually supposed to give us more information, like maybe someone has Alzheimer's, then those who come for training don't know how to treat such a person and strokes, things like that. I know how to handle that type of thing, but there are those who do not know how to handle this because they do not have the training	

Figure 4.1: Sample of transcription

4.5.2 Thematic analysis

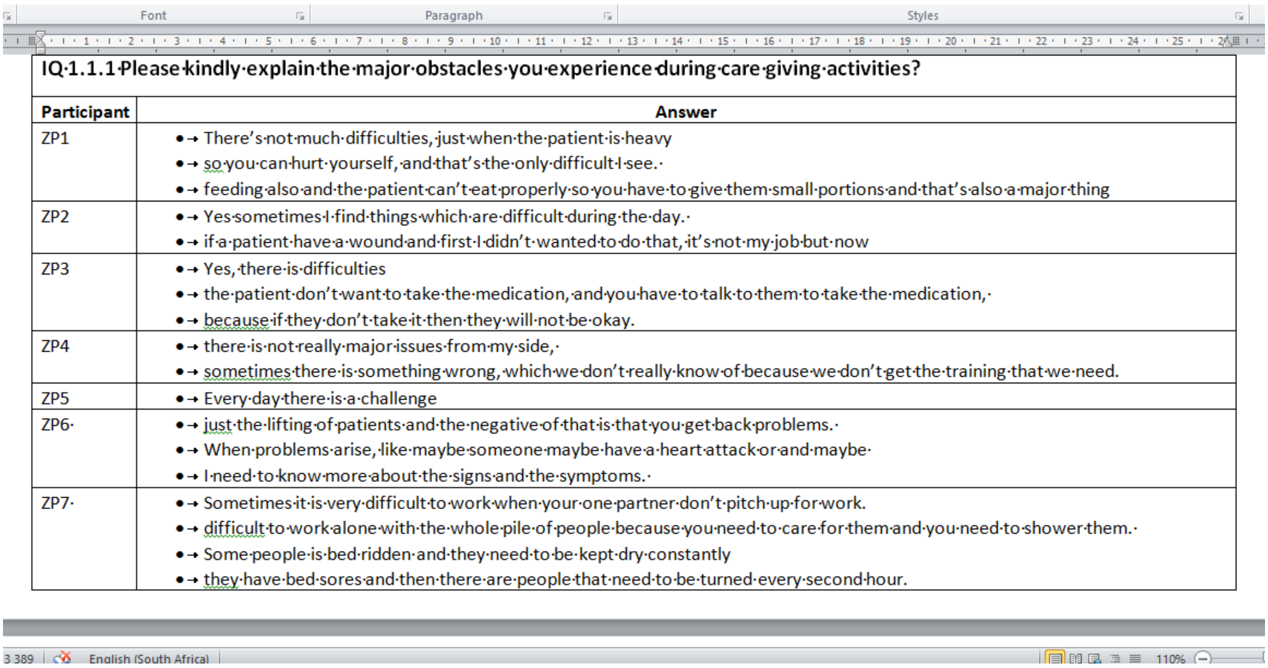
The data transcripts were printed on hard copies after data were correctly transcribed, where after the process of coding and analysis commenced, applying the thematic analysis process. The first step in thematic analysis comprises systematic reading of all transcribed data (Saunders et al., 2012). All transcripts were thoroughly read through by the researcher to grasp and understand the content and context of the responses. Responses captured which provided answers to interview questions were highlighted (Figure 4.2).

Relevant keywords and phrases directly linked to an interview question were coded with a descriptive label. After the process of coding was done for one transcript, the same process was applied to the next transcript, and this process continued until all the transcripts were coded. Thereafter, all highlighted themes were combined into a single document and grouped under the interview question (Saunders et al., 2012) (Figure 4.3).



<table>
<tr><th colspan="2">Interview Transcription: ZP11</th><th>Interview length: 23 mins</th><th>Years of experience:15 years</th></tr>
<tr><td colspan="4">Could I have your permission to record this interview?</td></tr>
<tr><td>ZP11</td><td colspan="3">Yes, its fine</td></tr>
<tr><td colspan="4">Please tell me about yourself, education, training, and experiences etc.?</td></tr>
<tr><td>ZP11</td><td colspan="3">I am Mrs (name), I am originally from the Northern Cape, I did my training at the Morrison Hospital as a carer and then I came here to Zonnebloem ACCV as a carer, and doing it for fifteen years. But here at Zonnebloem, they didn't actually give is the training as a carer. I did lots of training, I washed patients, I did the blood pressure and I made the beds, I actually did all sorts of training. That is why when I came to work here, they took me on because I was able to do anything and work alone on a floor. Yes, for night shifts I worked alone on the floor because of the training that I had, but they don't actually pay you the salary that you are supposed to have. Here we did the work of the assistant nurse but we were not paid that money. There are now ENAs, but before that, there was no such thing as an ENA. It was only a sister, two staff nurses and all the carers. Now us as the carers, we did the work of the ENA but we were not paid to do it. But now that they have ENA, then we are no longer needed it's as if, it's okay, you can go now, we have our people. They don't give you any further training here, it's only the training that you already have and they did not send us for more training. The government, I don't know if they do, then I am not aware of it, and if they do it will only be downstairs and they would probably just leave afterwards. They don't come up and see maybe there is a sister or a staff nurse to check on the people, no, they don't.</td></tr>
<tr><td>IQ 1.1.1</td><td colspan="3">Please kindly explain the major obstacles you experience during care giving activities?</td></tr>
<tr><td>ZP11</td><td colspan="3">If there is a problem that I cannot solve and then I will ask, but here, most of the problems I can sort out. Do you understand what I mean, because I had to learn at the hospital where I was and I knew how to sort things out. That's why when I carers come here, then the sister will always ask me to show them how to do it and to show them how to do this and that, to make beds for example. . The most difficult thing is that sometimes you work with the patient all by yourself, and then you work alone on the second floor and then there is nobody to help you. A patient example like Mr Griffiths, for him we will need three carers to lift him, so its difficult.
During handover, a person has to write a report for example if someone fell then they have to convey that to us and maybe he has to go the hospital and then one of us has to go with him to the hospital.</td></tr>
<tr><td>IQ 1.1.2</td><td colspan="3">What challenges do you encounter in terms of the information provided to you by the task team/coordinators?</td></tr>
<tr><td>ZP11</td><td colspan="3">If there is a problem that I cannot solve and then I will ask, but here, most of the problems I can sort out. Do you understand what I mean, because I had to learn at the hospital where I was and I knew how to sort things out. That's why when I carers come here, then the sister will always ask me to show them how to do it and to show them how to do this and that, to make beds for example</td></tr>
<tr><td>IQ 1.1.3</td><td colspan="3">In your opinion, is the information sufficient to support your work activities?</td></tr>
<tr><td>ZP11</td><td colspan="3">No, I don't think it is enough. They are actually supposed to give us more information, like maybe someone has Alzheimer's, then those who come for training don't know how to treat such a person and strokes, things like that. I know how to handle that type of thing, but there are those who do not know how to handle this because they do not have the training</td></tr>
</table>

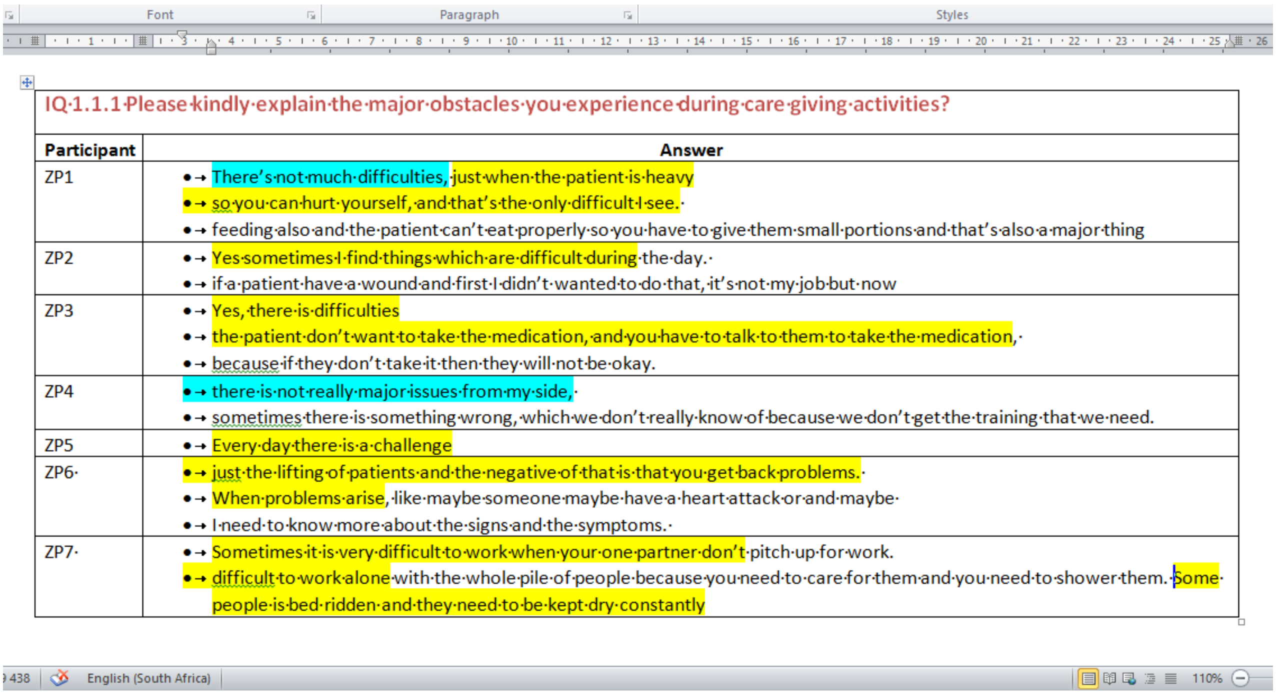
Figure 4.2: First stage of coding



<table>
<tr><th colspan="2">IQ 1.1.1 Please kindly explain the major obstacles you experience during care giving activities?</th></tr>
<tr><th>Participant</th><th>Answer</th></tr>
<tr><td>ZP1</td><td>• There's not much difficulties, just when the patient is heavy
• so you can hurt yourself, and that's the only difficult I see.
• feeding also and the patient can't eat properly so you have to give them small portions and that's also a major thing</td></tr>
<tr><td>ZP2</td><td>• Yes sometimes I find things which are difficult during the day.
• if a patient have a wound and first I didn't wanted to do that, it's not my job but now</td></tr>
<tr><td>ZP3</td><td>• Yes, there is difficulties
• the patient don't want to take the medication, and you have to talk to them to take the medication,
• because if they don't take it then they will not be okay.</td></tr>
<tr><td>ZP4</td><td>• there is not really major issues from my side,
• sometimes there is something wrong, which we don't really know of because we don't get the training that we need.</td></tr>
<tr><td>ZP5</td><td>• Every day there is a challenge</td></tr>
<tr><td>ZP6</td><td>• just the lifting of patients and the negative of that is that you get back problems.
• When problems arise, like maybe someone maybe have a heart attack or and maybe
• I need to know more about the signs and the symptoms.</td></tr>
<tr><td>ZP7</td><td>• Sometimes it is very difficult to work when your one partner don't pitch up for work.
• difficult to work alone with the whole pile of people because you need to care for them and you need to shower them.
• Some people is bed ridden and they need to be kept dry constantly
• they have bed sores and then there are people that need to be turned every second hour.</td></tr>
</table>

Figure 4.3: Coding under interview questions

Once this stage was completed, the researcher further highlighted similar words and themes under each interview question in order to develop the findings for the study (Figure 4.4).



IQ 1.1.1 Please kindly explain the major obstacles you experience during care giving activities?

Participant	Answer
ZP1	- There's not much difficulties, just when the patient is heavy - so you can hurt yourself, and that's the only difficult I see. - feeding also and the patient can't eat properly so you have to give them small portions and that's also a major thing
ZP2	- Yes sometimes I find things which are difficult during the day. - if a patient have a wound and first I didn't wanted to do that, it's not my job but now
ZP3	- Yes, there is difficulties - the patient don't want to take the medication, and you have to talk to them to take the medication, - because if they don't take it then they will not be okay.
ZP4	- there is not really major issues from my side, - sometimes there is something wrong, which we don't really know of because we don't get the training that we need.
ZP5	- Every day there is a challenge
ZP6	- just the lifting of patients and the negative of that is that you get back problems. - When problems arise, like maybe someone maybe have a heart attack or and maybe - I need to know more about the signs and the symptoms.
ZP7	- Sometimes it is very difficult to work when your one partner don't pitch up for work. - difficult to work alone with the whole pile of people because you need to care for them and you need to shower them. Some people is bed ridden and they need to be kept dry constantly

Figure 4.4: Coding with highlights

4.6 Respondent narratives and findings

In the following sub-sections, narratives of relevant interview responses from the data collection process are presented. Based on the responses of the 21 participants, findings were drawn from each interview question. The interviews were conducted at the two organisations of the caregivers as well as the homes of the private caregivers. Thereafter, the interviews were transcribed, wherein keywords and key phrases were identified and coded accordingly. The coded keywords and phrases were then summarised and further developed into categories. From the categories, themes emerged, and relationships were established among similar categories.

To show a logical flow of inference of the findings, this section further presents the research questions, sub-research questions, and interview questions in relation to the summary of responses and corresponding findings deduced through the interpretation of analysis from the responses in subsequent sub-sections.

PRQ: What are the unmet information needs of caregivers in South Africa?

SRQ 1.1: What are the work practices of caregivers and their related information needs in Cape Town, South Africa?

Interview questions (IQs) were designed to focus on determining the work practices of caregivers in South Africa and the related information requirements. The interview questions explore aspects of daily caregiving activities, information required before and in the process of attending to clients, information channel between caregiver and care recipients, and situations where additional information support is required while performing their duties. The focused interview questions together with the corresponding responses and deduced findings are further presented in this section.

IQ 1.1.1: Please explain the major obstacles you experience during care giving activities.

The participants narrated different experiences of challenges faced in their line of care duty. This section presents some specific challenges highlighted by the participants. Some of the participants agreed that they do experience some sort of difficulty or challenge in their daily tasks. Many of the difficulties are related to a fear of back injuries as a result of lifting heavy patients. ZP1 stated that, “There’s not much difficulties, just when the patient is heavy… so you can hurt yourself” (Appendix B1). Some of the participants (ZP1, ZP3, ZP6) indicated that the obstacles they experience are related to a lack of cooperation of the patient and an inability to deal with difficult situations (Appendix B1).

PP3 stated that, “The challenges are co-operation with the patient, that is the biggest challenge, because there are other patients used to his family” (Appendix B1). SP3 and SP4 supported PP3 in that tasks are difficult when they do not know how to handle a patient and how to handle the situation (Appendix B1).

Most of the participants who are involved in frail-care of elderly individuals highlighted that their most challenging duties are those related to treatment of bedsores and handling violent patients, whereas the private caregivers mostly related difficulty of having too many duties placed on them. Caregivers who work with children also corresponded with difficulties relating to lifting children. Some participants related a lack of knowledge about medication, treatment options, signs, and symptoms of illnesses as obstacles in performing their daily tasks optimally. ZP6 said that, “When problems arise, like maybe someone maybe have a heart attack or… and maybe I need to know more about the signs and the symptoms” (Appendix B1). SP4 indicated the following: “Children that have a fit, different types, and you have to handle each one in its own way” (Appendix B1). This is confirmed by ZP7 who also mentioned that, “Sometimes it makes it difficult for me yes, because I don’t understand what’s going on around me… I can’t just make the decision if I don’t know” (Appendix B1).

IQ 1.1.2: What challenges do you encounter in terms of the information provided to you by the task team/co-ordinators?

This section provides some of the challenges faced by the caregivers in terms of the information provided to them by the co-ordinators or task team. Most of the caregivers (15 of 21) confirmed that they face challenges with the information provided to them. Most of the challenges are related to not receiving sufficient information to do the task. ZP3 said, “If they give us… they don’t give us the full information” and SP5 indicated that, “it’s not enough” (Appendix B2). SP1 also confirmed this by stating, “If they give you a task, and then you feel that the time is not enough for you to master that particular thing” (Appendix B2). Similarly, SP2 argued that, “It’s not enough, I would like to know more about how to deal with the child, because you don’t know what that person needs right now” (Appendix B2). This is supported by ZP5 who confirmed a lack of knowledge, stating, “…and you don’t know what is going to happen during the day” (Appendix B2).

PP2 mentioned that her personal challenges are related to not knowing how to use a computer and sites such as Google, and that this would alleviate the challenge of the lack of information. SP4, SP5, SP3, PP3, ZP7, and ZP4 indicated that they do not encounter any real challenges in terms of the information provided to them. ZP4 related her challenges to a lack of proper equipment (Appendix B2).

IQ 1.1.3: In your opinion, is the information sufficient to support your work activities?

The majority of participants (ZP1, ZP2, ZP3, ZP4, ZP5, ZP6, ZP7, PP2, SP1, ZP9, PP1, SP2, SP3, SP4, SP5) confirmed that the information is not enough to support their work activities (Appendix B3). SP2 said, “It’s not enough, I’d like to know what to really do with this child, because there is something more that you can do for the child, it’s better to learn more” (Appendix B3), which is confirmed by SP3 who said, “No, I don’t think it is enough, like they give you something and then you have to elaborate on it though I want to have more activities and more ideas of how to further develop their skills” (Appendix B3). PP1 said:

> “No it isn’t, I need to learn more, but this is very risky to work as a caregiver when you know that you do not have the full information about the job. I need to have my own knowledge, and my own qualifications about this job” (Appendix B3).

ZP7 further added: “No, it’s very difficult, because it is not always the same you see” (Appendix B3). ZP5 confirmed that more information was needed to complete their tasks as new information is always being discovered: “We need more because everything changes outside, people get wiser outside" (Appendix B3). Similarly, ZP4 said the following: "No, we do not get a lot of information. A lot of people here with different types of sickness, we would like them to tell us that… we don't actually know what to do" (Appendix B3). ZP3 argued, "No, it's not enough, because there are other things we don't know" (Appendix B3). ZP1 followed up by stating that, "We need to get more information about what we need to do" (Appendix B3). ZP4 and ZP8 expressed their concerns regarding the lack of information about the patient/client's illnesses and how it impacts on their health directly as they are not informed of their illnesses or are not told that a patient is sick.

Thus, the majority of caregivers (15 of 21) are of the opinion that information is not enough to support their activities and express a need to want to learn more.

IQ 1.1.4: What do you do when you do not have enough information to attend to a client?

Most of the respondents from Zonnebloem as well as the private caregivers (ZP1, ZP2, ZP3, ZP5, ZP6, ZP8, ZP9, ZP10, PP3, PP1) confirmed that they seek help and assistance from medical staff such as nurses or the sisters in charge. ZP2 said, "The sister or the staff nurse in charge, I will ask one of the carers or, I'll go ask for help" (Appendix B4). Similarly, ZP5 stated: "I go to the sister, staff nurse, then ENAs also, then they will see to the problem and they will come and show us" (Appendix B4). Likewise, ZP4 said: "I don't know but mostly we go to the staff nurse or the sister" (Appendix B4). PP1 confirmed this by saying, "If I don't know, then I know a lot of people in the medical field and I will phone one of my ex-colleagues" (Appendix B4). PP3 mentioned that, "I am connected to a lot of sisters in charge and nurses; I call them if I got a problem" (Appendix B4).

Some participants (ZP2, ZP7, ZP10, SP1, SP2, SP3, SP4) sought assistance from their colleagues. ZP7 stated that, "I talk amongst my other colleagues, we brainstorm and look for a solution" (Appendix B4). SP1 affirmed that they will have "a meeting with the carers for what their needs are" (Appendix B4). SP2 also confirmed that she will "talk to my colleague" (Appendix B4), similar to SP3 who indicated, that she will "speak to another carer and find out if they don't have a different idea or a different view on the situation or the challenge that I am facing" (Appendix B4). Some participants (SP2, SP4, SP5, PP1) indicated that they use their own ideas and observations to solve a problem. SP2 said, "Sometimes I use my own ideas" (Appendix B4). Similarly SP4 and SP5 respectively said, "I use my own initiative" and you "use your own mind and use own ideas" (Appendix B4). Only

SP3 indicated that, “I will go to Google” if “I do not have enough information” (Appendix B4). The private caregivers (PP1, PP2, PP3) confirmed that they communicate freely with the family members who are an important source of information when they need more information. PP1 said, “We ask for as much questions as possible to the relatives”, while PP3 stated, “I ask the family” (Appendix B4).

IQ 1.1.5: In your opinion, does/will the lack of adequate information affect your work activities as caregivers?

This question deals with how caregivers think the lack of information will affect their work. The majority of participants (ZP1, ZP2, ZP3, ZP4, ZP5, ZP6, ZP7, ZP8, ZP9, ZP10, PP1, PP2, PP3, ZP13, SP1, SP2) agreed that a lack of information will impact negatively on their caregiving activities. ZP1 said, “Because I did it the way you wanted to do it and then it doesn’t work, then I am in the wrong, it is a problem” (Appendix B5). ZP2 confirmed: “Yes, it will affect my work” (Appendix B5). ZP5 supported these views that the lack of information is a concern for her, “because people’s lives are at stake” (Appendix B5). This is shared by ZP8, who felt that the lack of information exposes caregivers and patients to health risks: “Definitely yes, because I cannot go to a patient and I don’t know what is going on there. I put myself and the patient at risk, because I don’t know what types of illnesses that patient has, they don’t tell us” (Appendix B5). The above are some of the concerns of caregivers who feel that the lack of information exposes both their patients and themselves to health risks.

The second concern highlighted by caregivers is the lack of medical information, and how they feel it affects their caregiving duties. For example, PP3 said, “If you know nothing about something, you cannot work exactly the way you are supposed to work, because you don’t know nothing, especially the medical stuff” (Appendix B5). PP2 said concerning medication, “Because I can’t do that alone, I need someone who is going to explain to me about the medications because I must know exactly what kind of tablet I am giving to” (Appendix B5). ZP5 stated that, “Medical information I think is the first thing we must know... To know about medication will be a good idea - we know what to do if they have pain or for instance” (Appendix B5). ZP4 argued that, “I think if we should know more of how to go about it. In terms of medical history, doing what the ENA does or what the staff nurse does, I think it will help more actually” (Appendix B5). However, three participants (SP3, SP4, SP5) indicated that it does not affect their work activities in any way: “I don’t think so” (Appendix B5, SP5).

SRQ 1.2: What are the factors affecting unmet information needs of caregivers in Cape Town, South Africa?

The objective of this question was to determine the factors affecting unmet information needs of caregivers during the course of their duty. Interview questions were designed to focus on the challenges caregivers experience in the course of their duty, sufficiency of information for a specific task, measures taken when information is deemed inadequate, and impact of lacking the necessary information in their work activities. The focused interview questions together with the corresponding responses and deduced findings are further presented in this sub-section.

IQ 1.2.1: Please describe the information you require before and during the course of attending to a client.

Background information highlighted by participants includes information relating to e.g. diet, as SP2 said, “I want to know about his background, what kind of food he can’t eat” (Appendix B6). PP3 indicated that, “I have to know what time he eats, he must have a protocol” (Appendix B6). ZP1 also added that she needs to know: “Do you eat by yourself? Do you drink fluids by yourself? All that things you need to find out before we start working on our patients?” (Appendix B6). Most of the participants (ZP2, ZP6, ZP8, ZP9, ZP10, PP1, PP3, SP2, SP3, SP4, SP5) indicated that they need to know the medical background and diagnosis of the patients before they attend to them in addition to the types of medication that that patient is taking. ZP2 said, “I need medical background” (Appendix B6) and PP1 stated that s/he needs to know “What is the condition? How is the health” (Appendix B6). Similarly, PP3 said, “The problem of the patient, how it started, how he is cooperating, the body signs” (Appendix B6). SP4 added: “I need to know the diagnosis of the child, the obstacles that hinder the development of the child” (Appendix B6), while SP2 stated: “What kind of disability, if he is on tablets and how to give it” (Appendix B6).

These responses show that caregivers should have access to the medical background of the patients they are attending to in order to perform their duties optimally. ZP4 said, “It’s just [a need to know] how you treat the person, basically how to handle the clients” (Appendix B6). It appears that the major concern of caregivers is that they need the basic protocol and daily routine of the patient as well as medical information before they start their duties.

All of the responses from the participants again confirm that they require personal and medical background of patients while they are working with them. Useful information includes establishing whether the client is able to eat and go to the bathroom by themselves and if the client is mobile. ZP9 said, “I feel like we need to be informed about everything about that client… and we need to know what is going on in that person’s life” (Appendix B7). SP2 responded as follows: “What I need to do with him, if he can’t move then I put him in his sitting position in his buggy” (Appendix B7). ZP7 stated that she needs to know about the temperament of the patient: “What kind of person that person is, like is he grumpy, easily agitated? How do I like calm that person when they are in a situation” (Appendix B7).

IQ 1.2.2: What type of information do you have access to during your caregiving activities?

Many respondents (ZP1, ZP2, ZP3, ZP4, ZP5, ZP6, SP3, SP4, SP4, SP5) said that the only information they have access to is that which is provided to them by the supervisors, sisters in charge, nurses and ENAs and in the medical file. ZP1 said, “We don’t have, we are not allowed to, ask our patients in and out. We are not allowed to work with medication… We will ask the staff nurse and staff sister” (Appendix B8). ZP2 stated that, “I will look in the folder” (Appendix B8), and ZP6 indicated that, “only the knowledge that I read from the medical file” (Appendix B8). PP1, PP2, and PP3 mentioned they have access to medical professionals, ex-colleagues and the family of the client. ZP8 said, “They don’t tell us and we don’t have access. They are supposed to call us in and tell us that the patient has that illness” (Appendix B8). SP2 stated: “Medical information we don’t have access to” (Appendix B8). SP4 said that she has access to Google and maybe from books as well.

IQ 1.2.3: Can you describe any difficulties experienced when trying to get the information that you need for your work activities?

Many participants (11) confirmed that they do not experience any difficulties when trying to obtain information. PP3 highlighted that, “No, unless, it’s private stuff like they always tell us what is happening [and] we also got access to anything” (Appendix B9). ZP7 said, “No, there is no difficulty. There is a Cardex, so you can go to your Cardex” (Appendix B9). ZP6 also mentioned that, “There won’t be any difficulties unless the family didn’t state it in their file when he was admitted, that’s the only difficulty or when there is not information given” (Appendix B9). ZP8, PP2, SP1, SP2 and SP4 stated that they do experience difficulties in trying to get the information they need to support work activities. ZP8 mentioned that her difficulty is related to the nurses, who she felt do not inform her about the types of sickness that the patient has. PP2 indicated that her difficulty relates to her inability to use the computer and the absence of someone who can explain to her. SP1 said that she experiences difficulties “from parents sometimes, they are not always honest” (Appendix B9). SP2 posited that her difficulty is related to a lack of communication between her and the supervisor when “sometimes, when I ask the supervisor, there is a bit of problem with communication; they tell me I’m a carer” (Appendix B9).

IQ 1.2.4: Do you share information about your caregiving experiences with other caregivers and care co-ordinators?

This section highlights the importance of information sharing among caregivers and other health professionals. Many (10 of 21) of the caregivers confirmed that they do share information with other caregivers. ZP9 stated: “If there is something that we need to talk about then we will share, then we will talk about it” (Appendix 10). ZP5 said that, “Yes, you can say every day, when while we are working, then I can ask my other colleague” (Appendix B10). PP1 mentioned that they held regular meetings:

> “We used to have our own meetings with all the caregivers. We can share ideas, we can go with our concerns there and they can give us. It’s a network, so everybody answers and this one gives me input [and] I phone ex-colleagues of mine and I ask for advice” (Appendix B10).

SP2 also confirmed that information is shared between colleagues: “Yes, me and my friend we talk to each other, in the morning we will discuss, if I don’t know and then I can always go back and ask her, we share information, I will ask the supervisor, it’s a good thing and it helps me” (Appendix B10). Similarly, SP3 indicated that, “Yes, we discuss this is what we did for the day” (Appendix B10). However, participant SP1 stated the following: “No, first of all, all the information stays in the office and does not go to the carers”. ZP8 emphasised that, “No, not here, but it is important, very important” (Appendix B10). In terms of how the information sharing occurs, some of the participants (ZP1, ZP2, ZP3, ZP6, ZP7, ZP9) from Zonnebloem said that sharing generally happens during the handover session in the mornings.

During the handover session all caregivers are required to report to the office where they will be briefed by the night shift staff of any incidences that occurred during the night. ZP1 stated: “Everything happens at handover… everything is recorded” (Appendix B10), while ZP9 mentioned that at the handover in the morning, when they are on duty, this is the first thing they do. “It is very good because then we know what is going on and then we know what to do during the day” (ZP9, Appendix B10). Other participants (ZP2, ZP4) stated that sharing of information occurred on a more informal basis, and would generally happen during lunch breaks when the ‘need to know how to handle a particular situation’ arises. In this regard, ZP2 said, “Yes, and at home, my one friend, she’s here so the two of us we discuss most of our work” (Appendix B10). ZP4 said: “Yes, I do, we will help one another if one of us goes wrong or don’t know how to do it then we will show them, the sister that gave us the training” (Appendix B10). PP3 also confirmed that information may be shared: “Yes, sometimes, we chat still like, not outside the premises but like if there is something that we needed to hear according to the problem of the patient. So, if the patient has this problem then we handle him in this way” (Appendix B10). SP4 stated: “Yes, then they can also tell you when you were right and when you were wrong. Give you input, and then we talk about this and then we share” (Appendix B10).

More formal modes of information sharing include a health forum, as PP1 highlighted: “We have this health forum” and have meetings with all the caregivers (Appendix B10). Participants also agreed that information sharing is very important and that it improves their overall work activities. ZP4 said: “I think it’s pretty important because we would know what to do, what to expect” if something has to happen (Appendix B10).

IQ 1.2.5: In what ways has the experience of information sharing amongst other care givers affected your work activities?

The purpose of this section is to elaborate on the impact of information sharing on the work activities of caregivers and how they feel about it. In terms of the benefits of information sharing among caregivers, the majority (17 of 21) agreed that the information is beneficial to their work activities and that it will assist, develop and improve their overall work activities. SP4 stated: “It’s very important because it will broaden your mind to certain issues about the client. On the developmental aspect it improved my work” (Appendix B11). SP5 said: “Yes, it is helpful [and] yes, it improves my work” (Appendix B11). Furthermore, ZP2 confirmed this by stating that, “Work will be much better and we will all learn” (Appendix B11). ZP9 mentioned the following: “It is very good because then we know what is going on and then we know what to do during the day” (Appendix B11). PP1 confirmed: “Yes, it’s good to share the information because they can learn through this and they can learn something” (Appendix B11). ZP13 was not sure as to how it impacts on her work activities: “Sometimes it does and sometimes it doesn’t, it depends on the type of person that you are” (Appendix B11). Only one participant (ZP3) stated that she does not engage in information sharing but related the lack of information sharing to a language barrier between other caregivers: “No, it doesn’t happen, the thing is here—we can’t share because we are to different people, so we don’t understand one another. They share it alone and they don’t share the information with us” (Appendix B11).

SRQ 1.3: How are information resources made available to caregivers in Cape Town, South Africa?

Interview questions under this category were designed to focus on examining the information resources available to caregivers, as well as the existing mediums through which information resources are made available to caregivers in South Africa. Interview questions probed into aspects of information required before and during the process of attending to clients, accessibility of information required during caregiving activities, challenges of accessing such necessary information, the experience of information sharing among caregivers, and the way this affects their duties. The focused interview questions together with the corresponding responses and deduced findings are further presented in this sub-section.

IQ 1.3.1: Please tell me about your daily work activities routine/programme and explain the steps you follow during your work activities.

This section explores the work practices of caregivers and the related information required for their duties. The purpose of this question was to establish to what extent care giving activities are aligned to the information provided and the actual need. Participants were asked to highlight their daily practices as caregivers. Data indicate that caregivers perform three major types of care services. The first one is related to general care and maintaining the hygiene and well-being of the client, and includes the grooming, feeding, bathing, massaging, diaper changing, and dressing of the client. The second type of care practice includes medical-related tasks such as wound dressing, treatment of bedsores, taking urine samples, taking blood pressure, and supervised administration of medication. The third service covers domestic-related tasks such as making beds, cleaning rooms, packing cupboards as well as collecting and folding laundry.

ZP1 stated: “I will come on duty, greet my parents, showering the people and washing, breakfast, cut nails or do hair, make them feel comfortable… and check if they’re dry or if they have any complaints” (Appendix B12). The private participants performed the same activities. PP1 said:

> “I bathe her in the morning, I make sure that she is clean, make sure that she sleeps in a clean place. She got clean clothes and she did eat, she’s happy

> and she is safe. I must make sure that I should give her the medication during that time" (Appendix B12).

Similarly, SP3 stated:

> "We will come in the morning, prepare everybody, we settle them in, we do the morning ring, a prayer, we brush our teeth, we have breakfast, we wash our faces again, we check their nappies and see who wants to go to the toilet, we have an activity depending on the theme for the week. After that they have lunch. We check the nappies again and we have another activity before lunch also and then we have a forty-five minute resting period before we go home" (Appendix B12).

Additional tasks that the caregivers of Sherwood Park perform include doing daily activities with the children provided to them by the programme implementer and supervisor. SP2 stated that after completing the feeding of children, "then we come in and do the morning ring, then we do the ABCs, then days of the week, months of the year, then when we [are] done we eat, then when we done feeding them, then we start with the programme" (Appendix B12).

IQ 1.3.2: How often do you need to seek additional information or advice to carry out your work activities?

The purpose of this question was to establish how often caregivers feel they need more information to complete their tasks. The majority of respondents (16 of 21) indicated that they need information all the time and often on a daily basis. PP3 stated the following: "Almost every time, every time. That's why each and every day, I need information from them, we need this, and you must handle him like this" (Appendix B13). Similarly ZP13 mentioned: "Yes, always, like we need it like a daily thing" (Appendix B13). ZP7 also said: "We need information a lot, you can't say that we don't need information, because every day you learn something new" (Appendix B13). This is confirmed by SP3, who reported that, "Once a week, because once a week I do a weekly report, then I would plan something for the following week and then sometimes I'm stuck and need to access other information" (Appendix B13). Words used to describe how often information is sought include "always" (ZP1, ZP3), "all the time" (SP5, PP1), "in the afternoon" (SP4), "once a week" (SP3, PP2, SP2), "twice a week" (ZP8, SP2), "every time" (PP3), "every week" (PP2), "daily basis" (ZP1), "every day" (ZP2, ZP4, PP3) and "once a month" (ZP12) (Appendix B13).

The participants who do not require information often related it to the fact that new information is only sought when the patient is new to them. ZP9 mentioned: "That is especially when you are working with a new patient, that you have never worked with before, like for instance, here comes a patient that has a sickness that you've never worked with before and then I feel that I need more information" (Appendix B13). ZP10 stated that she does not require new information, "not a lot. For me it is experience work" (Appendix B13), whereas ZP11 said that she only asks when the need arises: "I'll ask what can I do with this patient here and how do I treat this bandage" (Appendix B13). These caregivers only seek additional information when faced with a new patient or problem, but mostly rely on their personal experience for guidance.

IQ 1.3.3: How is important information communicated between you and a client or the guardian of your client?

This section outlines how participants communicate with their clients and how they convey important information. The participants agreed that communication is very important, but differ as to how information is communicated. The Zonnebloem participants indicated that important information is conveyed verbally to the residents after they have been made comfortable. ZP1 said, "It's important to communicate with them so that you can know how they feel and what they want and it's not about you" (Appendix B14). ZP3 confirmed that important information is verbally communicated: "It happens when I talk to the patient, first talk to them about general, if there is something, and then I try to talk to the patient. I don't like to go direct; I like to go in another way, around, to get the information from them" (Appendix B14). ZP11 said: "How I do it is I go to his room and make him comfortable and then we have a good chat, and then we make a cup of tea and then we have a nice chat" (Appendix B14). Similarly, PP1 mentioned that confidentiality is very important in addition to making the client feel comfortable: "[I] mention confidentiality then they are comfortable with you" (Appendix B14).

Some participants from Zonnebloem also indicated that they experience difficulties when trying to communicate important information to the client due to aggressive or difficult behaviour. ZP10 stated: "Some clients are good and some are okay and then you just have to try, sometimes it's hard but you just have to be strong" (Appendix B14). ZP6 said, "It's hard, all the new patients are very frail, they can't speak" (Appendix B14). Similarly, ZP4 confirmed that, "Sometimes it's very hard; especially when they're trying to speak to you, then you can't communicate because it's hard for you to understand the person" (Appendix B14). The private participants (PP1, PP2, PP3) all agreed that information is obtained and communicated to the family and relatives of the client. PP1 stated, "I normally ask the relatives what is wrong" (Appendix B14). Similarly PP2 argued that, "The communication with the family is very important, so if there is a communication then everything is easy" (Appendix B14). PP3 confirmed that communication was direct "with the family...they can tell you that we need you maybe to do this this and this" (Appendix B14).

The caregivers from Sherwood Park indicated that important information is communicated either directly or indirectly to the parents of the children at the institution. In terms of indirect communication, SP2 said, "We don't talk to the parents, we write a letter, and we are not allowed to" (Appendix B14). SP3 stated, "We have a message book, so if I need to communicate something to the parents, then I will write it in the message book" (Appendix B14). SP4 emphasised the importance of communication: "It is important for the communication between the caregiver and the parent; it should be always be in a good spirit. Because it is, the parent knows the child better than the carer". SP5 said, "Okay we have a message book, direct communication sometimes with the parent" (Appendix B14).

IQ 1.3.4: Can you describe any aspect (areas) of your work that you think requires any improvement?

This section attempts to explore the areas that caregivers think requires improvement. The main areas of improvement that emerged from the data include: i) the need for more training and workshops; ii) the need for more information relating to the client; and iii) the need for better equipment and resources.

The majority (16 of 21) of participants stated that training and workshops is a major need and an area that requires improvement. ZP5 said, "We must do first aid training… we need training on anything, we need more information and they can give us workshops" (Appendix B15). ZP7 stated that, "First aid is very important" (Appendix B15). Similarly, PP2 stated that her work will be improved "by going back and learning more about caregiving" (Appendix B15), while ZP7 said, "You need to know CPR" (Appendix B15). SP3 said:

> "Like getting a better way to teach them for their intellectual development. I think workshops and training. Yes, we do training with the Western Cape forum and they teach us about different types of things but I think they should elaborate, like they just give a brief description of something or what it's about but I think we need it more in depth" (Appendix B15).

Some participants (ZP8, ZP12, SP1, SP2, SP4, SP5) mentioned that the lack of equipment and resources is an area that needs to be improved. SP2 said, "Get more stuff to work with the children, they need more equipment" (Appendix B15. Similarly, SP4 mentioned: "We need more resources… like unfortunately this place is too small, like different stuff for the children to explore, like equipment" (Appendix B15). Participants from Zonnebloem stated that, "There was no gloves, so how do you work without gloves?" (Appendix B15, ZP12), and "We need aprons, masks – what is there – a lot of things…" (Appendix B15, ZP8). Participant ZP8 further argued that the areas requiring the most improvement relate to the lack of knowledge and information about the client. In this regard, ZP8 said, "Information about the patient, the sister must give us the information about the patient" (Appendix B15). PP3 said that better communication with the family of the client is an area that needed improvement: "The communication between the caregiver and the family. That is a challenge, because if we are not communicating well then the job is hell" (Appendix B15).

IQ 1.3.5: Based on your experience, can you suggest ways to improve information needs for caregiving practices in South Africa?

This section explores the opinions of caregivers in terms of how they feel the information needs of caregiving practices in South Africa can be improved. The majority of participants (14 out 21) argued that a lack of training is a major contributor to the information needs of caregivers in South Africa. ZP10 said, "We must have training, you see we did the training, but we must do more training also" (Appendix B16). ZP9 argued that, "They can offer us like to do courses or open up a college for nursing so that we can learn more about nursing" (Appendix B16). ZP4 said:

> "The courses that we did was six months and I think it's too short, so I think we can have it extended longer to maybe a year or longer. I think they should include everything in the course for medical, like giving out medication, seeing to the patient, doing the temperature, doing the bed sores and how to put in catheters, how to put in nasal tubes. They can give us training on that also because we only had like a few people that had, three people that had, the stomach and the nasal tube, is mostly for people that had strokes" (Appendix B16).

Some of the areas highlighted that may assist in addressing the information needs of the caregivers include more information about medication (ZP4); blood pressure, temperature, bed sores and nasal drips (ZP4); first aid (ZP7, PP2, SP3, SP4); basic physiotherapy (SP2); and how to handle a client (SP2). Participants ZP8, ZP9 ZP13 and SP1 on the other hand felt that the information needs of caregivers may be linked to the being underpaid, as they cannot afford to get further training and the institutions where they are at do not offer any opportunities for further training. ZP8 said, “The majority of caregivers are complaining about money” (Appendix B16). Similarly, SP1 opined that, “I think that they are not paid enough for the work that they are doing” (Appendix B16).

SRQ 1.4: How do caregivers obtain/access alternative sources of information necessary for their care activities in Cape Town, South Africa?

Interview questions under this category were designed with a focus of establishing information networks/platforms through which caregivers can source additional information for their activities in Cape Town, South Africa. Interview questions designed were aimed at: i) aspects of alternative sources of information to support caregivers; ii) usefulness of the mentioned sources in dealing with client care; iii) the role of government in providing support and resources to caregivers; iv) and concluding recommendations on how the current situation can be improved to address the unmet information needs of caregivers. The corresponding responses to the focused interview questions together with deduced findings are further presented in this sub-section.

IQ 1.4.1: What alternative sources of information are available to you when you need information about caregiving activities?

The purpose of this section is to discuss the existing platforms through which information sources are made available to caregivers.

In terms of ICT usage, some (ZP2, ZP3, ZP3, SP2, SP3, SP4) participants stated that they use websites and Google for information. SP2 said, “I’ll use my phone and I get information” (Appendix B17). SP3 and SP4 both said “Google”, and PP3 indicated, “I go on the Internet where I can go look and check” (Appendix B17). ZP5 said that she uses “Facebook and WhatsApp” (Appendix B17). However, there are participants who do not use websites or the Internet to search for information, such as ZP10 who said, “We don’t use computers” (Appendix B17) and ZP12: “I don’t go on websites” (Appendix B17).

Some of the participants (SP13, PP2, PP3, SP1, SP2, SP5) stated that the main sources of information for them are their supervisors, staff nurse, medical professionals, nurses, ENAs and the task team. In this regard, ZP1 said: “If we need some information we go to the staff nurse or the sister” (Appendix B17). PP3 mentioned, “I think I am being connected to a lot of sisters in charge and nurses and with lots of them, I call them if I got a problem or whatever” (Appendix B17). SP2 indicated, “The task team, we have a programme implementer, she’s the one who gives us work and tells us we must do this and that and that. I'll go to my supervisor" (Appendix B17).

ZP12 and ZP13 both confirmed that they have access to books. In this regard ZP12 said, "Yes there are books", while ZP13 indicated, "Yes, books too" (Appendix B17).

PP1 stated she relies on her own experience when she needs more information: "I have worked from home all these years and al my experiences come from this house" (Appendix B17).

IQ 1.4.2: Which of these sources are most useful for your work activities as a caregiver?

The purpose of this section is to indicate which sources of information are most useful to caregivers. The majority of participants (12 of 21) stated that the most useful source of information for them is other health professionals such as the nurses, sisters in charge, the supervisor and task teams. In this regard, ZP12 said, "I prefer the person in charge because they are more; they describe it better to you" (Appendix B18). ZP13 also stated, "I would say that somebody someone gives you the training and should lead you by the hand and teach you step by step" (Appendix B18). These caregivers prefer the information provided to them by the health professionals as it is a more interactive and practical means of obtaining information. Similarly, ZP2 argued that, "…because they will give me more information, they will explain to me and the sister will explain to me in detail" (Appendix B18).

Some participants (ZP2, ZP3, SP3, SP3) regarded websites as the most useful source of information when they need more information. SP3 said in reference to using Google and other websites:

> "I do find it useful most of the time, but when it comes to like activities for the children with mental disabilities then I don't find it useful, then I as the programme implementer, and I should plan programmes for all the classes but I'm not in the classroom with all the children to know what they are capable of…" (Appendix B18).

In terms of personal experience, PP1 regarded her personal experience of caregiving as the most useful source of information: "The best for me is that I work on my own at the moment" (Appendix B18). Lastly, ZP10 and PP3 stated that the information obtained from the file and relatives of the client are in their opinion the most useful: "Information from the family" (Appendix B18, PP3).

IQ 1.4.3: What are your experiences of interacting with these sources of information?

The purpose of this question was to establish the impact these sources of information have on the caregiving practices of participants. The participants (ZP2, ZP4, ZP5, ZP6, ZP7, ZP8, ZP9, ZP11, ZP12, ZP13, PP2, SP2, SP5) who said that the health professionals are the most useful source of information, also agreed that their experiences are positive. Terms used to describe their experiences include "good" (ZP6, ZP9, ZP10, ZP11, SP2, SP5, PP2); "beneficial" (ZP8, SP4); "positive" (ZP10, ZP12); "very important" (ZP11); "useful" (SP3, ZP8) (Appendix B19).

ZP7 said, "You will have more knowledge and you will know what to do and you will be wiser" (Appendix B19). This was confirmed by ZP4: "We do know how to do it but when she came we knew a little bit more" (Appendix B19).

IQ 1.1.4: Does the government provide you with any training on information resources relating to your work activities?

The purpose of this question was to establish if the government provides caregivers with resources. The majority of participants (18 of 21) confirmed that the government does not provide them with any information resources or training.

In this regard, ZP5 said, "Nothing like that, yes it's important because it's just that a lot of people are in homes but I think the government must come and see what's going on here" (Appendix B20). ZP7 similarly argued that, "They don't provide us with nothing, but we would like to that and that will be useful for us yes" (Appendix B20). ZP9 argued that the government should send caregivers for further training: "It will be very good if they provide that for us" (Appendix B20). As was said by ZP10, "The government should do it. Because you want to learn more from other caregivers from other places, and we meet other caregivers from other places" (Appendix B20). PP1 indicated that the government did provide training caregivers in the past but has since stopped:

> "They trained us at the beginning in 1996 and not anymore and they trained us, then they were gone, we didn't see them, we didn't hear from them. They should train. That would be fantastic, because people phone here at all times here for a caregiver" (Appendix B20).

Similarly, PP2 added that the government should provide further training to caregivers:

> "if our government in South Africa can open up some places where the people can go and the caregiver and get more experience, then that thing will help us

> a lot, or he can take as a student in school, if there is a centre that we can go, and we can go and learn more about these things. We need government to intervene in these things” (Appendix B20).

The participants from Sherwood Park (SP1, SP3, SP4, SP5) confirmed that they receive training from the Western Cape Forum.

SP4 said, “Partly, like the task team, the Education Department, then come here and give us information” (Appendix B20), while SP5 mentioned, “Only Western Cape [Forum]” (Appendix B20).

4.7 Summary of findings and themes related to research questions

This section provides the overall findings of the sub-research questions and their related themes (see Tables 4.2, 4.3, 4.4, 4.5).

4.7.1 Findings and themes related to SRQ 1.1

The table below indicates the findings and themes related to SRQ 1.1.

Table 4.2: Findings and themes related to SRQ 1.1

SRQ 1.1:	**What are the work practices of caregivers and their related information needs in Cape Town, South Africa?**		
Finding 1:	Activities of caregivers include educational tasks, domestic-related tasks, caregiving practices and medical-related tasks.		
Category: Educational tasks			
Case A	**Case B**	**Case C**	**Theme**
Educational tasks include daily educational activities such as drawing, puzzles, as well as fine motor skill development activities	None	None	Caregiver work practices
Category: Domestic-related tasks			
Case A	**Case B**	**Case C**	**Theme**
None	Making beds, cleaning rooms, packing cupboards and collecting and folding of laundry	Making beds, cleaning rooms, packing cupboards and collecting and folding of laundry	Caregiver work practices
Category: Caregiving practices			
Case A	**Case B**	**Case C**	**Theme**
Grooming and washing, maintaining the hygiene and well-being of the client, feeding, bathing, massaging, and diaper changing and dressing of the client	Grooming and washing, maintaining the hygiene and well-being of the client, feeding and bathing, massaging, diaper changing and dressing of the client	Grooming and washing, maintaining the hygiene and well-being of the client, feeding and bathing, massaging, diaper changing and dressing of the client	Caregiver work practices

Category: Medical-related tasks			
Case A	**Case B**	**Case C**	**Theme**
Supervised administration of medication	Wound dressing, treatment of bed sores, urine sampling, blood pressure monitoring, and supervised administration of medication	Wound dressing, treatment of bed sores, urine sampling, blood pressure monitoring, and supervised administration of medication	Caregiver work practices

4.7.2 Findings and themes related to SRQ 1.2

The table below indicates the findings and themes related to SRQ 1.2.

Table 4.3: Findings and themes related to SRQ 1.2

SRQ 1.2:	**What are the factors affecting unmet information needs of caregivers in Cape Town, South Africa?**		
Findings		**Category**	**Theme**
Finding 2	Caregivers expressed lack of information and knowledge about handling an emergency situation	Inability to cope in an emergency situation	Unmet information need
Finding 3	Caregivers are faced with challenges relating to physical limitations when performing their duties	Physical challenges	Challenges of caregiving
Finding 4	Caregivers expressed feelings of emotional stress	Psychological and emotional challenges	Challenges of caregiving
Finding 5	The information provided is not enough to support caregiving activities	Need information	Unmet information need
Finding 6	Caregivers are at risk of contracting illnesses due to lack of knowledge about the medical status of the patient	Need information	Unmet information need
Finding 7	Caregivers expressed need for medical background, physical mobility, dietary information and behavioural issues of client	Need information	Unmet information need
Finding 8	Caregivers identified a need for further training such as CPR and first aid	Challenges relating to training	Unmet information need
Finding 9	Caregivers identified a lack of protective equipment such as gloves, aprons and masks	Lack of protective equipment	Unmet resource need
Finding 10	Caregivers expressed difficulty with communication with clients	Challenges relating to conveying information	Challenges of caregiving

4.7.3 Findings and themes related to SRQ 1.3

The table below indicates the findings and themes related to SRQ 1.3.

Table 4.4: Findings and themes related to SRQ 1.3

SRQ 1.3:	**How are information resources made available to caregivers in Cape Town, South Africa?**		
Findings		**Category**	**Theme**
Finding 11	Caregivers identify health professionals (nurses, sisters), task teams, families, supervisors and other caregivers as primary sources of information	Primary source of information	Caregiver information resources
Finding 12	Secondary sources of information include books and own initiatives	Secondary sources of information	Caregiver information resources
Finding 13	Most caregivers do not access websites to gain more information	Unused sources of information	Caregiver information resources
Findings		**Category**	**Theme**
Finding 14	Personal experience is considered a useful source of information	Own source of information	Caregiver information resources
Finding 15	Caregivers consider Information obtained from health professionals and the family of the client as the most useful	Most useful sources of information	Caregiver information resources
Finding 16	Caregivers identified that government does not provide information resources and further training to them	Lack of information resources from government	Unmet information need

4.7.4 Findings and themes related to SRQ 1.4

The table below indicates the findings and themes related to SRQ 1.4.

Table 4.5: Findings and themes related to SRQ 1.4

SRQ 1.4:	**How do caregivers obtain/access alternative sources of information necessary for their care activities in Cape Town, South Africa?**		
Findings		**Category**	**Theme**
Finding 17	Information sharing occurs on a formal and informal basis	Caregivers share information with each other	Information sharing
Finding 18	Information sharing is important to caregivers	Information sharing is important and necessary	Information sharing
Finding 19	Information sharing improves and enhances care activities	Information sharing improves care activities	Information sharing

4.8 Summary

Chapter Four presented the background of the three cases used for the study, based on the perspectives of the twenty-one (21) participants who were interviewed. All of the participants have years of experience in caregiving. The collected data were transcribed, summarised, categorised and then developed into themes using a thematic analysis. From the eighteen (18) findings (finding 2 – 19), five themes were extracted and identified, namely: i) Caregiver work practices; ii) Caregiver challenges; iii) Unmet information needs; iv) Caregiver information resources; v) Information sharing.

The next chapter (Five) provides the discussion and links the major themes to the objectives of the study.

CHAPTER FIVE: DISCUSSION

5.1 Introduction

Information is an important resource for individual growth and survival. The progress of society is dependent upon the provision of the right kind of information, at the appropriate time and form, and more importantly, the needed information should be used to make the right decision and reduce uncertainty. Information is thus valuable and has to be put to good use and made available to the people who need it, once the need has been ascertained. According to Taylor (2008, cited by Isebe et al., 2017), information need refers to “an individual or group’s desire to locate and obtain information to satisfy a conscious need or unconscious need”.

The study aimed to explore the unmet information needs of caregivers in their work activities in order to identify and address the information need challenges during the course of performing their duties.

From the findings described in Chapter Four, five themes have been identified. These themes are: i) Caregiver work practices; ii) Caregiver challenges; iii) Unmet information needs; iv) Caregiver information resources; and 5) Information sharing. Themes are aligned to the relevant research question and presented as such.

Chapter Five provides a discussion of the findings, linked to the research questions, and concludes with proposed guidelines to address the research problem. Tables 4.2 to 4.5 in Chapter Four provide details of each finding and the corresponding themes developed based on the 19 findings. For ease of reference, the problem statement and research questions are mentioned hereunder.

Problem statement: The information needs and challenges relating to a lack of information available to caregivers are considerably unclear and unidentified in different contexts. It is therefore important to identify the information needs of caregivers in South Africa in order to improve their work conditions and the services they provide.

One primary research question with four sub-research questions were asked to address the research problem.

Primary research question:

PRQ: What are the unmet information needs of caregivers in South Africa?

Sub-research questions (SRQs):

SRQ 1.1: What are the work practices of caregivers and their related information needs in Cape Town, South Africa?

SRQ 1.2: What are the factors affecting unmet information needs of caregivers in Cape Town, South Africa?

SRQ 1.3: How are information resources made available to caregivers in Cape Town, South Africa?

SRQ 1.4: How do caregivers obtain/access alternative sources of information necessary for their care activities in Cape Town, South Africa?

5.2 The themes

The five themes identified are: i) Caregiver work practices; ii) Caregiver challenges; iii) Unmet information needs; iv) Caregiver information resources; v) and Information sharing.

Each of the themes is discussed in the following sections.

5.3 Theme 1: Caregiver work practices

The type of caregiver investigated in this study has been categorised as formal employed caregiver. Some respondents have achieved an element of education or training in the field, viewed as formal caregiver training (Table 4.1). The majority (13 of 21) caregivers completed basic HBC training at different institutions; three participants (SP2, SP4, PP2) have no formal training and received in-house training, whereas three participants (ZP11, PP1, PP3) completed professional nursing courses, and one participant (SP3) completed an EC three year course. When probed about their work practices and care services provided (SRQ 1.3), four main types of care emerged. These are activities relating to: i) general grooming of the client; ii) tasks related to medication; iii) domestic related tasks and; iv) educational tasks (Table 4.2, Finding 1). Literature provides various definitions for care work. England et al. (2002:455) define care work as follows:

> “Occupations in which workers are supposed to provide a face to face service that develops the human capabilities of the recipient. By ‘human capabilities’ we refer to health, skills, or proclivities that are useful to oneself or others. These include physical and mental health, physical skills, cognitive skills, and emotional skills, such as self-discipline, empathy, and care. Examples of caring labour include the work of teachers, nurses, childcare workers, and therapists.”

The majority of caregivers indicated that they are not adequately trained at the institutions and felt that their care activities often exceed their skills. Caregivers also have concerns that they are required to do the work of the nurses and ENAs but are not paid nor trained to do so. A lack of medical information during care activities is highlighted as a major concern. “Because I can’t do that alone, I need someone who is going to explain to me about the medications because I must know exactly what kind of tablet I am giving to” (Appendix B5, PP2).

It is evident that there is a misalignment between home-based care courses, the care activities of the caregiver, and the type of care services required by the recipient. Therefore, it is important to establish the care work (practices) of caregivers in order to assist government, policy-makers, NGOs, and community-based organisations (CBOs) to align care services with the appropriate training. In this regard, Mollica et al. (2017) explored the role of medical/nursing skills training in caregiver confidence and burden. According to these authors, training and skills of caregivers should include decision making, actioning, monitoring, adopting to various needs, retrieving and reading resources, interpreting, reassuring with practical and proactive care, providing care to ill people, and using the health care system as best as possible. Table 5.1 shows the type of care work provided and the recommended training for caregivers.

Table 5.1: Practices of caregivers and recommended training

Type of care	Description	Recommended training
General grooming	Tasks related to maintaining general hygiene and well-being of the client, including the grooming, feeding, bathing, dressing, massaging, and diaper changing	Basic training in home-based care
Medical-related tasks	Tasks include wound dressing, treatment of bedsores, taking urine samples, taking blood pressure, and administration of medication	Basic first aid, medication administration, information access to information about diagnosis and symptoms
Domestic-related tasks	Tasks include making beds, cleaning rooms, packing cupboards, collecting and folding of laundry	Basic training in home-based care
Educational tasks	Tasks include planning and implementing daily activities for CP, physically and mentally disabled children	Attend workshops and training for CP, physically and mentally disabled children

Caregivers state a need for more education on caregiver training, and more public education on hospice services. Government intervention, further education, training, and coordination of public health services may help alleviate caregiver burden, which will improve quality of life for both patient and caregiver (Mollica et al., 2017).

Many caregivers admit that their care work often exceeds their training and that most training is done in-house. Some admit that the institutions do not provide the necessary training and skills, and that they felt inadequate when performing their duties. As a result they would often seek information from peers and senior staff when they require more information.

5.4 Theme 2: Caregiving challenges

Caregiving is a physically and emotionally taxing task and caregivers often face many challenges on a daily basis. These challenges may be physical, psychological, and even financial. However, literature suggests that many of the challenges of caregiving are related to a lack of knowledge and training, which prevents caregivers from adequately complete their caregiving tasks (Denham et al., 2018; Galvin et al., 2018; Jukic et al., 2017; Lambert & Girgis, 2017; Lim et al., 2017; Masuku et al., 2018). Many caregivers have expressed a need for more information and training from medical professionals in order to address this problem. The findings associated with the challenges of caregivers are mentioned in Chapter Four (Table 4.3, Findings 2-10). Caregivers who participated in the study agree that the task of caregiving has its challenges, which include physical and psychological challenges, challenges relating to a lack of training, and challenges relating to conveying information (Table 4.3, Finding 10). This finding is supported by Denham et al. (2018) who confirm that health care workers (HCWs) and caregivers have expressed major needs and challenges in their daily caregiving tasks.

5.4.1 Physical challenges

In terms of physical challenges, some participants mentioned that lifting heavy patients does have physical consequences for them, especially if they have not received any training on how to lift patients properly (Table 4.3, Finding 3). ZP1 confirmed this by stating that, “There’s not much difficulties, just when the patient is heavy… so you can hurt yourself” (Appendix B1). Those participants who are involved in frail-care of elderly individuals highlighted that their most challenging duties are those related to handling violent patients, which is physically and mentally taxing and requires a degree of physical strength to restrain the person. Werner et al. (2017) highlight that female caregivers are more exposed to and experience physical aggression towards them.

Similarly, caregivers of mentally and physically challenged children stated that the physical challenges often exceed their capabilities (Table 4.3, Finding 3). In this regard, SP4 mentioned that, “Children that have a fit, different types, and you have to handle each one in its own way” (Appendix B1). The physical challenges of the private caregivers are related to having too many duties placed on them, as they are required to do domestic tasks such as house cleaning and cooking as well (Werner et al., 2017).

5.4.2 Psychological/emotional challenges

Caregiver burden refers to the load carried by caregivers, which may be objective or subjective (Adelman et al., 2014). Objective caregiver burden is described as “the physical cost that the caregiver faces when caring for the patient” and is related to the physical experiences of caregiving, whereas subjective burden is defined as the caregivers’ perception of their responsibility and their role in providing care for the recipient (Adelman et al., 2014:1054). Both objective and subjective wellbeing can be emotionally and physically taxing on the caregiver (Adelman et al., 2014). Many studies have been conducted on the emotional stress and burden experienced by caregivers (Chen et al., 2016; Galvin et al., 2017; Jukic et al., 2017; Lambert & Girgis, 2017; Lim et al., 2017).

Caregivers work very hard, often for much longer hours than conventional jobs, which may lead to burnout. Some of the caregivers have expressed feelings of discouragement, a general sense of hopelessness and in some cases, depression. In terms of the psychological obstacles that impact on their caregiving duties, some caregivers mentioned feeling emotional stress and burden (Table 4.3, Finding 4). Participants ZP1, ZP3 and ZP6 related their emotional challenges to an inability to deal with difficult situations, because of a lack of cooperation on the part of the recipient and feeling that too much is required of them. This causes them to feel “stressed” and experience feelings of burnout, because they do not know “how to deal” with the situation. Chen et al. (2016) confirm that many caregivers report feeling anxious and depressed, and are not able to function properly as a result of this. When probed about why they think they have these feelings, most of the caregivers related it to the lack of knowledge, information and a need for more training (Table 4.3, Finding 4).

It is evident that most of the challenges faced by caregivers such as those related to physical injuries and psychological burnout may be addressed if they receive the necessary information and develop the skills required to deal with the situations. This is confirmed by ZP7 who also mentioned that, “Sometimes it makes it difficult for me yes, because I don’t understand what’s going on around me… I can’t just make the decision if I don’t know” (Appendix B1).

In this regard, Masuku et al. (2018) mention that caregivers should be assisted in the development of skills they need, which will lead to lowered experiences or feelings of burden, stress, and distress. The emotional burden and stress experienced by caregivers of young children are directly related to the lack of support and information provided to them by the families and health professionals (Lim et al., 2017). These responses indicate that a lack of knowledge on how to ‘handle’ the situation plays an important role in the challenges faced by caregivers (Table 4.3, Finding 2).

5.4.3 Challenges relating to lack of information and training

Denham et al. (2018) researched the unmet needs of the caregivers of stroke survivors and indicated in their study that, firstly, caregivers do not receive training for all the care provided, and secondly, their duties exceed their training. This study confirms that the lack of receiving training correlates with increased levels of stress and burden, and this affects the caregiver’s ability to provide good care. The study recommends skills training as a possible area of intervention to address this problem (Denham et al., 2018).

Some studies in sub-Saharan Africa also investigated the physical and psychological challenges of caregiving and needs of caregivers working in AIDS care. Masuku et al. (2018) explored the challenges of primary caregivers in a South African township. According to their findings, caregivers felt that their basic training does not cover all their work activities and that they need more information. Findings from this study also point to caregivers feeling they are not properly educated and trained on delivering frail-care (Table 4.3, Findings 2-10).

Werner et al. (2017) found that caregivers who provide care to recipients with serious chronic illness encountered many physical and emotional challenges due to a lack of education and training. In terms of the physical risks of caregiving, ZP8 and ZP4 expressed their concern regarding the physical risks of being exposed to sick patients (Appendix B1). This risk is further exacerbated by the fact that caregivers are not provided with information on the client’s medical status (Table 4.3, Finding 7).

The lack of information and knowledge about medication, treatment options, signs and symptoms of illnesses have emerged as some of the major obstacles for caregivers to perform their daily tasks (Table 4.3, Finding 5, 6, 7). ZP6 said, “When problems arise, like maybe someone maybe have a heart attack or… and maybe I need to know more about the signs and the symptoms” (Appendix B1). The caregivers (SP3, SP4, PP3) also emphasised the difficulty of their tasks when they do not know how to handle a patient and the situation (Appendix B1).

SP4 stated the following: “Children that have a fit, different types, and you have to handle each one in its own way” (Appendix B1). This is confirmed by ZP7 who mentioned that, “Sometimes it makes it difficult for me yes, because I don’t understand what’s going on around me… I can’t just make the decision if I don’t know” (Appendix B1). These responses indicate that a lack of knowledge and training on how to ‘handle’ the situation plays an important role in the challenges faced by caregivers.

5.4.4 Challenges relating to poor communication with client

Some caregivers also indicated that they experience difficulties when trying to communicate important information to the client due to aggressive or difficult behaviour. Caregivers who are involved in frail-care related their challenges to difficulties when trying to communicating with elderly patients who are unable to express themselves clearly (Table 4.3, Finding 10).

In this respect, one participant (ZP4) related, “Sometimes it’s very hard; especially when they’re trying to speak to you, then you can’t communicate because it’s hard for you to understand the person” (Appendix B14). Similarly ZP6 confirmed that, “It’s hard; all the new patients are very frail, they can’t speak” (Appendix B14). ZP10 stated that, “Some clients are good and some are okay and then you just have to try, sometimes it’s hard but you just have to be strong” (Appendix B14). Some of the participants (ZP1, ZP3, ZP6) stated that the obstacles they experience are related to the lack of cooperation of the patient and an inability to deal with difficult situations (Appendix B14). Private Participant 3 (PP3) stated that, “The challenges are co-operation with the patient, that is the biggest challenge, because there are other patients used to his family” (Appendix B1).

5.4.5 Financial challenges

Some caregivers were of the opinion that working in AIDS care has financially impacted on them, whereas other caregivers indicated that a better salary with benefits would alleviate some of the stress. Some participants (ZP8, ZP9, ZP13, SP1) related that the information needs of caregivers are linked to being underpaid, as they cannot afford to get further training. Similarly, ZP8 said, “The majority of caregivers are complaining about money” (Appendix B16). SP1 mentioned the following: “I think that they are not paid enough for the work that they are doing” (Appendix B16). This finding supports the study of Moreno-Jiménez et al. (2006)

who report similar findings. In summary, some of the major challenges of caregiving may be alleviated with the provision of better training, more information, and financial support to caregivers.

5.5 Theme 3: Unmet information need

As noted previously, information need refers to an individual or group’s desire to locate and obtain information to satisfy a conscious or unconscious need (Taylor, 2008, cited by Isebe et al., 2017). Because the aim of the study was to explore the information needs of caregivers, respondents were asked if they require additional information to complete their tasks, and if the information provided to them is sufficient to support their care activities. The overall sentiment shared by the majority of the participants was that the information is not sufficient (Table 4.3, Findings 2-10; Appendix B2). Some participants expressed their view of the lack of information and how the “need to know basis” affects their ability to complete their tasks properly.

Although the majority of participants (15 of 21) confirmed that they receive information from their supervisors and managers, many felt it not to be adequate. Participant ZP3 said, “If they give us… they don’t give us the full information”, while SP5 emphasised, “It’s not enough” (Appendix B2). Similarly, SP2 argued that, “It’s not enough, I would like to know more about how to deal with the child, because you don’t know what that person needs right now” (Appendix B2). Some (SP4, SP5, SP3, PP3, ZP7, ZP4) participants reported that they do not encounter any real challenges in terms of the information provided to them (Appendix B2).

5.5.1 Need for training

Lund and Budlender (2009) report that despite the significant role caregivers play in South Africa, many have received minimal to no training from government. The majority of participants (14 out 21) argued that the lack of training is a major contributor to the information needs of caregivers in South Africa (Appendix B15). ZP10 said, “We must have training, you see we did the training, but we must do more training” (Appendix B16). ZP9 argued that, “They can offer us like to do courses or open up a college for nursing so that we can learn more about nursing” (Appendix B16). SP3 stated:

> “Like getting a better way to teach them for their intellectual development. I think workshops and training. Yes, we do training with the Western Cape forum and they teach us about different types of things but I think they should elaborate, like they just give a brief description of something or what it’s about but I think we need it more in depth” (Appendix B15).

Findings indicate that caregivers need more background information before attending to a client, and they need to the capabilities of the patient (Table 4.3, Finding 7). A qualitative study by Hirakawa et al. (2011) on information needs and sources of family caregivers of elderly home patients confirms the need for more information on dementia, first aid and the availability of public long-term care insurance services for such patients. The study also notes food and nutrition information as a priority of caregivers and that they lack sources of information. This view is supported by participant ZP5, "We must do first aid training… we need training on anything, we need more information and they can give us workshops" (Appendix B15). ZP7 confirmed, "First aid is very important" (Appendix B15). Participant ZP8 argued that the information about the client was not enough: "Information about the patient, the sister must give us the information about the patient" (Appendix B15).

It is evident that caregivers feel they are not adequately trained and only receive limited information from their care managers or physicians. Findings confirm that caregivers who provide frail-care need more background information on the type of illness, especially when providing care for dementia patients (Table 4.3). This supports Hebert et al. (2007), who confirm that caregivers of patients with severe dementia report a greater need for information on the spread of dementia and dementia-specific care.

Some caregivers expressed a general need for more information and training to handle emergency situations, such as heart attacks and seizures (Table 4.3, Finding 2). These findings support Galvin et al. (2018), confirming that caregivers do not have enough information about crisis and pain management and express a need for more medical information on the client. Furthermore, the study highlights the importance of effective communication and information sharing between patient and caregiver. Similarly, Leung et al. (2017) identify the information needs of caregivers, which may inform organisations and agencies on providing disease and illness-related information.

Caregivers also related that they do not have information on the physical mobility, dietary requirements, and behavioural issues of the client while they attend to them, which causes major difficulties in their caregiving tasks (Hirakawa et al., 2011).

Figure 5.1: Modes of caregiving
(Source: Sterling, 2015:5)

According to Sterling (2015), the information needs of caregivers are dependent on the different situations they find themselves in. This study confirms that caregivers need skills for crisis management (emergency situations) (Table 4.3, Finding 2), training in rehabilitative programmes (physiotherapy), medical background information (type of illness, signs, symptoms, risks for caregiver, administration of medication, blood pressure checking, urine sampling), physical mobility of recipients, dietary information and behavioural issues (dementia, CP), information about daily maintenance of recipients (wound dressing, bed sores, lifting patients), and training on the use of assistive devices and medical equipment. Some of the areas that are highlighted might assist in addressing the information needs of the caregivers, including more information on medication (Appendix B5, ZP5; Appendix B14, PP2); blood pressure, temperature, bed sores and nasal drips (Appendix B14, ZP4); first aid (Appendix B16, ZP7, PP2, SP3, SP4); basic physiotherapy (Appendix B16, SP2); and how to handle a client (SP2).

Sterling (2015) grouped the information needs of caregivers into three modes: i) crisis mode; ii) care transition; and iii) maintenance mode. Caregivers are either dealing with a crisis (emergency situation) in an assistive mode where the client is in the transition or recovery stage (rehabilitative mode), or in a maintenance mode, which entails trying to get through the daily activities and challenges (Sterling, 2015). The information needs of the caregiver thus vary according to the mode and situation the caregivers find themselves in (Sterling, 2015). The caregivers in this study clearly expressed a need for more information and indicated areas they think require improvement, although do not have access to this type of information.

Sterling (2015) offers some guidelines and confirms that caregivers need access to the patient's allergies and health history, family health history, immunisations and test results. During a crisis, in addition to the previous information, caregivers need to gather diagnosis or injury details, disease-specific information and care options. During care transition or maintenance, caregivers need access to information about instructions for performing caregiving activities and medical equipment. The information needs for the maintenance mode includes information on long-term care support, knowledge, and training on the use of assistive devices and medication regimes (Sterling, 2015).

5.6 Theme 4: Caregiver information resources

Caregivers have been probed about the types of services, resources (Table 4.4, SRQ 1.3) and information resources made available to them in order to further understand their information needs. Resources are defined as "a stock or supply of money, materials, staff, and other assets that can be drawn on by a person or organisation in order to function effectively", whereas information resources refer to "a collection of valuable information generated by human activities" (Moshfeghi et al., 2016:336). The term also includes related equipment, personnel, and capital (Onyango, 2018).

5.6.1 Health care professionals

Some participants (SP13, PP2, PP3, SP1, SP2, SP5) stated that their main information resources are from staff: their supervisors, staff nurse, medical professionals, nurses, ENAs and the task teams assigned to them (Table 4.4, Finding 11). PP3 stated, "I think I am being connected to a lot of sisters in charge and nurses and with lots of them, I call them if I got a problem or whatever" (Appendix B4). SP2 said, "The task team, we have a programme implementer, she's the one who gives us work and tells us we must do this and that and that. I'll go to my supervisor" (Appendix B17). Caregivers prefer that the information provided to them come from medical staff (Table 4.4, Finding 15) as it is much more interactive and practical. Some caregivers use their own initiative and ideas when they do not have sufficient information to complete tasks, whereas some rely on personal experience gained over the years (Table 4.4, Finding 14).

5.6.2 Internet

Secondary information resources include using the Internet to gain more information (Table 4.4, Finding 13). SP2 stated, "I'll use my phone and I get information (Appendix B17), while PP3 mentioned that, "I go on the Internet where I can go look and check" (Appendix B17). However, there are participants who do not use websites or the Internet to search for information (Table 4.3, Finding 3), such as ZP10 and ZP12 (Appendix B17), whereas others (Appendix B17, ZP2, ZP3, SP3, SP4) regard websites as the most useful source of information when they need more information. In a cohort study by Basch et al. (2004), the use of the Internet to obtain information on care recipients' conditions was reported by 44% of caregivers, and over 60% of caregivers received their information from health care professionals and other caregivers.

Caregivers prefer the information provided by health professionals as it is a more interactive and considered a more practical means of obtaining information, "because they will give me more information, they will explain to me and the sister will explain to me in detail" (ZP2, Appendix B17). Information obtained from the personal files and "information from the family" (PP3, Appendix B17) are also considered to be useful (Table 4.4, Finding 11).

Sterling (2015) developed categories for the information needs of caregivers and how these may be aligned to the information resources available to them. In this regard, the needs of caregivers may fall within one of the following six categories: Access, Track, Manage, Coordinate, Connect, and Learn, as described in Table 5.2 below:

Table 5.2: Information needs of caregivers
(Source: Sterling, 2015:4)

Category	Information needs of caregivers
Access	Family health history, medical records, test results, medication lists, insurance statements/bills, legal documents such as healthcare proxy
Track	Immunisations, vital signs, blood sugar, weight, food intake, mood, rest, patient location
Manage	Medication administration, refills, and care plans
Coordinate	Doctor appointments and referrals, in-home care and services, other family caregivers
Connect	With other caregivers, providers, family members, and friends
Learn	About a diagnosis, disease, treatment, or the latest research

Table 5.3 categorises the type of information that caregivers would need to manage and access when they operate in the various modes.

Table 5.3: Information needs of caregivers in three modes
(Source: Sterling, 2015:5)

Category	Crisis mode	Transition	Maintenance
Access	Family health history, test results, medication lists	Medical records	-
Track	-	-	Blood sugar, weight, nutrition
Manage	-	Medication administration, care plans	Medication and refills
Co-ordinate	-	In home care	Doctor appointments and referrals
Connect	Family members	Providers	Other caregivers
Learn	Diagnosis, disease	Rehabilitative treatment	Diagnosis

Categorising the actions of the caregiver may provide guidelines on the type of information that should be made available to caregivers (Table 5.3).

The problem with ICT information resources is that accessibility to the Internet is difficult and limited at the institutions. Caregivers do not have access to the Internet and some do not know how to use the Internet. Secondly, some of the caregivers felt it would be impractical to access information from the Internet during the day, as they are required to be on duty all the time. For this reason, many caregivers rely on the expertise of their colleagues and nursing staff who provide them with basic information and practical training on caregiving.

5.6.3 Material resources

As previously mentioned, resources refer to “a stock or supply of money, materials, staff, and other assets that can be drawn on by a person or organisation in order to function effectively” (Moshfeghi et al., 2016:336). Besides a lack of information resources expressed by caregivers (Table 4.3, Finding 9), a lack of material resources was also mentioned. When probed about areas they think require improvement (IQ 1.3.4), some participants (ZP8, ZP12, SP1, SP2, SP4, SP5) mentioned that the equipment and devices needed to complete their caregiving tasks are sometimes unavailable. Caregivers who provide care to children mentioned a special need for material resources such as books, learning aids and devices. “We need to get more stuff to work with the children, they need more equipment” (SP2, Appendix B15). Similarly SP4 mentioned, “We need more resources… like unfortunately this place is too small, like different stuff for the children to explore, like equipment” (Appendix B15).

Participants from the ATKV OAH were more concerned about exposure to illness due to a lack of protective wear such as gloves, masks, aprons and resources like cotton wool and disinfectants (Table 4.3, Finding 9). Caregivers felt they are at risk of getting sick, especially when being exposed to a TB patient. ZP12 stated that, “There was no gloves, so how do you work without gloves?”, while ZP8 said, “We need aprons, masks – what is there – a lot of things…” (Appendix B15). Majumdar and Mazaleni (2010) report that in addition to a lack of funding, caregivers also feel the provision of equipment such as dressing, gloves, toiletries, linen, cotton wools and sheets will improve their care work, but these are not provided to them.

5.6.4 Government resources

When probed about the availability of government resources and training programmes, many of the caregivers (18 of 21) indicated that none are provided by government (Table 4.4, Finding 16). ZP5 admitted: “Nothing like that, yes it’s important because it’s just that a lot of people are in homes but I think the government must come and see what’s going on here” (Appendix B20). ZP7 similarly argued that, “They don’t provide us with nothing, but we would like to that and that will be useful for us yes” (Appendix B20). Government should provide caregivers with further training. “It will be very good if they provide that for us” (ZP9, Appendix B20). As was said by ZP10, “the government should do it. Because you want to learn more from other caregivers from other places, and we meet other caregivers from other places” (Appendix B20).

The study also shows that caregivers are willing to undergo further training by government, because there is a demand for trained caregivers: “People phone here at all times here for a caregiver” (PP1, Appendix B20). Mansfield et al. (2017) explored the unmet needs of caregivers of people with dementia and confirmed that they receive very little to no support from government and from the healthcare system. The study suggests the planning and provision of rehabilitation interventions (Mansfield et al., 2017). Kumar and Das (2017) report that many caregivers confirm their frustration with the government processes, health programmes, lack of information campaigns and misleading health messages. Chironda and Bhengu (2018, 2019) highlight the many challenges faced by caregivers in South Africa and establish that barriers for proper home-based care (HBC) include poverty, poor access to basic health care, limited information, and the limited capacity within impoverished rural communities to deal with HIV infection in addition to poor support from government and social services. Morton et al. (2018) recognise a need for government-based interventions and training for caregivers in South Africa. Policies for Community Home-Based Care (CHBC) should address the need for standardised training programmes for caregivers, and provide a clear scope of practice for caregivers to standardise their competencies and boundaries so that they are equipped with multiple skills; In this regard, participant PP2 added that the government should provide further training to caregivers:

> “if our government in South Africa can open up some places where the people can go and the caregiver and get more experience, then that thing will help us a lot, or he can take as a student in school, if there is a centre that we can go, and we can go and learn more about these things. We need government to intervene in these things” (Appendix B20).

The participants from Sherwood Park (SP1, SP3, SP4, SP5) confirmed that they received in-house training from the Western Cape Forum. SP4 said, “Partly, like the task team, the Education Department, then come here and give us information”, while SP5 mentioned, “Only Western Cape [Forum]” (Appendix B20).

Participants opined that they need the assistance of the public health system and that government should assist communities in funding a CHBC system. Caregivers also confirmed that they do not receive medical support such as accessing medication.

5.7 Theme 5: Information sharing

Many sources describe peer education as “people of a similar level of education, who are not professional teachers, helping each other and learning themselves by teaching” (Kageyama et al., 2017:408). Peer education is considered an effective means of bringing about continuous knowledge, attitude change and coping skills. Caregivers admit to sharing knowledge with their peers, colleagues, managers and supervisors, and in a sense, they have developed their own unique community of practice at their work places (Table 4.5, Finding 17).

Participant SP2 admitted: “Yes, me and my friend we talk to each other, in the morning we will discuss, if I don’t know and then I can always go back and ask her, we share information, I will ask the supervisor, it’s a good thing and it helps me” (Appendix B10). Similarly SP3 said, “Yes, we discuss this is what we did for the day” (Appendix B10). ZP4 agreed: “I don’t know [but mostly we] go to the staff nurse or the sister” (Appendix B4). PP1 confirmed by saying, “If I don’t know, then I know a lot of people in the medical field and I will phone one of my ex-colleagues”

(Appendix B4). PP3 mentioned that, “I am connected to a lot of sisters in charge and nurses; I call them if I got a problem” (Appendix B4).

Caregivers also admitted that sharing information with peers is beneficial and necessary, and it enhances care practices and alleviates challenges (Table 4.5, Finding 19). In the traditional sense, such knowledge would have been accessed via published best evidence, which may not provide the solutions to challenges faced by caregivers in their day-to-day caregiving duties. Caregivers need to be able to access a tacit knowledge base, drawn from the personal experiences, intuitions and perspectives of other caregivers and health care professionals who face similar challenges and problems (Reinders, 2010).

Pinto et al. (2012) view community caregivers as important sources of expertise who act as liaisons between community members and medical care providers. However, the growing reliance of health care systems worldwide on home caregivers has exceeded research on their praxis. In other words, the communities of caregiving practitioners, particularly in the informal sense, have not yet been provided with the tools or the appropriate forums to combine and integrate their indigenous (tacit) knowledge with technical knowledge of caregiving practices.

This integration is essential to alleviating caregiving challenges, which will ultimately affect patient outcomes. Pinto et al. (2012) also recommend the development of a framework based on community health care work to enhance caregiving services and achieve improved patient outcomes. In addition, caregivers also require and should have access to actionable knowledge such as the development of new treatments, guidelines in caregiving, procedures and delivery practices as opposed to just service quality and outcome measurement treatments.

5.8 Guidelines

From the findings, a set of guidelines are proposed, consisting of components that could assist caregivers in their information needs and presented in the following format: i) training; ii) information accessibility; iii) screening; iv) resources; v) support services; and vi) peer information sharing.

5.8.1 Training

i) Institutions should provide comprehensive caregiver courses that are based on practice. The training should incorporate home-based care, theoretical knowledge of caregiving, practicalities of the work, medication administration, and coping skills.

ii) Training and courses must adequately train caregivers in the three modes of care (crisis, transition and maintenance).

iii) Caregivers should be prepared for the physical challenges of caregiving, such as lifting heavy patients, and trained accordingly.

iv) Caregivers should be informed of the psychological and emotional impact of caregiving on their lives, and provided with the necessary coping skills to deal with situations. This could be done through regular workshops and sessions where caregivers are allowed to freely discuss issues relating to emotional burden, bereavement and coping.

v) Caregivers must receive training on the proper use of basic medical equipment such as catheters and blood pressure monitors. This must be based on practice, so that they are adequately prepared before commencement of work.

vi) Specialised training caregiver courses should be offered on chronic illness and disease, frail-care, chronic disease care and childcare. Caregivers should be educated about the challenges they will face when providing care to patients with special conditions including dementia, Alzheimer’s, ADHD, cancer, HIV/AIDS and CP.

vii) Training programmes need to be standardised across the country to get all caregivers on the same qualifications level in order to standardise salaries.

viii) The care services and duties of caregivers should be clearly stipulated by the employer or organisation before commencement of work so that caregivers are aware of the extent of their duties and not become overwhelmed by caregiver burden, burnout or stress.

ix) Continuous onsite training: Caregivers should updated constantly by employers and organisations on the latest developments in care services and treatments.

5.8.2 Information accessibility

i) Caregivers must have access to background information of the client, including medical history and current medical status. This information should be provided to the caregiver before commencement in order to familiarise himself/herself with the condition of the client.

ii) Caregivers must have access to information on the mobility, dietary specifications, temperament and moods of the client.

iii) Access to the Internet must be made available to caregivers at the workplace.

iv) Access to the Internet must be monitored by a designated senior health professional to ensure that the information is understood by the caregiver and applied properly.

v) Caregivers must have access to community health workers to encourage peer information sharing. Information sharing may take place on a formal basis through the introduction of workshops by health care professionals (nurses). Informal information sharing should be encouraged among caregivers and could be done on a daily basis.

5.8.3 Screening

i) Caregivers must be screened by the employer and/or organisation before commencement of work to ensure that their skillset matches the care services required.

ii) Screening should cover the basic home care services and specialised care services and aligned to the care service required from the caregiver.

5.8.4 Resources

i) To fulfil their care services, caregivers need to be provided with the necessary resources and equipment, including protective equipment that will minimise patient-to-caregiver infection.

ii) Caregivers should be provided with gloves, aprons, masks and sanitiser on a daily basis when attending to clients.

iii) Information resources such as books and access to the Internet need to be made available to caregivers when they need more information. Organisations could stipulate specific times during the day when caregivers are allowed access to resources.

5.8.5 Support services

i) Caregivers are in need of support services from the government. Government should develop initiatives that provide emotional support services to caregivers.

ii) These services should include emotional support and coping skills to deal with caregiver burden.

iii) The government should provide better salaries to caregivers to alleviate the financial burden of caregivers.

5.8.6 Peer information sharing

i) Peer sharing information should be encouraged among caregivers and with their supervisors in order to alleviate information needs.

5.9 The aim

The aim of this study was to explore the unmet information needs of caregivers during their work activities in order to identify and address the challenges of information needs during the course of performing their duty.

To achieve this aim, it was important to determine the challenges, obstacles and information needs of the caregivers. The information needs of the caregivers have indeed been identified in this study. From the research conducted, guidelines were proposed to assist caregivers in their information needs.

However, there are gaps in the information seeking and training processes of caregivers. Institutions offering training should develop better programmes to equip caregivers with the necessary information, skills and training so that they can conduct their tasks. Caregiver organisations should consider providing onsite training to caregivers if they lack the necessary skills. In this regard, government may assist by recruiting healthcare professionals to provide onsite training and workshops at the various organisations.

5.10 Conclusion

Chapter Five discussed the themes identified in Chapter Four, and elaborated on how each theme is linked to the research questions of the study. The author proposed guidelines to assist caregivers with their information needs. The proposed guidelines can assist caregivers, institutions, organisations, and government to address the phenomena being studied by adopting and enforcing the guidelines properly.

The next and final chapter (Six) discusses the recommendations, reflections, and research contributions.

CHAPTER SIX: RECOMMENDATIONS, CONTRIBUTIONS AND REFLECTION

In Chapter Six, the research questions are answered and recommendations are proposed. The chapter discusses the contributions towards research and concludes with research limitations and a reflection.

6.1 Answering the research questions

PRQ: What are the unmet information needs of caregivers in South Africa?

6.1.1 Research question 1

SRQ 1.1: What are the work practices of caregivers and their related information needs in Cape Town, South Africa?

The present study shows that caregiver duties vary depending on the type of care recipient they provide care for. Older patients who suffer from illnesses such as dementia and Alzheimer's disease have different care needs to children who suffer from CP or other physical or mental disabilities. The tasks of the ATKV OAH caregivers and the private caregivers are more focused on providing care and comfort to the client on a daily basis. Their care recipients are mostly the elderly who suffer from dementia or Alzheimer's, or those who are unable to take care of themselves due to old age or recovery after hospitalisation. The primary duties of the caregivers are to provide comfort and care to these recipients on a daily basis. Their daily tasks include basic grooming of the client, washing, diaper changes, dressing, feeding, and attending to the daily needs of the client. Medical related tasks include administration of medication, testing blood pressure, testing urine, and providing basic wound care. Caregivers are constantly exposed to the client and their tasks are physically more challenging as they are required to physically lift and engage with clients at all time. Furthermore, these caregivers also perform domestic duties such as cleaning the bedroom, packing cupboards and folding laundry.

The tasks of the SPSCC caregivers slightly differ, as the children do not spend the entire day at the centre. Their tasks are centred on feeding and keeping the children clean and occupied until they go home. The tasks of these caregivers are also physically challenging, as caregivers are required to lift children and young adults out of their buggies and into chairs due to physical and/or mental disabilities. The caregiver tasks also include basic activities to keep the children occupied throughout the day.

6.1.2 Research question 2

SRQ 1.2: What are the factors affecting unmet information needs of caregivers in Cape Town, South Africa?

This question is directly linked to SRQ 1.1 as the challenges of caregiving are directly linked to the type of tasks performed by the caregivers. The study shows a lack of information on how to deal with the care recipient as the biggest factor affecting the unmet information need of the caregivers.

6.1.3 Research question 3

SRQ 1.3: How are information resources made available to caregivers in Cape Town, South Africa?

From the research, it is evident that limited information resources are made available to caregivers and that they rely heavily on information obtained from colleagues, other health care professionals, and the family of the recipients.

6.1.4 Research question 4

SRQ 1.4: How do caregivers obtain/access alternative sources of information necessary for their care activities in Cape Town, South Africa?

From the research, it is evident that the majority of caregivers rely on the expertise of their fellow caregivers and other health care professionals. All three cases confirmed that information sharing is very important and a primary source of information to caregivers in the study. Other sources such as the Internet were identified as a secondary source of information.

The study answered the primary research question and achieved the aim set out at the beginning of the research. The study confirmed that caregivers face many obstacles, which are related to a number of physical and emotional challenges as well as those relating to training and information.

Caregivers in this study confirmed that they experienced major challenges due a lack of information and training. The most important factor causing this lack of information is the inadequate caregiver programmes and training provided at HBC institutions. The study confirmed that a misalignment exists between the information and training provided at the institutions and the care services needed from caregivers. Caregivers also related that inadequate training could be attributed to them not having the necessary skills to perform the tasks required of them, and this leads to caregiver burden and burnout. Secondly, the study confirmed that the information received from family, supervisors and administrative staff is sometimes insufficient in supporting work caregiver activities. A lack of background and disease-specific information was specifically highlighted as a major information need. In terms of resource availability and accessibility, a lack of resources was cited as a major challenge to caregivers who need more information. In addition, caregivers who do not receive any support from family members and the community at large, have to endure economic and financial strain.

6.2 Recommendations

The results of the study point to various gaps in the information needs of caregivers. Organisations need to follow the guidelines as described in Chapter Five. In order to resolve these gaps, the study offers the following list of recommendations.

6.2.1 Information and training

i) The development of better home-based care (HBC) modules at institutions
ii) The recruitment of professional nurses to assist volunteer caregivers in terms of training
iii) Organisations need to provide caregivers and staff with on-going in-service training and education
iv) Caregivers need to receive adequate education and training on the holistic management of disease-specific care such as AIDS, HIV, dementia and Alzheimer’s disease
v) The study recommends that the direct informal caregivers (DICGs) should be provided with information on infection control and basic medical care in addition to counselling

6.2.2 Caregiver burden

i) Provision of continual psychosocial and emotional support to caregivers
ii) Provision and appointment of staff or mentors with counselling skills who are responsible for the emotional and psychological welfare of caregivers
iii) Reduction of workload placed on caregivers
iv) Provision of counselling to caregivers to alleviate caregiver burden
v) Debriefing of caregivers after a stressful experience
vi) Identification of caregiver burden through regular screening to prevent burnout
vii) Evaluation of caregiver coping strategies, and encouraging caregivers to take care of themselves

6.2.3 Resources

i) Revision of the allocation of resources at organisations

ii) Prioritising the purchasing and allocation of resources such as gloves, as well as compiling motivations to potential funders

6.2.4 Financial support

i) Providing better salaries or incentives to caregivers

6.2.5 Government

i) Government needs to provide trained counsellors to staff at caregiver institutions

ii) Encouraging increased communication and coordination between the public health care facilities and the community in order to facilitate service utilisation for the caregivers

iii) Encouraging social care decision makers to design strategies that address the needs of caregivers of PLWHA

6.2.6 Future research

The findings of the research may open the doors to more unanswered questions such as, “How can caregiver training be standardised in South Africa”, “How do we ensure that care services and aligned to the information needs of caregivers?” and “How will caregiver burden be alleviated for caregivers in South Africa?” Thus, further studies on the information needs and challenges that caregivers face are still very necessary in South Africa.

6.3 Contributions

Caregivers are considered a source of untapped knowledge. The nature of their work allows them to build a bank of experiential knowledge. However, they are unable to access a larger tacit knowledge base drawn from the personal experiences, intuition, and perspectives of other caregivers and health care professionals who face similar challenges and problems, due to a lack of information sharing and management. Due to technical and operational reasons, this specific type of health care knowledge is not accessible to caregivers. Findings from the study may encourage policy makers and government to develop collaborative programmes and initiatives for health care professionals, government, institutions, organisations, and caregivers to ensure better knowledge sharing.

Although two conceptual frameworks – Community of Practice (COP) and Knowledge Management (KM) – were discussed in literature (Chapter Two), neither of these frameworks are used to address the information needs of caregivers. These frameworks may provide guidelines on how caregivers could gain and share actionable knowledge such as: i) the development of new treatments; ii) guidelines in caregiving; iii) procedures; and iv) delivery practices, as opposed to mere service quality and outcome measurement treatments. Knowledge management (KM) should develop strategies to acquire the tacit knowledge of formal and informal health care professionals and caregivers in order to improve and achieve a better quality of life for the care recipient. The NHD is in the process of proposing new arrangements that will focus on formulating the work of informal community care workers (caregivers) through the integration of their work into formal health facilities of the communities they work in. In addition, it has also been proposed that NPO-based community caregiver programmes continue to operate alongside the outreach teams in such communities, thereby exposing informal caregivers to a range of training and informational workshops.

6.4 Contribution to Information Technology

Information is the most important tool for a caregiver. Without it, proper care cannot be provided to the recipient and decisions regarding their health cannot be made. This research identified the importance of managing the information of caregivers. It is therefore suggested that the human factor related to the provision of information be researched further.

6.5 Limitations of research

The research followed a multi-case study approach, limited to two NGOs, namely: i) the Sherwood Park Special Care Cente; and ii) the ATKV Zonnebloem Old Age Home. Three private caregivers with no affiliation were also part of the study. Interviews were conducted with 21 participants, ranging from semi-trained caregivers to fully trained caregivers. The study was based in the Western Cape Province on South Africa. A number of research limitations were identified. The research results are as accurate as possible and the findings formulated are based on the analysis of the 21 participants' answers. Due to the research conducted using three case studies, generalisation of findings to all caregivers cannot be done.

No major challenges were presented during the interview process and caregivers were eager to participate in the study. Although caregivers answered the questions to the best of their knowledge, ability and experience, some of them declined answering certain questions, as they believed that their work might be in jeopardy despite the fact that the author confirmed the confidentiality of the responses.

6.6 Reflection

In retrospect, I feel that caregivers play a major role in providing care to those who are unable to care for themselves. They are often the first, last and sometimes the only person the recipient interacts with on a daily basis. They are compelled to deal with the moods, tantrums and emotions of the recipient on a daily basis, yet they do so with a smile and a gentle hand. Caregivers go well beyond the call of duty, and despite the financial constraints placed on them, they become emotionally invested in the recipient. When the recipient passes on or the caregiver is removed from employment, the caregiver experiences a form of bereavement, and more often than not, the caregiver does not have access to support structures to cope with this bereavement.

I have developed newfound respect for these men and women who dedicate their lives, and sacrifice their families and time, to provide care for the sick, the fragile, and the elderly. Despite the negative effects of caregiving, my experience with caregivers has also demonstrated that many caregivers find a deep sense of fulfilment in their work. I hope that this research will encourage government and policy makers to provide better support structures to caregivers who, to some extent, have become the backbone of home-based care in the country and all over the world.

REFERENCE LIST

Aantjes, C., Quinlan, T. & Bunders. J. 2014. Integration of community home based care programmes within national primary health care revitalisation strategies in Ethiopia, Malawi, South Africa and Zambia: a comparative assessment. *Globalisation and Health*, 10(article 85). https://doi.org/10.1186/s12992-014-0085-5.

Abdelmoneium, A.O. & Alharahsheh, S.T. 2016. Family home caregivers for old persons in the Arab region: perceived challenges and policy implications. *Open Journal of Social Sciences*, 4(01):151.

Adelman, R.D., Tmanova, L.L., Delgado, D., Dion, S. & Lachs, M.S. 2014. Caregiver burden: a clinical review. *JAMA*, 311(10):1052-60. March. doi:10.1001/jama.2014.304.

Akbari, M., Alavi, M., Irajpour, A., Maghsoudi, J., Lopez, V. & Cleary, M. 2018. Support needs for family caregivers of clients with mental illness in Iran: a qualitative study. *Issues in Mental Health Nursing,* 39(10):896-903. doi:10.1080/01612840.2018.1445324.

Akintola, O., Hlengwa, W.M. & Dageid, W. 2013. Perceived stress and burnout among volunteer caregivers working in AIDS care in South Africa. *Journal of Advanced Nursing*, 69(12):2738-49. doi:10.1111/jan.12166.

Allan, A.J. & Randy, L.J. 2005. *Writing the winning thesis or dissertation: a step-by-step guide*. California: Corwin Press.

Allison, B., Hilton, A., O'Sullivan, T., Owen, A. & Rothwell, A. 2015. *Research skills for students.* Kogan Page. ISBN: 9780749418755 - CAT# RU34551.

Anderson, E. 2018. Uses of value judgments in science: a general argument, with lessons from a case study of feminist research on divorce. In Rutzou, T. & Steinmetz, G. (Eds.), *Critical realism, history, and philosophy in the social sciences,* 47-71. Emerald Publishing.

Archer, M., Lawson, T. & Norrie, A. 2013. *Critical realism: essential readings*. London, New York: Routledge.

Ataman, L.M., Rodrigues, J.K., Marinho, R.M., Caetano, J.P., Chehin, M.B., Alves da Motta, E.L., Serafini, P., Suzuki, N., Furui, T., Takae, S. et al. 2015. Creating a global community of practice for oncofertility. *Journal of Global Oncology*, 2(2):83-96.

Babbie, E.R. 2015. *The practice of social research*. 14th ed. eBook. US: Cengage Learning.

Barley, W.C., Treem, J.W. & Kuhn, T. 2018. Valuing multiple trajectories of knowledge: a critical review and agenda for knowledge management research. *Academy of Management Annals*, 12(1):278-317.

Barrué, C., Cortés, A., Cortés, U., Tétard, F. & Gironès, X. 2017. CAREGIVERSPRO-MMD: community services, helping patients with dementia and caregivers connect with others for evaluation, support and to improve the care experience. *Computación y Sistemas*, 21(1):23-33.

Basch, E.M., Thaler, H.T., Shi, W., Yakren, S. & Schrag, D. 2004. Use of information resources by patients with cancer and their companions. *Cancer*, 100(11):2476-83. June.

Baudry, A.S., Anota, A., Bonnetain, F., Mariette, C. & Christophe, V. 2018. Psychometric validation of the French version of the Supportive Care Needs Survey for partners and caregivers of cancer patients. *European Journal of Cancer Care*, 28(1):e12896. doi:10.1111/ecc.12896.

Bernard, H.R. 2011. *Research methods in Anthropology*. 5th ed. Lanham, MD: AltaMira.

Black, B.E., Johnston, D., Reuland, M., Lyketsos, C. & Samus, Q.M. 2018. Unmet needs of community-residing persons with dementia. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, 14(7):543-544.

Blaikie, N. 2010. *Designing social research*. 2nd ed. Malden, MA: Polity Press.

Bloor, M., McKeganey, N. & Fonkert, D. 2018. *One foot in Eden: a sociological study of the range of therapeutic community practice*. Routledge.

Brown, R.B. 2006. *Doing your dissertation in business and management: the reality of research and writing*. Sage.

Bryman, A. 2015. *Social research methods*. 5th ed. Oxford university press. ISBN: 9780199689453.

Cacchione, P.Z. 2018. Engaging caregivers during hospitalisations to improve hospital transitions: the CARE Act. *Clinical Nursing Research*, 27(3):255-257. https://doi.org/10.1177/1054773818759083.

Castaneda, D.I., Manrique, L.F. & Cuellar, S. 2018. Is organisational learning being absorbed by knowledge management? A systematic review. *Journal of Knowledge Management*, 22(2):299-325.

Leung, D.Y.P., Chan, H.Y.L., Chan, C.W.H., Kwan, J.S.K., Yau, S.Z.M., Chiu, P.K.C., Lo, R.S.K. & Lee, L.L. 2017. Psychometric properties of the caregiver inventory for measuring caregiving self-efficacy of caregivers of patients with palliative care needs. *Neuropsychiatry*, 7(6):872-879.

Chan, Z.C., Fung, Y. & Chien, W. 2013. Bracketing in phenomenology: only undertaken in the data collection and analysis process. *The Qualitative Report*, 18(30):1-9.

Chen, W., Zheng, R., Baade, P.D., Zhang, S., Zeng, H., Bray, F., Jemal, A., Yu, X.Q. & He, J. 2016. Cancer statistics in China, 2015. *CA: A Cancer Journal for Clinicians*, 66(2):115-132.

Chironda, G. & Bhengu, B. 2018. Perceptions of caregivers regarding engagement with integrated management of chronic kidney disease patients in selected public hospitals of KwaZulu-Natal region, South Africa. *Health SA Gesondheid*, 23:9.

Chironda, G. & Bhengu, B.R. 2019. Motivators of adherence to integrated management among patients with chronic kidney disease: a qualitative study. *Nursing & Health Sciences,* 21(1):63-70. doi:10.1111/nhs.1255.

Collis, J. & Hussey, R. 2014. *Business research: a practical guide for undergraduate and postgraduate students*. 4th ed. New York, US: Palgrave Macmillan.

Comfort Keepers. 2017. *What is private duty home care?* [Online]. Available: https://www.comfortkeepers.com/info-center/category/in-home-care/article/what-is-private-duty-home-care [Accessed: 4 October 2019].

Conrad, I., Alltag, S., Matschinger, H., Kilian, R. & Riedel-Heller, S.G. 2018. Quality of life among older informal caregivers of people with dementia. *Der Nervenarzt,* 89(5):500-508. doi:10.1007/s00115-018-0510-8.

Dageid, W., Akintola, O. & Sæberg, T. 2016. Sustaining motivation among community health workers in aids care in Kwa-Zulu Natal, South Africa: challenges and prospects. *Journal of Community Psychology*, 44(5):569-585.

Darkwah, E., Daniel, M. & Asumeng, M. 2018. The impact of organisational structure and funding sources on the work and health of employed caregivers in children's homes in Ghana. *Occupational Health Science*, 2(3):299-321.

Denham, A.M.J., Baker, A.L., Spratt, N., Guillaumier, A., Wynne, O., Turner, A., Magin, P. & Bonevski, B. 2018. The unmet needs of informal carers of stroke survivors: a protocol for a systematic review of quantitative and qualitative studies. *BMJ Open*, 8(1):e019571.

Denscombe, M. 2014. *The good research guide: for small-scale social research projects*. 5th ed. Maindenhead: Open University Press. http://hdl.handle.net/2086/10239.

England, P., Budig, M. & Folbre, N. 2002. Wages of virtue: the relative pay of care work. *Social Problems*, 49(4):455-473 doi:10.1525/sp.2002.49.4.455.

Eriksson, P. & Kovalainen, A. 2015. *Qualitative methods in business research*. 2nd ed. Sage.

Explorable.com. 2009. *Non-probability sampling*. [Online]. Available: https://explorable.com/non-probability-sampling [Accessed: 4 October 2019].

Farrant, L., Harding, R., Krause, R., Anderson, D., Parkes, J. & Gwyther, L. 2017. Abstract B41: an evaluation of palliative care needs among South African patients attending oncology services in a metropolitan setting. *Cancer Research*, 77(22 Supplement):B41. doi:10.1158/1538-7445.NEWFRONT17-B41.

Fauer, A.J., Hoodin, F., Lalonde, L., Errickson, J., Runaas, L., Churay, T. et al. 2018. Impact of a health information technology tool addressing information needs of caregivers of adult and paediatric hematopoietic stem cell transplantation patients. *Supportive Care in Cancer*, 27(6):2103-2112. doi:10.1007/s00520-018-4450-4.

Fellows, R.F. & Liu, A.M.M. 2015. *Research methods for construction*. 4th ed. Wiley Blackwell. ISBN: 978-1-118-91574-5.

Fraley, R.C. & Hudson, N.W. 2013. Review of intensive longitudinal methods: an introduction to diary and experience sampling research. *The Journal of Social Psychology*, 154(1):89-91. https://doi.org/10.1080/00224545.2013.831300.

Galletta, A. 2013. *Mastering the semi-structured interview and beyond: from research design to analysis and publication*. New York University Press. https://www.jstor.org/stable/j.ctt9qgh5x.

Galvin, M., Carney, S., Corr, B., Mays, I., Pender, N. & Hardiman, O. 2018. Needs of informal caregivers across the caregiving course in amyotrophic lateral sclerosis: a qualitative analysis. *BMJ Open*, 8(1):e018721.

Ghimire, P.R., Agho, K.E., Renzaho, A.M., Dibley, M. & Raynes-Greenow, C. 2018. Association between health service use and diarrhoea management approach among caregivers of under-five children in Nepal. *PloS One*, 13(3):e0191988.

Gill, P., Stewart, K.F., Treasure, E.T. & Chadwick, B.L. 2008. Methods of data collection in qualitative research: interviews and focus groups. *British Dental Journal Official Journal of the British Dental Association (BDJ Online)*, 204(6):291-5. doi:10.1038/bdj.2008.192.

Ginter, P.M., Duncan, W.J. & Swayne, L.E. 2018. *The strategic management of health care organisations*. 8th ed. John Wiley & Sons. ISBN: 978-1-119-34970-9.

Given, B.A., Given, C.W. & Sherwood, P. 2015. Caregiver burden. In Holland, J.C., Weiss Wiesel, T., Nelson, C.J., Roth, A.J. & Alici, Y. (Eds.), *Geriatric psycho-oncology: a quick reference on the psychosocial dimensions of cancer symptom management.* Oxford University Press: 131.

Goddard, W. & Melville S. 2001. *Research methodology: an introduction*. 2nd ed. Lansdowne: Juta.

Graesser, A.C., Foltz, P.W., Rosen, Y., Shaffer, D.W., Forsyth, C. & Germany, M.L. 2018. Challenges of assessing collaborative problem solving. In Care, E., Griffin, P. & Wilson, M. (Eds.), *Assessment and teaching of 21st century skills.* Cham: Springer: 75-91.

Gray, A. & Vawda, Y. 2017. Health policy and legislation. *South African Health Review*, (1):13-24.

Hancock, D.R. & Algozzine, B. 2016. *Doing case study research: a practical guide for beginning researchers.* 3rd ed. Press Amsterdam, New York: Teachers College. ISBN: 978-0-8077-5813-7.

Hanrahan, K.B. 2018. Caregiving as mobility constraint and opportunity: married daughters providing end of life care in northern Ghana. *Social & Cultural Geography*, 19(1):59-80.

Hay, C. 2002. *Political analysis: a critical introduction*. Basingstoke: Palgrave.

Heckel, L., Fennell, K.M., Orellana, L., Boltong, A., Byrnes, M. & Livingston, P.M. 2018. A telephone outcall program to support caregivers of people diagnosed with cancer: utility, changes in levels of distress, and unmet needs. *Supportive Care in Cancer*, 26(11):3789-3799. doi:10.1007/s00520-018-4246-6.

Hebert, R.S., Dang, Q. & Schulz, R. 2007. Religious beliefs and practices are associated with better mental health in family caregivers of patients with dementia: findings from the REACH study. *The American Journal of Geriatric Psychiatry*, 15(4):292-300.

Hirakawa, Y., Kuzuya, M., Enoki, H. & Uemura, K. 2011. Information needs and sources of family caregivers of home elderly patients. *Archives of Gerontology and Geriatrics*, 52(2):202-5. doi:10.1016/j.archger.2010.03.019.

Hislop, D. 2013. *Knowledge management in organisations: a critical introduction*. 3rd ed. Oxford University Press.

Hislop, D., Bosua, R. & Helms, R. 2018. *Knowledge management in organisations: a critical introduction*. Oxford University Press.

Horwood, C., Haskins, L., Engebretsen, I.M., Phakathi, S., Connolly, C., Coutsoudis, A. & Spies. L. 2018. Improved rates of exclusive breastfeeding at 14 weeks of age in Kwa-Zulu Natal, South Africa: what are the challenges now? *BMC Public Health*, 18(1):757.

Imran, M.K., Iqbal, S.M.J., Aslam, U. & Fatima, T. 2019. Does social media promote knowledge exchange? A qualitative insight. *Management Decision,* 57(3):688-702. https://doi.org/10.1108/MD-05-2017-0477.

Isebe, M.L., Ejedafiru, E.F. & Emo-Okpidi, U. 2017. Journal of Information and Knowledge Management, 8(3):73-82. ISSN: 2141 – 4297 (print). ISSN: 2360 – 994X (e-version).

James, S., Martin, C.E., Moalusi, B., Beery, M., Pahad, S. & Imrie, J. 2018. Integrated access to care and treatment (I ACT) support groups for adolescents living with HIV in public healthcare facilities in South Africa: feasibility and acceptability for scaling up. *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV*, 30(9):1107-1113. https://doi.org/10.1080/09540121.2018.1478384.

Janasz, W. & Janasz, K. 2018. Categories of knowledge in innovative organisation processes. *Studia i Prace WNEiZ,* 52(2):9-23.

Janich, P., Hayot, E. & Pao, L. 2018. *What is Information?* University of Minnesota Press.

Janse, B. 2018. *Great expectations of integrated care: an investigation of assumptions regarding the impacts of integrated care for frail elderly people on formal and informal caregivers*. Erasmus University Rotterdam. http://hdl.handle.net/1765/105647.

Jukic, N., Gagliardi, C., Fagnani, D., Venturini, C. & Orlandoni, P. 2017. Home enteral nutrition therapy: difficulties, satisfactions and support needs of caregivers assisting older patients. *Clinical Nutrition*, 36(4):1062-1067.

Kageyama, M., Yokoyama, K., Nakamura, Y. & Kobayashi, S. 2017. Changes in families' caregiving experiences through involvement as participants then facilitators in a family peer-education program for mental disorders in Japan. *Family Process*, 56(2):408-422.

Kiyange, F. 2018. Volunteering in hospice and palliative care in Africa. In *The changing face of volunteering in hospice and palliative care*. Oxford Scholarship Online: 142. doi:10.1093/oso/9780198788270.003.0011.

Kolanowski, A., Fortinsky, R.H., Calkins, M., Devanand, D.P., Gould, E., Heller, T., Hodgson, N.A., Kales, H.C., Kaye, J., Lyketsos, C., Resnick, B., Schicker, M. & Zimmerman, S. 2018. Advancing research on care needs and supportive approaches for persons with dementia: recommendations and rationale. *Journal of the American Medical Directors Association,* 19(12):1047-1053. doi:https://doi.org/10.1016/j.jamda.2018.07.005.

Kumar, R. & Das, A. 2017. Needs of caregivers of people with mental illness-rehabilitation perspective. *Indian Journal of Psychiatric Social Work*, 8(2):18-22.

Lambert, S., Bellamy, T. & Girgis, A. 2018. Routine assessment of unmet needs in individuals with advanced cancer and their caregivers: a qualitative study of the palliative care needs assessment tool (PC-NAT). *Journal of Psychosocial Oncology*, 36(1):82-96.

Lambert, S.D. & Girgis, A. 2017. Unmet supportive care needs among informal caregivers of patients with cancer: opportunities and challenges in informing the development of interventions. *Asia-Pacific Journal of Oncology Nursing*, 4(2):136.

Lambert, S.D., Hulbert-Williams, N., Belzile, E., Ciampi, A. & Girgis, A. 2018. Beyond using composite measures to analyse the effect of unmet supportive care needs of caregivers' anxiety and depression. *Psycho-Oncology*, 27(6):1572-1579. doi:10.1002/pon.4696.

Lethin, C., Leino-Kilpi, H., Roe, B., Soto, M.M., Saks, K., Stephan, A., Zwakhalen, S., Zabalegui, A., Karlsson, S. & RightTimePlaceCare Consortium. 2016. Formal support for informal caregivers to older persons with dementia through the course of the disease: an exploratory, cross-sectional study. *BMC Geriatrics*, 16(1):32.

Levy, P.S. & Lemeshow, S. 2013. *Sampling of populations: methods and applications*. 4th ed. Wiley.

Li, X., Xia, X., Wang, P., Zhang, S., Liu, M. & Wang, L. 2017. Needs and rights awareness of stroke survivors and caregivers: a cross-sectional, single-centre questionnaire survey. *BMJ Open*, 7(10):e013210.

Lim, B.T., Butow, P., Mills, J., Miller, A. & Goldstein, D. 2017. Information needs of the Chinese community affected by cancer: a systematic review. *Psycho-Oncology*, 26(10):1433-1443.

Litzelman, K., Kent, E.E. & Rowland, J.H. 2018. Interrelationships between health behaviours and coping strategies among informal caregivers of cancer survivors. *Health Education & Behavior*, 45(1):90-100.

Longacre, M.L. 2013. Cancer caregivers information needs and resource preferences. *Journal of Cancer Education*, 28(2):297-305.

Longacre, M.L., Ross, E.A. & Fang, C.Y. 2014. Caregiving choice and emotional stress among cancer caregivers. *Western Journal of Nursing Research*, 36(6):806-24. doi:10.1177/0193945913510211.

Lund, F. & Budlender, D. 2009. *Paid care providers in South Africa: nurses, domestic workers, and home-based care. Research Report 4.* Geneva, Switzerland: United Nations Research Institute for Social Development (UNRISD).

Lundberg, P.C., Doan, T., Dinh, T.T.X. & Oach, N.K. 2016. Caregiving to persons living with HIV/AIDS: Experiences of Vietnamese family members. *Journal of Clinical Nursing,* 25(5-6):788-98. doi:10.1111/jocn.13099.

Mackey, A. & Gass, S.M. 2016. *Second language research: methodology and design*. New York: Routledge.

Majumdar, B. & Mazaleni, N. 2010. The experiences of people living with HIV/AIDS and of their direct informal caregivers in a resource-poor setting. *Journal of the International AIDS Society*, 13:20.

Manogaran, G., Thota, C., Lopez, D., Vijayakumar, V., Abbas, K.M. & Sundarsekar, R. 2017. Big data knowledge system in healthcare. In *Internet of Things and big data technologies for next generation healthcare.* Cham: Springer: 133-157.

Mansfield, E., Boyes, A.W., Bryant, J. & Sanson-Fisher, R. 2017. Quantifying the unmet needs of caregivers of people with dementia: a critical review of the quality of measures. *International Journal of Geriatric Psychiatry*, 32(3):274-287.

Masuku, K.P., Mophosho, M. & Tshabalala, M.D. 2018. 'I felt pain. Deep pain…': experiences of primary caregivers of stroke survivors with aphasia in a South African township. *African Journal of Disability (Online)*, 7:1-7.

Matsea, T., Ryke, E. & Weyers, M. 2018. Stakeholders' views regarding their role as support system for people with mental illness and their families in rural South Africa. *Community Mental Health Journal*, 55(4):672-679. doi:10.1007/s10597-018-0337-6.

McIlfatrick, S., Doherty, L.C., Murphy, M., Dixon, L., Donnelly, P., McDonald, K. & Fitzsimons, D. 2018. 'The importance of planning for the future': burden and unmet needs of caregivers' in advanced heart failure: a mixed methods study. *Palliative Medicine*, 32(4):881-890.

Meyer-Weitz, A., Asante, K.O. & Lukobeka, B.J. 2018. Healthcare service delivery to refugee children from the Democratic Republic of Congo living in Durban, South Africa: a caregivers' perspective. *BMC Medicine*, 16(1):163.

Migdadi, M.M., Zaid, M.K.S.A., Yousif, M. & Almestarihi, R.D. 2018. An empirical examination of collaborative knowledge management practices and organisational performance: the mediating roles of supply chain integration and knowledge quality. *International Journal of Business Excellence*, 14(2):180-211.

Millenaar, J.K., Bakker, C., Van Vliet, D., Koopmans, R.T., Kurz, A., Verhey, F.R. & De Vugt, M.E. 2018. Exploring perspectives of young onset dementia caregivers with high versus low unmet needs. *International Journal of Geriatric Psychiatry*, 33(2):340-347.

Mollica, M.A., Litzelman, K., Rowland, J.H. & Kent, E.E. 2017. The role of medical/nursing skills training in caregiver confidence and burden: a CanCORS study. *Cancer*, 123(22):4481-4487.

Monette, D.R., Sullivan, T.J. & DeJong, C.R. 2013. *Applied social research: a tool for the human services*. 9th ed. Belmont, USA: Cengage Learning.

Moon, K. & Blackman, D. 2014. A guide to understanding social science research for natural scientists. *Conservation Biology*, 28(5):1167-77. doi:10.1111/cobi.12326.

Moreno-Jiménez, B., Gálvez, M., Garrosa, E. & Mingote, J.C. 2006. New proposals for evaluating burnout: The specific evaluation of professional medical burnout. *Atencion Primaria*, 38(10):544-549.

Morton, D., Mayekiso, T. & Cunningham, P. 2018. Structural barriers to South African volunteer home-based caregivers providing quality care: the need for a policy for caregivers not affiliated to primary healthcare clinics. *African Journal of AIDS Research*, 17(1):47-53.

Moshfeghi, Y., Triantafillou, P. & Pollick, F.E. 2016. Understanding information need: an FMRI study. *Proceedings.* The 39th ACM International Conference on Research and Development in Information Retrieval (SIGIR 2016), Palazzo dei Congressi di Pisa, Italy, 17-21 July: 335-344. ACM.

Myers, M.D. & Klein, H.K. 2011. A set of principles for conducting critical research in information systems. *MIS Quarterly*, 35(1):17-36. doi:10.2307/23043487.

Naidoo, N., Railton, J., Jobson, G., Matlakala, N., Marincowitz, G., McIntyre, J.A., Struthers, H. & Peters, R.P.H. 2018. Making ward-based outreach teams an effective component of human immunodeficiency virus programmes in South Africa. *Southern African Journal of HIV Medicine*, 19(1):1-6.

Neuman, W.L. 2003. *Social research methods: qualitative and quantitative approaches*. New York: Allyn and Bacon.

Neuman, W.L. & Robson, K. 2014. *Basics of social research*. Canada: Pearson.

Nikolai, C., Johnson, T., Prietula, M., Becerra-Fernandez, I. & Madey, G. 2015. SimEOC: a distributed web-based virtual emergency operations centre simulator for training and research. *International Journal of Information Systems for Crisis Response and Management (IJISCRAM)*, 7(1):1-21.

Nour, M., Renaud, J. & Gardoni, M. 2018. Place of caregiver who accompanies a person with Alzheimer's disease or related, what should be their role. *Advances in Social Sciences Research Journal*, 5(10):442-451. doi:10.14738/assrj.510.5332.

O'Neil, D.S., Prigerson, H.G., Mmoledi, K., Sobekwa, M., Ratshikana-Moloko, M., Tsitsi, J.M., Cubasch, H., Wong, M.L., Omoshoro-Jones, J.A., Sackstein, P.E., Blinderman, C.D., Jacobson, J.S., Joffe, M., Ruff, P., Neugut, A.I. & Blanchard, C. 2018. Informal caregiver challenges for advanced cancer patients during end-of-life care in Johannesburg, South Africa and distinctions based on place of death. *Journal of Pain and Symptom Management*, 56(1):98-106. doi:10.1016/j.jpainsymman.2018.03.017.

Ormston, R., Spencer, L., Barnard, M. & Snape, D. 2014. The foundations of qualitative research. In *Qualitative research practice: a guide for social science students and researchers.* 2nd ed. London: Sage.

Ouma-Onyango, R. 2018. *Information resources and technology transfer management in developing countries*. New York: Routledge.

Onwuegbuzie, A.J. & Frels, R. 2013. Methodology of the literature review. In Steele, M. & Piper, J. (Eds.), *7 Steps to a comprehensive literature review: a multimodel and cultural approach*. Croydon: CPI Group.

Palinkas, L.A., Sarah M., Horwitz, S.M., Green, C.A., Wisdom, J.P., Duan, N. & Hoagwood, K. 2015. Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Administration and Policy in Mental Health*, 42(5):533-544. doi:10.1007/s10488-013-0528-y.

Park, E.O. & Schumacher, K.L. 2014. The state of the science of family caregiver-care receiver mutuality: a systematic review. *Nursing Inquiry*, 21(2):140-152.

Paulin, D. & Suneson, K. 2015. Knowledge transfer, knowledge sharing and knowledge barriers–three blurry terms in KM. *Leading Issues in Knowledge Management*, 2:73-94.

Pinquart, M. 2018. Parenting stress in caregivers of children with chronic physical condition—a meta-analysis. *Stress and Health*, 34(2):197-207.

Pinto, R.M., Da Silva, S.B. & Soriano, R. 2012. Community health workers in Brazil's Unified Health System: a framework of their praxis and contributions to patient health behaviours. *Social Science & Medicine*, 74(6):940-947.

Punch, K.F. 2013. *Introduction to social research: quantitative and qualitative approaches*. 3rd ed. Sage.

Reblin, M., Small, B., Jim, H., Weimer, J. & Sherwood, P. 2018. Mediating burden and stress over time: caregivers of patients with primary brain tumour. *Psycho-Oncology*, 27(2):607-612.

Reinders, H. 2010. The importance of tacit knowledge in practices of care. *Journal of Intellectual Disability Research*, 54(Suppl.1):28-37.

Resnik, D.B. 2015. *What is ethics in research & why is it important?* [Online]. Available: https://www.niehs.nih.gov/research/resources/bioethics/whatis/ [Accessed: 4 October 2019].

Ritchie, J., Lewis, J., Nicholls, C.M. & Ormston, R. (Eds). 2013. *Qualitative research practice: a guide for social science students and researchers*. 2nd ed. Sage.

Robson, C. & McCartan, K. 2016. *Real word research: a resource for users of social research methods in applied settings*. 4th ed. UK: Wiley.

Rogerson, C. 2018. *Local economic development in the changing world: the experience of Southern Africa*. Routledge.

Romero, R.H., Hall, J., Cluver, L. & Meinck, F. 2018. Can supportive parenting protect against school delay amongst violence-exposed adolescents in South Africa? *Child abuse & Neglect*, 78:31-45.

Rowley, J. & Hartley, R. 2017. *Organising knowledge: an introduction to managing access to information*. 4th ed. London: Routledge. https://doi.org/10.4324/9781315247519.

Sanders, E.B.N., Singh, S. & Braun, E. 2018. Co-designing with communities. *Presentation*. Community Engagement Conference, the Ohio State University, Columbus, Ohio, 24-25 January.

Sandy, P.T., Kgole, J.C. & Mavundla, T.R. 2013. Support needs of caregivers: case studies in South Africa. *International Nursing Review*, 60(3):344-350.

Saunders, M., Lewis, P. & Thornhill, A. 2009. *Research methods for business students*. 5th ed. Essex, England: Pearson Education.

Saunders, M., Lewis, P. & Thornhill, A. 2012. *Research methods for business students*. 6th ed. Harlow: Pearson Education.

Selman, L.E., Brighton, L.J., Sinclair, S., Karvinen, I., Egan, R., Speck, P., Powell, R.A., Deskur-Smielecka, E., Glajchen, M., Adler, S., Puchalski, C., Hunter, J., Gikaara, N., Hope, J. & InSpirit Collaborative. 2018. Patients' and caregivers' needs, experiences, preferences and research priorities in spiritual care: a focus group study across nine countries. *Palliative Medicine*, 32(1):216-230.

Shapiro, C.S. & Varian, H.R. 1998. *Information rules: a strategic guide to the network economy*. Harvard Business Press.

Singh, D., Chaudoir, S.R., Escobar, M.C. & Kalichman, S. 2011. Stigma, burden, social support, and willingness to care among caregivers of PLWHA in home based care South Africa. *AIDS Care*, 23(7):839-845. doi:10.1080/09540121.2010.542122.

Sklenarova, H., Krümpelmann, A., Haun, M.W., Friederich, H.C., Huber, J., Thomas, M., Winkler, E.C., Herzog, W. & Hartmann, M. 2015. When do we need to care about the caregiver? Supportive care needs, anxiety, and depression among informal caregivers of patients with cancer and cancer survivors. *Cancer,* 121:1513-9. doi:10.1002/cncr.29223.

Slaboda, J., Fail, R., Bowman, B., Wade, A., Morgan, L., Norman, G. & Meier, D. 2018. Focus group findings on needs and supports for family caregivers caring for a family member with cognitive impairment (S749). *Journal of Pain and Symptom Management*, 55(2):683-684.

Smith, J. & Firth, J. 2011. Qualitative data analysis: application of the framework approach. *Nurse Researcher*, 18(2): 52-62.

Sterling, M. 2015. *What family caregivers need from health IT and the healthcare system to be effective health managers*. Connected Health Resources, HIMMS Foundation.

Stoeffler, K., Greiff, S., Von Davier, A. & Rosen, Y. 2018. Toward a new model of collaborative problem solving definition and assessment. *Proceedings*. 13th International Conference of the Learning Sciences, London, UK, 23-27 June.

Tatangelo, G., McCabe, M., Macleod, A. & You, E. 2018. ‘I just don’t focus on my needs.’ The unmet health needs of partner and offspring caregivers of people with dementia: a qualitative study. *International Journal of Nursing Studies*, 77:8-14.

Toomey, A.H. 2011. Empowerment and disempowerment in community development practice: eight roles practitioners play. *Community Development Journal*, 46(2):181-195. doi:10.1093/cdj/bsp060.

Tsang, E.W.K. 2017. *The philosophy of management*. London: Routledge.

Tsolekile, L.P., Puoane, T., Schneider, H., Levitt, N.S. & Steyn, K. 2014. The roles of community health workers in management of non-communicable diseases in an urban township. *African Journal of Primary Health Care & Family Medicine*, 6(1):693. doi:10.4102/phcfm.v6i1.693.

Van Pletzen, E. & MacGregor, H. 2013. *Multi country research on community caregivers: the backbone of accessible care and support – South Africa report*. The Caregivers Action Network.

Walliman, N. 2011. *Research methods: the basics*. Routledge. ISBN: 9780415489942.

Walsh, C.M. & Van Rooyen, F.C. 2014. Household food security and hunger in rural and urban communities in the Free State province, South Africa. *Journal: Ecology of Food and Nutrition*, 54(2): 18-137.

Wang, T., Molassiotis, A., Chung, B.P.M. & Tan, J.Y. 2018. Unmet care needs of advanced cancer patients and their informal caregivers: a systematic review. *BMC Palliative Care*, 17(1):96.

Wendlandt, B., Ceppe, A., Choudhury, S., Nelson, J.E., Cox, C.E., Hanson, L.C., Danis, M., Tulsky, J.A. & Carson, S.S. 2018. Risk factors for post-traumatic stress disorder symptoms in surrogate decision-makers of patients with chronic critical illness. *Annals of the American Thoracic Society*, 15(12):1451-1458. doi:10.1513/AnnalsATS.201806-420OC.

Wenger, E. 2011. *Communities of practice: a brief introduction*. [Online]. Available: https://www.researchgate.net/publication/235413087_Communities_of_Practice_A_Brief_Introduction [Accessed: 4 October 2019].

Werner, N.E., Stanislawski, B., Marx, K.A., Watkins, D.C., Kobayashi, M., Kales, H. & Gitlin, L.N. 2017. Getting what they need when they need it. Identifying barriers to information needs of family caregivers to manage dementia-related behavioral symptoms. *Applied Clinical Informatics*, 8(1):191-205.

Whitlatch, C.J. & Orsulic-Jeras, S. 2018. Meeting the informational, educational, and psychosocial support needs of persons living with dementia and their family caregivers. *The Gerontologist*, 58(suppl_1):S58-S73.

Williamson, V., Halligan, S.L., Coetzee, B., Butler, I., Tomlinson, M., Skeen, S. & Stewart, J. 2018. Caregiver experiences of public services following child trauma exposure: a qualitative study. *International Journal of Mental Health Systems*, 12(article 15). doi:10.1186/s13033-018-0190-6.

Wingham, J., Frost, J. & Britten, N. 2017. Behind the smile: qualitative study of caregivers' anguish and management responses while caring for someone living with heart failure. *BMJ Open*, 7(7):e014126.

Yamaoka, Y., Tamiya, N., Moriyama, Y., Sandoval Garrido, F.A., Sumazaki, R. & Noguchi, H. 2015. Mental health of parents as caregivers of children with disabilities: based on Japanese nationwide survey. *PloS One*, 10(12):e0145200.

Yin, R.K. 2017. *Case study research and applications: design and methods*. 6th ed. Sage.

Zachariadis, M., Scott, S. & Barrett, M. 2013. Methodological implications of critical realism for mixed-methods research. *MIS quarterly*, 37(3):855-879. doi:10.25300/MISQ/2013/37.3.09.

Zwingmann, I., Michalowsky, B., Esser, A., Kaczynski, A., Jessica, M., Keller, A., Hertel, J., Wucherer, D., Thyrian, J.R., Eichler, T., Kilimann, I., Teipel, S., Wolfgramm, A.D. & Hoffmann, W. 2019. Identifying unmet needs of family dementia caregivers: results of the baseline assessment of a cluster-randomized controlled intervention trial. *Journal of Alzheimer's Disease*, 67(2):527–539 doi:10.3233/JAD-180244.

APPENDIX A: INTERVIEW

Cape Peninsula
University of Technology

Semi-structured-questionnaires

Interview schedule:

Introductory remarks: South Africa has a large community of caregivers who provide care to members of the community who are too ill or unable to care for themselves. These informal caregivers usually lack adequate knowledge and access to information about caregiving practices. This study is investigating the information needs of informal caregivers in South Africa and the related challenges faced in their caregiving tasks.

The aim: The study aimed to explore the unmet information needs of caregivers in their work activities in order to identify and address the information need challenges during the course of performing their duties.

You are kindly requested to answer the questions listed below in good faith. Your responses will be used specifically for the purpose of this study only and they will be treated with the highest degree of confidentiality and privacy. Also, participation in this interview is voluntary and guarantees anonymity as well as autonomy of participants willing to participate in this research study.

Participant's details

Name: ______________________________ surname:____________________________ Position: ___________________________	Date:__________________________ Contact No:_____________________

SECTION A: DEMOGRAPHIC INFORMATION

Please tell us about your NGO/company.
Tell us about yourself, experience, education etc.
What are your daily tasks?

SECTION B: QUESTIONS

PRQ:	**What are the unmet information needs of caregivers in South Africa?**
SRQ 1.1:	**What are the work practices of caregivers and its related information needs in Cape Town, South Africa?**
IQ 1.1.1	Please explain the major obstacles you experience during care giving activities.
IQ 1.1.2	What challenges do you encounter in terms of the information provided to you by the task team/co-ordinators?
IQ 1.1.3	In your opinion, is the information sufficient to support your work activities? In what way is the information provided sufficient or why do you think it is not adequate?
IQ 1.1.4	What do you do when you do not have enough information to attend to a client? Assuming you do not have enough information for your work activities, what will you do?
IQ 1.1.5	In your opinion, does/will the lack of adequate information affect your work activities as caregivers? Please describe how the lack of adequate information affects your work activities as caregivers.
Comment:	
SRQ 1.2:	**What are the factors affecting unmet information needs of caregivers in Cape Town, South Africa?**
IQ 1.2.1	Please describe the information you require **i) before and ii) during** the course of attending to a client.
IQ 1.2.2	What type of information do you have access to during your caregiving activities? How do you get access to this required information during your care giving activities?
IQ 1.2.3:	Can you describe any difficulties experienced when trying to get the information that you need for your work activities?
IQ 1.2.4:	Do you share information about your caregiving experiences with other caregivers and care co-ordinators? How do you go about sharing information with other caregivers?
IQ 1.2.5:	In what ways has the experience of information sharing amongst other care givers affected your work activities?
Comment:	

SRQ 1.3	**How are information resources made available to caregivers in Cape Town, South Africa?**
IQ 1.3.1	Please tell me about your daily work activities routine/programme and explain the steps you follow during your work activities.
IQ 1.3.2	How often do you need to seek additional information or advice to carry out your work activities? Can you give me some examples of such a situation?
IQ 1.3.3	How is important information communicated between you and a client or the guardian of your client?
IQ 1.3.4	Can you describe any aspect (areas) of your work that you think requires any improvement? If yes, can you please describe these?
IQ 1.3.5	Based on your experience, can you suggest ways to improve information needs for care giving practices in South Africa?
Comment:	
SRQ 1.4:	**How do caregivers obtain/access alternative sources of information necessary for their care activities in Cape Town, South Africa?**
IQ 1.4.1	What alternative sources of information are available to you when you need information about caregiving activities?
IQ 1.4.2	Which of these sources are most useful for your work activities as a caregiver? And why?
IQ 1.4.3	What are your experiences of interacting with these sources of information?
IQ 1.1.4	Does the government provide you with any training on information resources relating to your work activities? If yes, please explain how, otherwise, why not?
Comment:	

Thank you for your time and patience in answering the questions. Your contribution is highly appreciated.

APPENDIX B1: PARTICIPANT ANSWERS FOR IQ 1.1.1

ZP	Zonnebloem
PP	Private
SP	Sherwood

IQ 1.1.1: Please explain the major obstacles you experience during care giving activities.

Participant	Answer
ZP1	• There's not much difficulties, just when the patient is heavy • So you can hurt yourself, and that's the only difficult I see • Feeding also and the patient can't eat properly so you have to give them small portions and that's also a major thing
ZP2	• Yes, sometimes I find things which are difficult during the day • If a patient have a wound and first I didn't wanted to do that, it's not my job but now
ZP3	• Yes, there are difficulties • The patient don't want to take the medication, and you have to talk to them to take the medication, because if they don't take it then they will not be okay
ZP4	• There is not really major issues from my side • Sometimes there is something wrong, which we don't really know of because we don't get the training that we need
ZP5	• Every day there is a challenge
ZP6	• Just the lifting of patients and the negative of that is that you get back problems • When problems arise, like maybe someone maybe have a heart attack or… and maybe I need to know more about the signs and the symptoms
ZP7	• Sometimes it is very difficult to work when your one partner don't pitch up for work • Difficult to work alone with the whole pile of people because you need to care for them and you need to shower them • Some people is bed ridden and they need to be kept dry constantly • They have bed sores and then there are people that need to be turned every second hour • Sometimes it makes it difficult for me yes, because I don't understand what's going on around me • I can't just make the decision if I don't know
ZP8	• You need to have nerves of steel to do this kind of work because you get different types of patients • You get violent patients • Patients who just want to stay in their environments, you can't get them out of their environment
ZP9	• No, I don't find difficulties as a caregiver
ZP10	• The most difficult thing is that sometimes you work with the patient all by yourself, and then you work alone on the second floor and then there is nobody to help you. A patient example like Mr Griffiths, for him we will need three carers to lift him, so it's difficult
ZP11	• The most difficult thing is that sometimes you work with the patient all by yourself, and then you work alone on the second floor and then there is nobody to help you. A patient example like Mr Griffiths, for him we will need three carers to lift him, so it's difficult

ZP12	• Yeah, and when I need some information then I just go to my staff nurse
ZP13	• No difficulty • Yes, there is, there is a big personal thing, because it’s like you play hide and seek, I don’t actually get to see the information and I don’t, It’s like a big a game you play hide and seek, I don’t know why
PP1	• We didn’t experience many problems because we had this health forum which we can go to and we can discuss monthly problems • Need to see who is available for what, and that is important
PP2	• Yes, I am doing the job of two people or three people • Old patients they need more care than other ones • I must see how is she
PP3	• Yes, it’s a big difficult task • The challenges are co-operation with the patient, that is the biggest challenge, because there are other patients used to his family
SP1	• Me – there’s a lot of challenges • Not only money • The child does not come in with the same mood every day because each child comes in with a different – with a different – issue… • You need to balance yourself to meet that child’s • You see challenges, you don’t get results immediately
SP2	• Some of the children are a bit heavy • There’s only one that can talk
SP3	• For me, no • I would like to have more ideas of work • How to handle a child
SP4	• You now everyday has a different challenge • Like how to handle the situation • Four different people or children that have a fit, different types, and you have to handle each one in its own way
SP5	• No, not really • The over twenty ones, they actually don’t understand, so they don’t take much in, they can’t absorb anymore, they are over forty, and they can’t take in information anymore, because the concentration span is low • Yes it is, because I have to do everything with them together, I have to take their hands

APPENDIX B2: PARTICIPANT ANSWERS FOR IQ 1.1.2

IQ 1.1.2: What challenges do you encounter in terms of the information provided to you by the task team/co-ordinators?

Participant	Answer
ZP1	• We face a lot of challenges, because we don't know what to expect
ZP2	• -
ZP3	• If they give us, sometimes they give us information • The other shift they give us the information • They don't give us the full information • Because you don't know what that person needs right now
ZP4	• Not really, because everybody does their work, so if the ENA is not here then we have to fall in their place • We can't do that like clean the wounds because we are not supposed to do that • Other challenges that we also face but we do not have the right equipment
ZP5	• I had a lot of challenges • Every day is a challenge and you don't know what is going to happen during the day • You get a heart attack or and then that's the challenge
ZP6	• Sometimes it is challenging • Like maybe she has water that is coming out and then you have to work with her like if you touch there then it will burst there
ZP7	• No, they give you the information that you need to know and they assist you in that way
ZP8	• Yes, that information is enough, yes, but sometimes it doesn't happen
ZP9	• Yes, because sometimes I feel like I am wearing this uniform and, the nursing uniform but I don't have enough experience as a nurse
ZP10	• No, our one, everything is there for us because even for those who are in the wheelchair, you tick it, we have everything
ZP11	• No, I do not think it is enough. They are actually supposed to give us more information, like maybe someone has Alzheimer's, then those who come for training don't know how to treat such a person and strokes, things like that. I know how to handle that type of thing, but there are those who do not know how to handle this because they do not have the training
ZP12	• It's generally there
ZP13	• Yes, there is, there is a big personal thing, because it's like you play hide and seek, I don't actually get to see the information and I don't know why they are so personal about it
PP1	• Not everybody is inclined to do everything, not all caregivers • Not everybody is inclined to do the dressing
PP2	• It is when you don't have a computer and some of this information, we are getting it from the network, from the social network Google now, so that one is a challenge for me • Sometimes I don't get the information because I don't have the time to go for the workshops now

PP3	• No, it depends if he can speak and if he is cooperating, that they can speak themselves but others they don't • We expect all the information from the parents, from the family
SP1	• Yes, because not really, I mean – information is never really enough, you'll always get more information • Also sometimes you go to a workshop the same workshop every year, new information gets added to each workshop that they go to every year • If they give you a task, and then you feel that the time is not enough for you to master that particular thing
SP2	• It's not enough • I would like to know more about how to deal with the child • I'd like to know what to really do with this child
SP3	• No
SP4	• Yes, sometimes it is enough, like how to handle somebody that is in in a -- in a strong mood, like they say tantrum…
SP5	• No, it's not enough • No, because we are short staffed and any difficulties, we just take it like that • During the day we can't ask anything because we are working here really long, because the child must trust you and you must trust that child, because you will know what he's like and know him properly

APPENDIX B3: PARTICIPANT ANSWERS FOR IQ 1.1.3

IQ 1.1.3: In your opinion, is the information sufficient to support your work activities? In what way is the information provided sufficient or why do you think it is not adequate?	
Participant	**Answer**
ZP1	• Sometimes it is enough • We need to get more information about what we need to do
ZP2	• Yes • We might need a bit more • Tell us about the patient, like what happened to the patient and more in detail
ZP3	• No, it’s not enough, because there are other things we don’t know • There are a lot of challenges
ZP4	• No • We do not get a lot of information • A lot of people here with different types of sickness • We would like them to tell us that • We dont actually know what to do • We should know more then we can do better
ZP5	• Yes, it’s enough • They explain to you what you need to do • We need more because everything changes outside, people get wiser outside • So we need to upgrade
ZP6	• No, not really • It’s not a carer’s duty for that task; maybe it’s someone who has a higher job than that task
ZP7	• No, it’s very difficult, because it is not always the same you see • They will tell you, that the client is always right and you will just have to continue doing
ZP8	• Yes, information is enough • Sometimes it doesn’t happen • They don’t tell you that that patient is sick
ZP9	• No, the sister who is in charge and the staff nurse, they learn (teach) us a lot of stuff, like working with sores some people have bed sores and so on, but some of them they learn (teach) us how to do those things
ZP10	• No, our one, everything is there for us because even for those who are in the wheelchair, you tick it, we have everything
ZP11	• No, I do not think it is enough. They are actually supposed to give us more information, like maybe someone has Alzheimer’s, then those who come for training don’t know how to treat such a person and strokes, things like that. I know how to handle that type of thing, but there are those who do not know how to handle this because they do not have the training
ZP12	• Yes
ZP13	• No, It is not enough, because if you can be more open to me and be more open to me and come to me with a righteous heart, then I think that everything will be better

PP1	• Yes • But if you think back twenty two years old, we didn’t go for revision for a long time • I think we need more of an upgrade there
PP2	• No it isn’t • I need to learn more, but this is very risky to work as a caregiver • When you know that you do not have the full information about the job • It’s very difficult for somebody who doesn’t have when you are facing this old lady • I need to have my own knowledge and my own qualifications about this job
PP3	• Yes, it is enough • But still there are things that you discover on your own as you are working, because the family they can tell you that the patient he has got this problem • Maybe as you are working with the patient you realise that maybe it is not the problem that they were telling you • If there is a bit of information and I can’t do much • If I try to talk to the family about the patient and I can’t get information, then it’s another big challenge
SP1	• No, not really • We always need more because we always get new children • Need more information
SP2	• No, it’s not enough • I’d like to know what to really do with this child • Because there is something more that you can do for the child • It’s better to learn more
SP3	• No, I don’t think it is enough, like they give you something and then you have to elaborate on it though • I want to have more activities • More ideas of how to further develop their skills
SP4	• No, you can have a vast pool of information and that information will not be enough because there will always be more • Yes, sometimes it is enough, like how to handle somebody that is in a tantrum • Enough is never enough
SP5	• No it’s not enough • Look, they mostly work with the young kids, I work with the over twenty ones, because I don’t work there anymore, because they have other teachers there with the small ones

APPENDIX B4: PARTICIPANT ANSWERS FOR IQ 1.1.4

IQ 1.1.4: What do you do when you do not have enough information to attend to a client?	
Participant	**Answer**
ZP1	• The sister in charge will find ways and means • Sister help us through and fix the problem
ZP2	• The sister or the staff nurse in charge • I will ask one of the carers or • I'll go ask for help
ZP3	• I ask for help • There are a lot of challenges
ZP4	• I don't know • Go to the staff nurse or the sister
ZP5	• I go to the sister, staff nurse, then ENAs also • Then they will see to the problem and they will come and show us • We need the information • They can give us more training
ZP6	• Then I go for assistance • I call for assistance from the staff nurse or the sister in charge
ZP7	• I talk amongst my other colleagues • We brainstorm and look for a solution
ZP8	• The sister or the staff nurse is, or the one who is in charge • I go to Sister [name deleted] that is where I get my information • Maybe the night people
ZP9	• I feel ashamed, I can't do anything, then I will ask the sister because she has more experience and so on
ZP10	• I always ask my partner, say for instance like you see there are those people who are new, yes, another caregiver, because we are two or three on a floor, because we don't work the same, and then we have our points and our strong points, then you say you're gonna help me make the bed and you are good with certain people
ZP11	• I will go to the staff nurse and I will ask her to give me a bit more, but here at Zonnebloem, they do not really give us more training. They will always tell me, [name deleted] can't you figure something out or the ENA will say let's use your insight, she is the ENA, she should be telling me and I shouldn't be telling her
ZP12	• Yes nurses and sisters • I don't go on websites • Yes, there are books
ZP13	• We will have a lack of getting better, a lack of understanding, a lack of communication and there won't be prosper then
PP1	• If I don't know, then I know a lot of people in the medical field and I will phone one of my ex-colleagues I will phone one of my ex-colleagues • Sometimes there is not enough • We ask for as much questions as possible to the relatives • We observe on our own and we see what the client's needs and that's important • It is about what that patient needs

PP2	• I have an assistant, she is available and explain to me something which I don't understand • When she is sick I phone them
PP3	• I am connected to a lot of sisters in charge and nurses • I call them if I got a problem • And ask the family
SP1	• They do ask us for our input for whatever we need • We'll ask them and they'll have a meeting with the carers for what their needs are
SP2	• I talk to my colleague • Sometimes I use my own ideas • I sit with the child talk to them and maybe give them something to do
SP3	• I go to Google • I'll speak to another carer and find out if they don't have a different idea or a different view on the situation or the challenge that I am facing
SP4	• I ask for assistance • My co-worker, or my supervisor • I use my own initiative • I trust their vision and they obviously have better experience than myself
SP5	• We have a programme implementer • Use your own mind and use my own ideas

APPENDIX B5: PARTICIPANT ANSWERS FOR IQ 1.1.5

IQ 1.1.5: In your opinion, does/will the lack of adequate information affect your work activities as caregivers?

Participant	Answer
ZP1	• Yes it will • If you didn't tell me enough about the patient and I'm going to the patient, and I'm doing what you told me to do, but it doesn't help –it doesn't help at all • So that is lack of information, because I did it the way you wanted to do it and then it doesn't work, then I am in the wrong • It is a problem
ZP2	• Yes, it will affect my work if they don't tell us how and tell us on detail, like the information they give me it's too little now I go and do my own thing
ZP3	• Yes
ZP4	• Yes, I think if we should know more of how to go about it • In terms of medical history, doing what the ENA does or what the staff nurse does, I think it will help more actually • Then nobody will sit around wondering and will just do what they need to do
ZP5	• Yes, because people's lives are at stake • Medical information I think is the first thing we must know • To know about medication will be a good idea - we know what to do if they have pain, for instance
ZP6	• Yes it would • When you don't know, what could happen? • Like maybe while I am bathing, then I need to know the right leg or the left leg, he can't stand or whatever
ZP7	• I don't think it affects my work because I ask around if I don't know anything • I ask my colleagues and staff because I don't understand
ZP8	• Definitely yes, because I cannot go to a patient and I don't know what is going on there • I put myself and the patient at risk, because I don't know what types of illnesses that patient has • They don't tell us • If we don't even know if the people have contagious sicknesses that we are able to pick up here • There was no communication about the sickness of the patient
ZP9	• Yes
ZP10	• I think it will be very difficult, very difficult, because you will think that you will do it right, but then you don't do it right
ZP11	• Yes
ZP12	• You never do your best, because at the end of the day, and it could save a life and to lose someone just because you didn't have that knowledge, it's a terrible feeling, because you could have had the information, but you don't have it
ZP13	• Yes, definitely, emotionally, I feel like getting up for work, there is nothing that I could look forward to and I feel more tired than

PP1	- Yes it does, because if you don't know how to handle people, then you won't be able to handle the clients - That's also why people drop out sometimes because they feel I can't handle it
PP2	- Yes, because I can't do that alone - I need someone who is going to explain to me about the medications because I must know exactly what kind of tablet I am giving to
PP3	- Yes, if you know nothing about something, you cannot work exactly the way you are supposed to work, because you don't know nothing, especially the medical stuff
SP1	- Yes it will affect our work - A lot of times the parents can't tell you a lot, then that is why we require from the doctor
SP2	- Yes, because I would like to know more - Because it is too little
SP3	- No, I'll just go on Google and see what it's all about and then I will implement it
SP4	- Not in so many ways
SP5	- I don't think so

APPENDIX B6: PARTICIPANT ANSWERS FOR IQ 1.2.1(I)

IQ 1.2.1(i): Please describe the information you require before attending to a client.	
Participant	**Answer**
ZP 1	• What would you like to wear today? • What would you like to do today? • Do you go to the toilet by yourself? • Do you eat by yourself? • Do you drink fluids by yourself? • All that things you need to find out before we start working on our patients
ZP2	• I need to know the patients • Like more about the patient • Who the patient is • What is wrong with the patient? • I need medical background, like in the file • I will look in the folder • Or will ask the sister or the staff sister and I will ask
ZP3	• You have to, sister or nurse have to tell you what you are going to do with that patient or client
ZP4	• It's just how you treat the person • Basically how to handle the clients
ZP5	• No I don't have anything else • I will come in by the door, knock on the door and wait for them to tell me to come in, and then when I approach her I will say good morning and how are you this morning? • I will ask how they are feeling
ZP6	• What is the patient's name? • Go to his file and see what diseases he has
ZP7	• We need to put our attention on because those were the people that were restless during the night • Maybe some people had the stomach bug • Some people didn't sleep well and maybe that is why they will be sleeping during the day • Such things over Handover and who is going for the doctor/s appointment
ZP8	• They should tell us that the patient has this or that illness
ZP9	• I need to know if this person has any sicknesses like any illness and what kind of sickness he/she has because, what kind of person she is and where she comes from and about the client
ZP10	• First you greet them, you must make sure if the person can walk • Ask her what does she eat • She got allergies or something like that or does she take a shower or what. We don't deal with medication

ZP11	• What he needs and who he is and he is so-and-so and he comes from so-and-so, and then she will tell me that he is on that type of medication and that I need to make him feel comfortable, and then I'll take him to wash. The first thing I need to see if he has bed sores, maybe he comes from home, so we don't know and then we call sister afterwards and tell her that the man came with that bed sores
ZP12	• His illness for number one. Let's be honest, some of them are very difficult. You need to get their pattern you know, their likes their dislikes, what are you going in to with this person. We need mostly medical which we get it from the files
ZP13	• I think I feel, I should be told that this is the turn over, and that this is what supposed happened last night and where you should catch up, which it is not being (done), nobody said nothing, you just have to see and smell and know by your own or figure it out by yourself
PP1	• I'll ask the relatives, give me a bit of a feedback • What is the condition? • How is the health? • The client's manners
PP2	• I come in the morning and If she's not responding then I have to go to see her • I need to find out everything today • I must make sure that she is fine
PP3	• I have to know what time he eats • I have to know what time he gets out of the bed • He must have a protocol • The family they sometimes they have got their own way in which they want things to be done and I have to know it • The problem of the patient, how it started • How he is cooperating • The body signs
SP1	• How they are feeling
SP2	• Yes, I want to know about his background • What kind of disability? • What kind of food he can't eat • If he is on tablets and how to give it
SP3	• Get like a review • Past review or mini-report, of how the child has progressed and where the child is at • Medical information • If you were unable to speak and then you learnt a few words
SP4	• I need to know the diagnosis of the child • The obstacles that hinder the development of the child
SP5	• I have to look for scratches and marks • See of the child is not hurt or anything • And tells us how much medication we must give because he is getting the fit • It is very important to know what you are dealing with

APPENDIX B7: PARTICIPANT ANSWERS FOR IQ 1.2.1(II)

IQ 1.2.1(ii): Please describe the information you require during the course of attending to a client.	
Participant	**Answer**
ZP1	• What would you like to wear today? • What would you like to do today? • Do you go to the toilet by yourself? • Do you eat by yourself? • And do you drink fluids by yourself? • All that things you need to find out before we start working on our patients
ZP2	• Yes, I need personal details • Why are they like that? • Like why does she have dementia?
ZP3	• Information for the client like what happened to her • Record keeping
ZP4	• Need to know what type of person we are handling • If it's a frail care person • Or a person that can help them • So we would know how to go about it
ZP5	• Medical information we get from sister
ZP6	• I go check what type of food he has • What he wants to drink • Do his bathing and all that • I need to know does he have a Kimbie (diaper)? • Does he go to the toilet himself? • Can he stand? • Can he lift his body up?
ZP7	• What kind of sickness that person has • What kind of person that person is, like is he grumpy, easily agitated? • I want to know what I am getting myself into • How do I like calm that person when they are in a situation? • That she's maybe got a sickness
ZP8	• I want to know what kind of diseases the patient has • What kind of tablets they are on
ZP9	• Sometimes I ask them, but sometimes they can't answer you, but I feel like we need to be informed about everything about that client, because I feel it is very important because at the end of the day, then we are the people that is working with that residents for the rest of their lives and as long as they are here – until they die. So I feel it is very important for us as caregivers, I don't want the other people who are higher than us that they must think little of us and must also inform us about what is going on, because I feel at the end of the day, we are the people who are working with the residents and we need to know what is going on in that person's life
ZP10	• If they are able to walk? • The way of getting into the bed

ZP11	• What he needs and who he is and he is so-and-so and he comes from so-and-so, and then she will tell me that he is on that type of medication and that I need to make him feel comfortable, and then I will take him to wash. The first thing I need to see if he has bed sores, maybe he comes from home, so we don't know and then we call sister afterwards and tell her that the man came with that bed sores
ZP12	• His illness, for number one. Let's be honest, some of them are very difficult. You need to get their pattern you know, their likes their dislikes, what are you going in to with this person. We need mostly medical which we get it from the files
ZP13	• Like what position the client is in • And how critical is this client maybe? • Should he or she be in the shower? • Or soft diet? • We should know specifically the situation of the client
PP1	• I'll ask the relatives, give me a bit of a feedback • What is the condition? • How is the health?
PP2	• How do you feel today, do you think this medication that you're taking is helping? • So after two days I must advise her to go and see the doctor • I must know everything about how she feels
PP3	• He must have a protocol
SP1	• Nothing
SP2	• What I need to do with him • If he can't move then I put him in his sitting position in his buggy
SP3	• The background • Do they work at a slower pace or faster pace? • What are their capabilities?
SP4	• The best thing to do is to observe
SP5	• Like if he is getting a fit on the bus • I need to know the condition of the child

APPENDIX B8: PARTICIPANT ANSWERS FOR IQ 1.2.2

IQ 1.2.2: What type of information do you have access to during your caregiving activities? How do you get access to this required information during your care giving activities?

Participant	Answer
ZP1	• We don't have, we are not allowed to, ask our patients in and out • They find it easy to open up to us, so that's the only information we will have • We are not allowed to work with medication • But we will know when our patient's medication is wrong • We will ask the staff nurse and staff sister
ZP2	• The sister, the staff nurse and the ENA • I will look in the folder • Yes, they gave me information
ZP3	• Not much, only the two of them
ZP4	• Not much, only sister
ZP5	• Medical information we get from sister • You must know where they come from and what kind of sickness • If they have a family, the family phone number
ZP6	• Only the knowledge that I read from his medical file
ZP7	• Yes, I would say medical information
ZP8	• They don't tell us and we don't have access • They are supposed to call us in and tell us that that patient has that illness • You have to be careful or you have to use masks
ZP9	• No, we can only write in the Cardex, like if anything happens to the resident or when the resident leaves the building then and like what condition he/she was in when they were leaving the building and so on
ZP10	• We do not have books, only magazines for like reading. We don't have like other. We ask the sister if we need information, we don't use computers
ZP11	• Nurse and sister
ZP12	• Yeah, she will inform me and I can go to the sister in charge, but you are not allowed to do your own thing, or you can go the ENA
ZP13	• By asking the nurse, there is a book, you can access the book, yeah
PP1	• Health forum and we have the meeting once a month • I phone ex colleagues of mine and I ask for advice
PP2	• No, there is a computer • I can't use a computer • I will WhatsApp her daughter in-law, and then she will give me the medication
PP3	• Most of the time I have got the access to any information • The family always is explaining to you • I think I am being connected to a lot of sisters in charge and nurses and with lots of them, I call them if I got a problem or whatever
SP1	• No • We do workshops and we have the task team, we do physio

SP2	• Medical information we don't have access to it • I think we should see it and we should know it, because if something happens then we need to know what we need to do
SP3	• I ask the supervisor for a file on how to handle a child
SP4	• I ask the supervisor like I can see the diagnosis • Yes, I use Google, but if you look it up on Google then there is always new information that you must know • Maybe from the books • I go to the supervisor or somebody that is more experience
SP5	• No I don't use that; I have Internet on my phone • Like I said, I use my own initiative • Then the programme implementer comes and then we come together

APPENDIX B9: PARTICIPANT ANSWERS FOR IQ 1.2.3

IQ 1.2.3: Can you describe any difficulties experienced when trying to get the information that you need for your work activities?	
Participant	**Answer**
ZP1	• No
	• No difficulties
ZP3	• No • When I come here they say you're going to do this and this and this, then you go and do it
ZP4	• No difficulties
ZP5	• No • The information is enough, detailed and step by step
ZP6	• No • There won't be any difficulties unless the family didn't state it in their file when he was admitted • That's the only difficulty or when there is not information given
ZP7	• No, there is no difficulty • There is a Cardex, so you can go to your Cardex
ZP8	• Yes • There was no communication about the sickness of the patient
ZP9	• No, we can all look at it
ZP10	• Not at all
ZP11	• No, it is not difficult to get that information, because I am a very open person, no it's not difficult for me, I ask openly
ZP12	• There are no difficulties I will say sister, please tell me about this person, because the patient is very important to me and it is my work, and I will ask what can I do with this patient here and how do I treat this bandage. No it's not a problem for me
ZP13	• It's always available
PP1	• I have worked with many people before and I will go back and ask
PP2	• Yes • I don't use the computer • I want someone to explain to me
PP3	• No, unless it's private stuff like, they always tell us what is happening • We also got access to anything • I am the one who is looking after the patient, so I have access to the files
SP1	• Yes • From parents sometimes, they are not always honest
SP2	• Yes, because sometimes, when I ask the supervisor, there is a bit of problem with communication • They tell me I'm a carer

SP3	- No - It’s easy, if I need help, I’ll go to the supervisor she’ll give me that I need or I will go to a different carer
SP4	- Yes - If probably the supervisor is not here and then I have to do my own observations
SP5	- No, because we are short staffed and any difficulties

APPENDIX B10: PARTICIPANT ANSWERS FOR IQ 1.2.4

IQ 1.2.4: Do you share information about your caregiving experiences with other caregivers and care co-ordinators? (How do you go about this? (sharing information with other caregivers)

Participant	Answer
ZP1	• Yes, everything happens at handover • In the morning is the only time basically that you will have time for it • To discuss our patients • To feel what we need to do better • Written down and verbally • Everything is recorded
ZP2	• Yes • And at home • My one friend, she's here so the two of us we discuss most of our work • The night shift people they like tell us what happened through the night then we know when we come who exactly is going on
ZP3	• Yes, I did once, and they told me no, so I left it there • Handover
ZP4	• Yes, I do • We will help one another if one of us goes wrong or don't know how to do it then we will show them • The sister that gave us the training • No, while we are busy with the patient • Doesn't happen a lot • I think it's pretty important because we would know what to do, what to expect if something has to happen – I terms of if the patient was sick
ZP5	• Yes • You can say every day, when while we are working, then I can ask my other colleague
ZP6	• In handover in the morning, the sister or the staff nurse will share it amongst us and we will discuss it
ZP7	• Yes we do • That's why the sister in charge she will be almost like a daily report where they will put each sisters names of the floors, and they will write down each floor's problems for the day • We share it in handover • Basically where the Cardex comes in
ZP8	• No not here • But it is important, very important
ZP9	• Yes, if there is something that we need to talk about then we will share, then we will talk about it
ZP10	• Yes, like I told you, it's only the ones that I worked with
ZP11	• I will go to the staff nurse and I'll ask her to give me a bit more

ZP12	• Yes, we all do, Just for instance, a patient of mine has a bed sore, then I will go to whoever on the next floor, how do I handle that, what do you think, should I put on for her other dressing, there is information sharing
ZP13	• No, we don't, it is very private we don't share
PP1	• Yes, we have this health forum • We used to have our own meetings with all the caregivers • We can share ideas, because you know they need to be briefed, they need to be debriefed grieve • We can go with our concerns there and they can give us • It's a network, so everybody answers and this one gives me input • I phone ex-colleagues of mine and I ask for advice
PP2	• Not around in Camps Bay here • Maybe in the township • Yes • She is helping but it is an old school • I said we need to refresh, we need to go now, we need to learn now
PP3	• Yes • Sometimes • We chat still like, not outside the premises but like if there is something that we needed to hear according to the problem of the patient • So, if the patient has this problem then we handle him in this way
SP1	• No • First of all, all the information stays in the office and does not go to the carers • It's not necessary for them to know about the personal issues of the parent • Yes, his condition, that needs to be shared, because that is the parent and the teacher and myself will sit in
SP2	• Yes • Me and my friend we talk to each other • In the morning we will discuss • If I don't know and then I can always go back and ask her • We share information • I will ask the supervisor • It's a good thing and it helps me
SP3	• Yes • We discuss this is what we did for the day
SP4	• Yes • Then they can also tell you when you were right and when you were wrong • Give you input • And then we talk about this and then we share
SP5	• Yes • We all have to share • Like when they come from a workshop then they have to share with us and when we come then we have to share with them • I will always share with everybody else

APPENDIX B11: PARTICIPANT ANSWERS FOR IQ 1.2.5

IQ 1.2.5: In what ways has the experience of information sharing amongst other care givers affected your work activities?	
Participant	**Answer**
ZP1	• It affects it in a good way • Not in a bad way
ZP2	• Yes, I think that we might need a bit more • That work will be much better • And we will all learn
ZP3	• No, it doesn't happen • The thing is here—we can't share because we are to different people, so we don't understand one another • They share it alone and they don't share the information with us
ZP4	• No, not negative impact • Yes, it does help to share information because it's not everybody that knows everything
ZP5	• Yes, it does improve my work
ZP6	• Yes, it helps a lot
ZP7	• Yes, we need to share information, we need to know and be aware • Maybe we try a new method on that person when it comes to bed sores
ZP8	• Yes, we must do it • If we do not share it with each other, then how will we develop? • We will get a solution at the end of the day • But it is important, very important
ZP9	• It is very good because then we know what is going on and then we know what to do during the day
ZP10	• I don't really know, I don't have that experience, because I only know the one that I am working with, I only know her and it makes me want to learn more. It was good, it was positive
ZP11	• Yes, it is a very good thing and it is very important
ZP12	• Yes, it was positive, like I had one on my floor, she passed on now, and she had the bed sores and we got it right with some honey
ZP13	• Sometimes it does and sometimes it doesn't, it depends on the type of person that you are I don't know, can you keep it personal I don't know, so sometimes it does not and sometimes it does not
PP1	• Yes, it's good to share the information • Because they can learn through this and they can learn something
PP2	• Yes, it's good • I also want someone who can share that information in Xhosa, that you can share how to look after them

PP3	• It depends • It depends with what information, because if it is that information that I was not allowed to have access to the information and if I share them with my friends and it leads to the family then it will be a problem, because I was not allowed to have access
SP1	• Helps us to the help the child
SP2	• It's a good thing • It helps me
SP3	• It has improved • Because the other caregivers have quite a lot of experience
SP4	• It's very important because it will broaden your mind to certain issues about the client • On the developmental aspect it improved my work
SP4	• Yes, it is helpful • Yes, it improves my work, you can tell me what you learned today and I can tell you what I learned today

APPENDIX B12: PARTICIPANT ANSWERS FOR IQ 1.3.1

IQ 1.3.1: Please tell me about your daily work activities routine/programme and explain the steps you follow during your work activities.

Participant	Answer
ZP1	• I will come on duty • Greet my parents • Showering the people and washing • Breakfast • Cut nails or do hair • Make them feel comfortable • Make them feel loved • Its tea time • In between we will give them water • Check if they’re dry or if they have any complaints
ZP2	• For the day, you must shower like five people • Then its breakfast • We feed the patients • We give them tablets • Ask the patient what we must do • Do their hair or their nails…
ZP3	• We give the tablets • We wash them • We change the nappies • Give them food • Take blood pressure and urine
ZP4	• See that they are washed • Dressed • Fed • Clean them • Make up their beds • Just see to them and shower them • Do their nails or do their hair
ZP5	•
ZP6	• Get showered, • Get bed washed • Breakfast, we get ready for breakfast • Gives out the tea • Then we give them water at eleven • Change nappies • Then it’s check who’s wet, then it’s toilet run, then going to see who needs the toilet • Showers also between • Then it’s supper time and then off to bed after that

ZP7	• First attend the handover • Take our tablets and go to our floors • I will check if everyone is in their rooms • Whoever needs to be showered for the day • I start making the beds and then its tea time • Clean the demotes • People’s wheelchairs need to be cleaned • Cut nails • Pack cupboards • Fetch the washing and pack that away • Its tea time • Sometimes chat with the residents • Supper • Take the laundry down and sign the book
ZP8	• Office first for handover and find out what happened • Start washing the people • Our job is to: wash the people • Dress the patients • Pack their cupboards • Check that the environment of the patient should be clean • Change diapers during the day • Feeding • We don’t work with tablets • We don’t give injections to anyone • We don’t take the blood pressure • But we learn about it • But we also have to do it sometimes when those people are not here, but we don’t get paid for that
ZP9	• In the morning we start at quarter to seven, that is the time we start, then we must look at the people, to you that you must wash and shower, and put on clean clothes on, make up their beds, brush their teeth, brush their hair, you must do everything for them, they can’t do it • Some of the residents can help themselves and then you just assist them. At eight o’ clock, it is breakfast then you take them to their breakfast, porridge bread tea, juice, whatever they want. And the others who need to be fed, they can’t help themselves and then we feed them, then after that then we have to check the nappies and change the nappies like seven o’ clock in the morning when we came in when we washed them and then like twelve o’ clock, like half past eleven, then its lunch time and after lunch time then we change the nappies again and wash the bottoms, and after that then they go to bed and lie down a bit and rest a little • Then three o’ clock its tea time and then we check their nappies again, then if its dry we leave it on and like half past four, its supper time and then we serve them their supper

ZP10	• There is nothing different here, we do the same thing over and over, because in the morning we take those and we wash them, full shower, and those who are bed-ridden, then after that eight o clock we must give them breakfast and take them to go watch TV, after that, we take those who need to take shower, because they do not have the same day • Then twelve o clock we give them lunch and then we take them to bed and then we put on nappies for those who wear the nappies and then before three, we wake them up, they must go watch TV and then half past four its super time and then we shower those who need to be showered and then we put them to bed • We work from seven til seven. Then after five, we pack the cupboards, because we take clothes for them in the morning and then we take clothes for them. We have the book, those who showered, etc. • That information is called handover for those who come [to] the night shift, etc. We write down all the information about the person and everyone has a page that you must fill in there
ZP11	• In the mornings we start at quarter to seven, and then the sister will hand over to us what has happened during the night. Then I will go around and say, “Good morning, How are you?” • If there are patients who are sick then I will go back and pack my trolley and then I will see to him first, and I will wash and dress him and then massage home and make him comfortable for the day, and then I will continue with my daily tasks, but I will first sort out my sick patients so that I know what I need to do for the day • The medication will be done by the staff nurse, or maybe she will tell me that there are the tablets of the patient, but I will go to her beforehand and ask her what that tablet does and why she is taking that pill, then she will inform me. I can’t just give her a tablet and I don’t know what it is for
ZP12	• Okay, I start at quarter-to-seven, get everybody ready for breakfast, Kimbie change, bed wash, those that needs bed wash, showers, everything in about forty-five minutes or less, then it’s breakfast time • After breakfast at 10 o ‘clock, then they get tea, then some more showers, like those I didn’t get to. The at twenty-to-twelve lunch time, then after lunch time, dry those that need dry Kimbies and put them to rest, three its tea time again and dry them again and get them ready for supper, but during those times you check the nails, you check the hair, anything that needs your….medication they get in the morning. I do the medication as well and some gets at lunch time and I give the evening tablets as well
ZP13	• When I come in the morning, then I will go to all the rooms to go and see who needs help and who can come out of the room, whether I need to change the pyjamas or the daily clothes, especially if one of them needs to be helped then, brush their hair or give them a full bath or a shower , when it needs to, it’s needed, then I should do that • And then when he is dressed, then I take him out to the dining room and make him sit down then when everybody comes to sit down, the breakfast time will come, then we feed them breakfast , then its porridge or what so ever, and then when they are finished with their breakfast, we will give them their tea time, which is ten o clock, and after tea time then maybe we can check their nails or their hair needs to be cut or maybe their massage, or something like that just to pamper them a little bit before lunch time starts, and then when twelve o clock starts then we assist them where they need to be assisted its maybe food or soft diet, then we feed them, if not them its lunch, then after lunch its three o clock, then it’s another tea time, then supper again at half past four, then we feed who needs to be fed and then its sleeping time, or when they finished at half past four then we put them back in bed • We need to put them back into the bed or change their Kimbies ad in between we see where we can pamper and massage and put lotion on or cut their nails or whatsoever
PP1	• Well I am seventy years old now so I don’t do patients anymore

PP2	• I bathe her in the morning • I make sure that she is clean • Make sure that she sleeps in a clean place • She got clean clothes • She did eat • She's happy and she is safe • I must know the time is now one o' clock, by eight half past eight, she is eating breakfast • I must make sure that I should give her the medication during that time • After lunch or before lunch and then I must make sure eleven o' clock, each and every hour I must check; "How are you feeling? Are you fine? Yes I am fine". If I am going downstairs, I have to let her know that I am not around in the house and if I'm going to clean outside, sweep outside, then I must let her know, every time if you lie down, I have to make sure if you are comfortable, do you need another cushion or what…you want to lie down in the computer room or he bedroom, taking out the clothes for her to wear then I must take out five of them and she must choose which one she wants to wear
PP3	• I must have the handover • What is happening and what is the next step • See my patient • Where is he sleeping, is it wet or is it dry? • If I found all those things and I see the environment, and if he is clean for him to start eating breakfast • If I am satisfied that he is sleeping on a dry then and he is clean
SP1	• I need to see to the admin • I need to see to the carers • The daily structure and see that they do whatever they need to do
SP2	• Okay, we come in in the morning and 'batcha' (pray), then we come in and do the morning ring, then we do the ABCs, then days of the week, months of the year, then when we done we eat, then when we done feeding them, then we start with the programme
SP3	• We will come in the morning, prepare everybody • We settle them in • We do the morning ring, a prayer • We brush our teeth • We have breakfast • We wash our faces again • We check their nappies and see who wants to go to the toilet • Have an activity depending on the theme for the week • After that they have lunch • We check the nappies again and we have another activity before lunch also and then we have a forty-five minute resting period before we go home
SP4	• We put them in their positions like sitting • We do our daily morning programme • They must go to the toilet, nappy changing and we feed those that cannot feed themselves • I have to clean them and wash them properly and put other clothes on
SP5	• -

APPENDIX B13: PARTICIPANT ANSWERS FOR IQ 1.3.2

IQ 1.3.2: How often do you need to seek additional information or advice to carry out your work activities? Can you give me some examples of such situation?	
Participant	**Answer**
ZP1	• Information is a daily basis • You always need it • So whenever things are not right on our floor then we will go and ask the sister, sister I need assistance , can you help me deal with this small problem that I have, and then she will help
ZP2	• Every day
ZP3	• Always want to ask • Yes, because I know if I'm going to ask, they're going to tell me that I'm a carer
ZP4	• Every day • During the day we just go about our work and do what we are supposed to do, and if we don't we go to the staff nurse and the sister
ZP5	• Its only when there is maybe someone new
ZP6	• No answer
ZP7	• We need information a lot, you can't say that we don't need information, because every day you learn something new
ZP8	• Twice a week
ZP9	• That is especially when you are working with a new patient, that you have never worked with before, like for instance, here comes a patient that has a sickness that you've never worked with before and then I feel that I need more information. Yes, sometimes it happens unexpectedly. We don't know what kind of people are coming in here, like one of my patients had a peg, I didn't know how to work with that so I learnt. The ENA nurse she teaches me, I think she teaches me enough but I feel that I need more information like where it comes from, how it happens
ZP10	• Not a lot • For me it is experience work, since I have been on this floor since 2011 until now and then I never stay at home
ZP11	• I'll ask what can I do with this patient here and how do I treat this bandage • No it's not a problem for me
ZP12	• Maybe once a month
ZP13	• Yes, always, like we need it like a daily thing
PP1	• All the time, I think we are never too old to learn, that is what keeps us going
PP2	• I think every week, once a week • I need to learn more but that lady, that daughter in-law she's helping me when I need something but I need my own information
PP3	• Almost every time, every time • That's why each and every day, I need information from them, we need this, and you must handle him like this • Sometimes, like I don't know if I am on the right track with the patient but sometimes it depends. You can be working with the patient and you think – I'm confident and I know what I'm doing – but maybe the family they are not satisfied or what, but also the family are sure that they can tell you that we need you maybe to do this this and this

SP1	- Not often, because I know what I need to do
SP2	- Twice a week, maybe once a week
SP3	- Once a week, because once a week I do a weekly report, then I would plan something for the following week and then sometimes I'm stuck and need to access other information
SP4	- In the afternoon and then we talk about this and then we share
SP5	- Yes, all the time

APPENDIX B14: PARTICIPANT ANSWERS FOR IQ 1.3.3

IQ 1.3.3: How is important information communicated between you and a client or the guardian of your client?	
Participant	**Answer**
ZP1	• It's important to communicate with them so that you can know how they feel and what they want and it's not about you
ZP2	• One, he also call me
ZP3	• It happens when I talk to the patient • First talk to them about general, if there is something, and then I try to talk to the patient. I don't like to go direct; I like to go in another way, around, to get the information from them
ZP4	• Sometimes it's very hard, especially when they're trying to speak to you, then you can't communicate because it's hard for you to understand the person
ZP5	• We talk and I ask the sister
ZP6	• Its hard, all the new patients are very frail, they can't speak so the people that are here already
ZP7	• We need information a lot, you can't say that we don't need information, because every day you learn something new
ZP8	• If he trusts me and we keep it to ourselves, but if it is serious then I have to tell the nurse
ZP9	• That is especially when you are working with a new patient, that you have never worked with before, like for instance, here comes a patient that has a sickness that you've never worked with before and then I feel that I need more information • Yes, sometimes it happens unexpectedly. We don't know what kind of people are coming in here, like one of my patients had a peg", I didn't know how to work with that so I learnt. The ENA nurse she teaches me, I think she teaches me enough but I feel that I need more information like where it comes from, how it happens
ZP10	• Some clients are good and some are okay and then you just have to try, sometimes it's hard but you just have to be strong
ZP11	• How I do it is I go to his room and make him comfortable and then we have a good chat, and then we make a cup of tea and then we have a nice chat
ZP12	• It's hard to say, it depends, yeah
ZP13	• Yes, always, like we need it like a daily thing
PP1	• I would never ask personal questions • Mention confidentiality then they are comfortable with you • I normally ask the relatives what is wrong
PP2	• The communication with the family is very important • So if there is a communication then everything is easy
PP3	• With the family they are not satisfied or what • But also the family are sure that they can tell you that we need you maybe to do this this and this
SP1	• The carer must send a letter to the parent
SP2	• We don't talk to the parents, we write a letter, and we are not allowed to • Sometimes at parents meeting and we discuss and we talk

SP3	- We have a message book, so if I need to communicate something to the parents, then I will write it in the message book
SP4	- Important for the communication between the caregiver and the parent; it should be always be in a good spirit. Because it is, the parent knows the child better than the carer
SP5	- Okay we have a message book - Direct communication sometimes with the parent

APPENDIX B15: PARTICIPANT ANSWERS FOR IQ 1.3.4

IQ 1.3.4: Can you describe any aspect (areas) of your work that you think requires any improvement? If yes, can you please describe them?

Participant	Answer
ZP1	• I would like first aid, because for example patients fall – they hurt their leg, it might be broken, we don't know, we can't just lift up a patient • I would like to do first aid
ZP2	• Give us more workshops • More training • Give us the opportunity to learn further
ZP3	• Everything • Like the nurses who work at night, they should check their patients if they get help. They must give the patient help and check what is wrong with the patient so that they can write it down • And at handover, so that we can know that especially if they got sick • They can improve and share then they can tell me all the things and the other one, they can take my number and phone and ask me
ZP4	• Nothing to improve, because every morning when we come they'll say what happened the previous night
ZP5	• We must do first aid training every second year • We must upgrade every day • We need blood pressure machines, temperature • We need training on anything • We need more information and they can give us workshops
ZP6	• More training
ZP7	• First aid is very important • You need to know CPR and why do you need • CPR is very important
ZP8	• Information about the patient • The sister must give us the information about the patient • Be honest with us, be careful maybe that person is very very sick • Tell us to be careful or something like that, don't let me just go into the room and I don't know what disease you have • We need aprons, masks – what is there – a lot of things • It's a big need, yes
ZP9	• Yes. I do feel like I don't want to stay just here, I want to go further, and I feel like maybe of there can be opportunities for us as caregivers, like even if the government can help us, to give us more opportunities to go and study further… • We need to learn more and that is my desire, to learn more
ZP10	• Then we should call all of us to now come and see and then see if you can do it, so we need more practical
ZP11	• Yes, they can send us away for an hour, may be for half a day, and maybe physio and we need to know about medication

ZP12	• From myself, there are such a lot of things • Yes, like I said, we need training with first aid, things like that we need that all of us don't need that, like for instance now, I went and there was no gloves so how do you work without gloves?
ZP13	• I think, there should be more teamwork man, and more teamwork, and they should work on more structure, not to work on and be so and so on
PP1	• I think refresher courses • Well, I think that you stay for a long time at home • Once a week to update and refresh, so it can be what's up to date in the medical field, like if you don't have refresher courses then you won't know
PP2	• The area of the medication things, I need to learn more about that, because maybe in some day, I will get another job and then there is no one like the daughter in law that is helping me, I'll be on my own • By going back and learning more about caregiving
PP3	• The communication between the caregiver and the family, that is a challenge, because if you are not communicating well, then the job is hell • This is not a simple job, it deals with your knowledge • So I think that that is also a big challenge
SP1	• Our space is a big factor • Equipment
SP2	• Get more stuff to work with the children, they need more equipment • Training it's good, and it will help • I think it will help because we have to do more with the child
SP3	• Like getting a better way to teach them for their intellectual development • I think workshops and training • Yes, we do training with the Western Cape forum and they teach us about different types of things but I think they should elaborate, like they just give a brief description of something or what it's about but I think we need it more in depth
SP4	• We need more resources – like unfortunately this place is too small, like different stuff for the children to explore, like equipment • Training? Yes that important because it will equip you to handle situations
SP5	• Every day we need workshops for improvement • We need it every day because there are many children coming with different disabilities, we need to help

APPENDIX B16: PARTICIPANT ANSWERS FOR IQ 1.3.5

IQ 1.3.5: Based on your experience, can you suggest ways to improve information needs for care giving practices in South Africa?	
Participant	**Answer**
ZP1	• Nothing
ZP2	• Training
ZP3	• No • The caregivers they need a lot of information, because some of us we don't come from the patient, so I think we need more
ZP4	• No • The courses that we did was six months and I think it's too short, so I think we can have it extended longer to maybe a year or longer • I think they should include everything in the course for medical, like giving out medication, seeing to the patient, doing the temperature, doing the bed sores and how to put in catheters, how to put in nasal tubes • They can give us training on that also because we only had like a few people that had, three people that had, the stomach and the nasal tube, is mostly for people that had strokes
ZP5	• Abuse an old person and I am registered then I should never get a job as a carer; It's a big problem
ZP6	• Nothing
ZP7	• First aid is very important because you need to know CPR • Training will be good
ZP8	• The majority of caregivers are complaining about money, but we are the people who are doing all the work • I must do your work, but you are an ENA and we don't get that money
ZP9	• They can offer us like to do courses or open up a college for nursing so that we can learn more about nursing, then we won't just be down there and never go up. Here at Zonnebloem they can't send us to the college, okay there's an opportunity to go learn further, they don't have that money to support us, so we need more
ZP10	• We must have training, you see we did the training, but we must do more training also. Like say for instance, you know, we are working this Wednesday, and then the others they are off and then we must go for training because there is no activity for those people who are up. They just sitting there and are watching that TV, it's not right. Like we must do something else with them, like play, like make them feel comfortable
ZP11	• Just to learn further
ZP12	• I honestly don't know
ZP13	• I think there is a lack of, a very low, increase of money; they should increase the salaries for caregivers…
PP1	• I think I have spent a lot about refresher courses and to keep people up to date what's happening • We need training so that we can always keep our stats the same • Our number, our numbers that we've got for the caregivers, we need to keep them the same, so if a few drop out then we need to train another few to make up for the numbers you know because I think that's why we lost, because we couldn't rain more people for free

PP2	• Information that I must know and things are changed now • I am still using the old tricks • Now things are improving and now you have to go and get more information about this and learn about the caregiver. Remember I must also do the first aid, yes they did show me how but another thing it is very important I must have, the old people they can fall any time and I must have the medical, that's why you need a full training about that caregiver
PP3	• They want to work as a caregiver but just because they need money. • My point is, maybe it is the way, and how they are trained, so there is a need to improve the training of this people • Training or workshops, yes, that would be very nice
SP1	• I think that they are not paid enough for the work that they are doing
SP2	• Like we need to learn how to do more about physio • Learn more how to handle the child about the bad behaviour
SP3	• Like a workshop, even a course, beside the normal course that home-based caregivers do • Get more experience from and more theory knowledge of what to do • First aid, they teach you about bandaging • How to work with epilepsy
SP4	• Get a caregiver ready for any situation • First aid is really important because you know anything can happen with these kids, so you have to be prepared for anything
SP5	• I think more information could help • Get training or workshops

APPENDIX B17: PARTICIPANT ANSWERS FOR IQ 1.4.1

IQ 1.4.1: What alternative sources of information are available to you when you need information about caregiving activities?

Participant	Answer
ZP1	• No, we don't have any other resources • Only if we need some information we go to the staff nurse or the sister • No workshops
ZP2	• We don't have a lot of information, unless you go and find it on your phone and you go Google it • Yes, I will use my phone
ZP3	• I think Internet
ZP4	• Not much, only the two of them
ZP5	• Facebook and WhatsApp
ZP6	• Not a lot
ZP7	• There's training • They do demos • No, they don't provide us with it
ZP8	• Yes, there are websites; I use that sometimes
ZP9	• We are not supposed to talk to the residents' family about their health or any outsider and we are not allowed to talk to anyone about anything that happens in here, that job is for the staff nurse and the sister who is in charge, only they can talk to the residents' family or friends or doctor whatever…
ZP10	• We don't have books, only magazines for like reading • We don't have like other • We ask the sister if we need information, we don't use computers
ZP11	• -
ZP12	• Yes nurses and sisters • I don't go on websites • Yes there are books
ZP13	• If there are no sources, then I can't • Do you have books? Yes, books too • Internet? No • Do you ask the nurse? Yes we ask the nurse
PP1	• I have worked from home all these years and al my experiences come from this house • There are no more resources that I know of, and I work on my own at the moment and there are no other sources
PP2	• The sister at the old-age home
PP3	• I go on the Internet where I can go look and check • I think I am being connected to a lot of sisters in charge and nurses and with lots of them • I call them if I got a problem or whatever

SP1	• No, it’s what we accumulate over the years • We don’t really have information about the parents • We only have the medical report and then we accumulate – we work with the child, every time then we learn what the child’s capabilities is… • We are working with the task team. It’s a team that Western Cape created to work with our learners. It’s a physiotherapist, OT, a speech therapist and a --er – a general educator
SP2	• The task team • We have a programme implementer, she’s the one who gives us work and tells us we must do this and that and that • I’ll go to my supervisor • No, we can’t use the Internet here • Google will be good • I’ll use my phone and I get information
SP3	• Google
SP4	• Google
SP5	• The programme implementer gives me like a week planner, then I’ll ask her • The task team -- they do help a lot

APPENDIX B18: PARTICIPANT ANSWERS FOR IQ 1.4.2

IQ 1.4.2: Which of these sources are most useful for your work activities as a caregiver? And why?	
Participant	**Answer**
ZP1	• No, they don’t give us training here • We are here, basically here to do just do our job, to look after old age people • We don’t get training but it will be very nice to have training
ZP2	• The sister, Google, because they will give me more information, they will explain to me and the sister will explain to me in detail
ZP3	• I think Internet
ZP4	• Nurses
ZP5	• Nurses
ZP6	• Sister
ZP7	• Nurses, f they can provide books for us • Train you maybe and come twice a week and share the information that you need
ZP8	• The staff nurse because she is here with us on the same shift
ZP9	• The staff nurse
ZP10	• Yes, each and every client has a file, and then everything is written in there, like maybe she is allergic with this and then maybe she got this disease like that I think I must learn more
ZP11	• The staff nurse
ZP12	• I prefer the person in charge because they are more; they describe it better to you
ZP13	• I would say that somebody, someone gives you the training and should lead you by the hand and teach you step-by-step
PP1	• No more resources that I know of • The best for me is that I work on my own at the moment
PP2	• But now I need to go back to the old-age home and sit down with the sister, give me more information about the old people
PP3	• Information from the family
SP1	• Nothing
SP2	• The task team • The programme implementer
SP3	• I do find it useful most of the time • But when it comes to like activities for the children with mental disabilities then I don’t find it useful, then I as the programme implementer, and I should plan programmes for all the classes but I’m not in the classroom with all the children to know what they are capable of, so when I search for an activity, then it will be more for like a normal child, instead of…
SP4	• Google
SP5	• They (task team) …they do help a lot

APPENDIX B19: PARTICIPANT ANSWERS FOR IQ 1.4.3

IQ 1.4.3: What are your experiences of interacting with these sources of information?	
Participant	**Answer**
ZP1	• No sources
ZP2	• No sources
ZP3	• No sources
ZP4	• We do know how to do it but when she came we knew a little bit more
ZP5	• Facebook and WhatsApp
ZP6	• The sister – good
ZP7	• You will have more knowledge and you will know what to do and you will be wiser
ZP8	• It was beneficial, the information is useful
ZP9	• It is very good because then we know what is going on and then we know what to do during the day
ZP10	• It was good, it was positive
ZP11	• Yes, it is a very good thing and it is very important
ZP12	• Yes, it was positive
ZP13	• We still need more training
PP1	• None
PP2	• Its good …where I can learn more about medication and caregiving
PP3	• Internet is good
SP1	• Nothing
SP2	• It's a good thing and it helps me. I like to know
SP3	• I do find it useful most of the time, but when it comes to like activities for the children with mental disabilities then I don't find it useful, then I as the programme implementer, and I should plan programmes for all the classes but I'm not in the classroom with all the children to know what they are capable of, so when I search for an activity, then it will be more for like a normal child, instead of…
SP4	• I think it broadens your mind and gives you a better understanding and it is beneficial, and sometimes it could be beneficial
SP5	• It's a good experience

APPENDIX B20: PARTICIPANT ANSWERS FOR IQ 1.4.4

IQ 1.4.4: Does the government provide you with any training on information resources relating to your work activities? If yes, please explain how, otherwise, why not?	
Participant	**Answer**
ZP1	• No
ZP2	• No
ZP3	• No
ZP4	• No
ZP5	• Nothing like that • Yes, it's important because it's just that a lot of people are in homes but I think the government must come and see what's going on here
ZP6	• No
ZP7	• No, they don't provide us with nothing, but we would like to that and that will be useful for us, yes
ZP8	• No, nothing
ZP9	• No, no, the government doesn't, we have to go and we have to go find our own people who an teach us about caregiving and then we have to pay out of our own pockets. It will be very good if they provide that for us
ZP10	• No, not at all. Nothing, you only go to school for yourself and after that you do volunteer work if you want to, and if you are lucky then you will get work. Yes the government should do it. Because you want to learn more from other caregivers from other places, and we meet other caregivers from other places
ZP11	• No, the government should help us but they don't
ZP12	• Not that I know of, I mean we take care of the old and they should
ZP13	• Because I haven't seen them yet
PP1	• Yes, they trained us at the beginning in 1996 and not anymore and they trained us, then they were gone, we didn't see them, we didn't hear from them • They should train • That would be fantastic, because people phone here at all times here for a caregiver
PP2	• No, if our government in South Africa can open up some places where the people can go and the caregiver and get more experience, then that thing will help us a lot, or he can take as a student in school, if there is a centre that we can go, and we can go and learn more about these things. We need government to intervene in these things
PP3	• No
SP1	• No
SP2	• No
SP3	• Yes, That's like the Western Cape forum
SP4	• Partly, like the task team, the Education Department, then come here and give us information. • Maybe we can have more interaction between these
SP5	• Yes. only Western Cape (task team)

APPENDIX C: INDIVIDUAL CONSENT FOR RESEARCH PARTICIPATION

Cape Peninsula
University of Technology

FID/REC/ICv0.1

FACULTY OF INFORMATICS AND DESIGN

Individual Consent for Research Participation

Title of the study: ***The information needs of caregivers in South Africa***

Name of researcher: ***Amna Ashour***

Contact details: email: ***amnaashour16@gmail.com*** phone: 062 259 7590

Name of supervisor: Dr A. De la Harpe

Contact details: email: andre@i2ifica.com phone: 082 448 1058

Purpose of the Study: To explore the information needs of informal caregivers in order to provide caregivers with the necessary tools, networks and information bases to improve the care services and assistance they provide to the care recipients.

Confidentiality: I have received assurance from the researcher (***Miss Amna Ashour***) that the information I will share will remain strictly confidential unless noted below. I understand that the contents will be used only for her ***BTech Thesis*** and that my confidentiality will be protected by creating a code for each learner. Only the outcome that will be a holistic view, will be made known for public domain.

Anonymity will be protected in the following manner (unless noted below). I will make use of a recording device to capture the interviewees' answers. I may object to media usage in the table below.

Conservation of data: The data collected will be kept in a secure manner. The researcher will keep data at his office and the offices of the supervisor, Dr de la Harpe. Data will be electronically stored and only the researcher and supervisors will have access to the data. The data will be collected and stored as per research method fully described by the researcher, especially for audit purposes.

Voluntary Participation: I am under no obligation to participate and if I choose to participate, I can withdraw from the study at any time and/or refuse to answer any questions, without suffering any negative consequences. If I choose to withdraw, all data gathered until the time of withdrawal will be disregarded.

Additional consent: I make the following stipulations (please tick as appropriate):

	In thesis	**In research publications**	**Both**	**Neither**
My image may be used:				
My name may be used:				
My exact words may be used:				
Any other (stipulate):				

Acceptance: I, ………………………… (print name) ________________(Signature)

agree to participate in the above research study conducted by ***Ms A Ashour*** of the Faculty of Informatics and Design, Information Technology Department at the Cape Peninsula University of Technology, which research is under the supervision of Dr Andre de la Harpe.

If I have any questions about the study, I may contact the researcher or the supervisor. If I have any questions regarding the ethical conduct of this study, I may contact the secretary of the Faculty Research Ethics Committee at 021 469 1012, or email naidoove@cput.ac.za.

I agree to do the interview, that it is recorded and that the student may use the data for her research work at CPUT.

Participant's signature: ______________________________ Date: _____________________

Researcher's signature: ______________________ Date: _____________________

APPENDIX D: INTRODUCTORY LETTER FOR COLLECTION OF RESEARCH DATA

Cape Peninsula
University of Technology

Introductory letter for the collection of research data

Amna Ashour is registered for the MTech (IT) degree at CPUT **(215301501).** The thesis is titled "*The information needs of caregivers in rural areas in South Africa".* The aim is to explore the unmet information needs of caregivers during their work activities in order to identify and address the challenges of information needs during the course of performing their duty.

The supervisor(s) for this research is/are:
Dr A. De la Harpe email: andre@i2ifica.com phone: 082 448 1058

In order to meet the requirements of the university's Higher Degrees Committee (HDC) the student must get consent to collect data from organisations and private individuals which they have identified as potential sources of data. In this case, the student will use the **in-depth interview** to gather data.

If you agree to this, you are requested to complete the attached form (an electronic version will be made available to you if you so desire) and print it on your organisation's letterhead.

For further clarification on this matter, please contact either the supervisor(s) identified above, or the Faculty Research Ethics Committee secretary (Ms V Naidoo) at 021 469 1012 or naidoovve@cput.ac.za.

Regards

Dr AC de la Harpe

Supervisor
IT department
CPUT
delaharpea@cput.ac.za
021 4603627
24 January 2018

APPENDIX E: PERMISSION FROM ZONNEBLOEM ACVV OAH TO CONDUCT RESEARCH

ZONNEBLOEM ACVV - DIENSTAK

-Tuiste vir Ouer Persone-
NPO 011-744

P80 930055018
BTW NR 4050107665

000

ACVV
www.ocvv.otgao

Tel: 021 462 1037
Faks: 021 461 9884
E-pos: zonnebloemacvv@telkomsa.net

Caledonstraat 61
KAAPSTAD
8001

I, Sr S van Zyl, in my capacity as Zonnebloem ACVV-Dienstak) at Zonnebloem ACW-Dienstak give consent in principle to allow Amna Ali Abdulsalam Ashour, a student at the Cape Peninsula University of Technology, to collect data in this company as part of his/her M Tech (IT) research. The student has explained to me the nature of his/her research and the nature of the data to be collected.

This consent in no way commits any individual staff member to participate in the research, and it is expected that the student will get explicit consent from any participants. I reserve the right to withdraw this permission at some future time.

In addition, the company's name may or may not be used as indicated below. (Tick as appropriate.)

	Thesis	**Conference paper**	**Journal article**	**Research poster**
Yes	Yes	Yes	Yes	Yes
No				

APPENDIX F: PERMISSION FROM SPSCC TO CONDUCT RESEARCH

SPECIAL CARE CENTRE

Established 1405 *11984*

SCHOOL FOR MENTALLY CHALLENGED CHILDREN

S E-OF CARE

50 FIRST AVENUE, SHERWOODPARK 7764
POSTAL ADDRESS: P.O. BOX 24179, LANSDOWNE 7779
TEL: 021 692 3700 I FAX: 086 245 2741
WEBSITE: www.sherwoodpark.org.za
EMAIL: info@sherwoodpark.org.za

N.P.O. NO. 004 – 515
P.B.O. NO. 980048795

I, Nabieya Allie Van Schoor in my capacity as Supervisor at Sherwood Park Special Care Centre give consent in principle to allow Amna Ashour, a student at the Cape Peninsula University of Technology, to collect data in this company as part of his/her M Tech (IT) research. The student has explained to me the nature of his/her research and the nature of the data to be collected.

This consent in no way commits any individual staff member to participate in the research, and it is expected that the student will get explicit consent from any participants. I reserve the right to withdraw this permission at some future time.

In addition, the company's name may or may not be used as indicated below. (Tick as appropriate.)

	Thesis	**Conference paper**	**Journal article**	**Research poster**
Yes	Yes	Yes	Yes	Yes
No				

Nabieya Allie Van S

30th January 2018

APPENDIX G: CPUT ETHICS FORM

Cape Peninsula University of Technology

P.O. Box 652 • Cape Town 8000 South Africa •Tel: +27 21 469 1012 • Fax +27 21 469 1002 80 Roeland Street, Vredehoek, Cape Town 800	
Office of the Research Ethics	Faculty of Informatics and Design Committee

Approval was granted by the Faculty Research Ethics Committee on 4 October 2017 to Ms Amna Ashour, student number 215301501, for research activities related to the MTech: Information Technology degree at the Faculty of Informatics and Design, Cape Peninsula University of Technology.

Title of dissertation/thesis: The information needs of informal caregivers in rural South Africa
Comments:

Research activities are restricted to those detailed in the research proposal and formal permission from the organisation involved in the research must be obtained.

Signed: Faculty Research Ethics Committee	\2017 Date

RESEARCH ETHICS COMMITTEE
INFORMATICS AND DESIGN
ETHICS APPROVAL GRANTED

- 4 OCT 2017

Cape Peninsula University of Technology