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THE EXPERIENCES OF EMPLOYED CAREGIVERS, WORKING IN PRIVATE SOUTH AFRICAN HOMES, WITH PATIENTS WHO HAVE SUFFERED FROM A STROKE

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A dissertation submitted in fulfilment of the requirements for the degree of
Master of Arts in Speech Pathology.

July, 2015

DECLARATION

I, Gina Posner, declare that the work on which this dissertation **"The experiences of employed caregivers, working in private South African homes, with patients who have suffered from a stroke"** is based on original work, except where acknowledgements and references indicate otherwise. This dissertation is being submitted for a Master's degree in Speech Pathology, Humanities, at the University of the Witwatersrand. This work has never been submitted as a part of, or in full, to any other university for examination.

_____

Gina Posner

The _____ day of _____, 2015

DEDICATION

The women I encountered on this journey inspired me and provided me with a new outlook on giving, caring, and friendship.

This study is dedicated to the brave, kind, and often voiceless women who devote their time, energy, and hearts to others in need. This study is for you. This is your voice. Thank you for allowing me to listen. Thank you for allowing me to share your stories.

A participant shared with me: "*I'm telling you, it's only prayers, that's how I've survived all these years."* I hope that this study will help employed caregivers so that they no longer need to rely on their prayers for survival.

ACKNOWLEDGEMENTS

Jennifer Watermeyer and Joanne Neille: My supervisors, thank you for the assistance, guidance, and wisdom you provided throughout this study. Your dedication and motivation has assisted me throughout this journey. Your insightful advice and comments have allowed this study to develop further than could ever have been imagined.

Lior Chernick: My dear husband, words are too finite to express the gratitude I feel towards you. I am forever grateful for your constant support, encouragement, love, and kindness. Thank you for inspiring me through your own work and for reminding me that I am able to achieve whatever I dream.

Leon and Aidi Posner: My parents, you are my number one supporters. Your constant care and genuine interest in my studies is so appreciated. Thank you for teaching, inspiring, and loving me unconditionally. You have always placed importance and emphasis on education and for this, I am eternally grateful.

Evan and Bianca Posner: My siblings, thank you for your support throughout this journey. Your interest and concern is appreciated.

Heena Chania: My dear friend, thank you for your constant advice, assistance, and concern throughout this journey. You are such an inspiration to me.

To my **friends and family** who supported and encouraged me through this journey, thank you for your kind words and wishes. I treasure you all.

My patients: You live the definitions of bravery, strength, and heroism daily. Thank you for showing me the meaning of life and determination. You inspire me to become a greater person daily.

Caregivers: Without you, this study would not exist. Without you, patients would not have a quality of life. Thank you for sharing your stories and opening your hearts to me.

Heila Jordaan and Sarah Mfupo: Thank you for your ongoing assistance.

To **Hashem, my G-d**, thank you for blessing me with the abilities and strength to complete this study.

ABSTRACT

Background: Many people who have suffered from a neurological condition, including stroke, have an employed caregiver who cares for them within their home environment. Previous studies have investigated caregiving within the family unit, when a family member takes the role of the primary caregiver. These family caregivers often experience many physical, emotional, and psychological burdens such as anxiety, depression, and stress. However, there seems to be a lack of investigation into the experiences and needs of employed caregivers, working as the primary caregiver within a patient's private home in South Africa.

Aims: This research aimed to explore the experiences and perceived needs of employed caregivers working for patients who have suffered from a stroke within home settings in South Africa. It further aimed to explore the unique challenges to caregiving that may be present within the South African context.

Methods: A sample of fifteen participants with experience in working as an employed caregiver for patients who have suffered from a stroke, within a home setting in South Africa, were included in the study. The qualitative research design took place in two phases. Phase one consisted of semi-structured interviews between each participant and the researcher. The open-ended questions focused on the caregivers' backgrounds, training, experiences, and possible needs while working within South African homes. Phase two involved two focus groups consisting of five participants per group. Within each focus group, open-ended questions and discussions allowed for exploration into the caregivers' experiences and needs while working in South African homes. Thematic analysis of the collected data from both phases was triangulated and analysed.

Results: The findings of the study revealed that the relationships that employed caregivers develop with patients, patients' families, and with other workers within the home setting, influence levels of happiness and burden in the caregiving role. Employed caregivers feel unheard and voiceless within South African society, as evident by their perceived lack of support, resources, and rights. The caregiver burden experienced by these caregivers seems to be influenced by contextual factors within South Africa. These factors include gender stereotypes and being task shifted between household roles, not receiving reciprocal care from employers, experiencing financial stressors, and receiving limited benefits and support both within the home and within South African society.

***Conclusion*:** The findings of this study provide insight into the experiences and needs of employed caregivers in South Africa, allowing for a recognized voice to be established for this caregiving population. The findings of this study contribute to current caregiving literature specifically with reference to employed caregivers, caring for patients who have suffered from a stroke, and caring within the South African context. The experiences and needs of employed caregivers explored in this study may lead to the development of various support structures for employed caregivers in South Africa.

Key words: Caregiver, Employed, Stroke, South Africa, Private home, Experiences, Needs, Voice, Care, Support, Training, Task shifting, Role delineation, Burden.

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LIST OF ABBREVIATIONS

ADL	Activities of Daily Living
AIDS	Acquired Immune Deficiency Syndrome
ANC	African National Congress
CBHW	Community Based Health Worker
CHW	Community Health Worker
COSATU	Congress of South African Trade Unions
CP	Cerebral Palsy
EPWP	Expanded Public Works Programme
HBC	Home Based Carers
HIV	Human Immunodeficiency Virus
ICF	International Classification of Functioning
JPHCF	Joint Primary Health Care Forum
MRC	Medical Research Council
NACOSA	National Aids Convention of South Africa
NEHAWU	National Education, Health, and Allied Workers Union
NGO	Non-Governmental Organization
NPO	Non-Profit Organization
PEG	Percutaneous Endoscopic Gastrostomy
PHC	Primary Health Care
PTSD	Post Traumatic Stress Disorder
TB	Tuberculosis
TBI	Traumatic Brain Injury
UK	United Kingdom
UNAIDS	Joint United Nations Programme on HIV/AIDS
US	United States
WHO	World Health Organization

GLOSSARY OF TERMINOLOGY

Aphasia: An acquired language disorder that impairs communication either receptively or expressively. The use of symbols may be disrupted due to damage to the brain affecting the ability to gesture, write and read (LaPointe, 2005).

Apraxia of speech: A motor disorder that affects speech production, defined by the inability to sequence motor movements on command (Freed, 2000).

Dysarthria: A deficit in speech production due to neuro-motor damage to the central or peripheral nervous system (Freed, 2000).

Dysphagia: Swallowing difficulties that may occur at a sensory, motor, or behavioural level in preparation of, or during a swallow (Logemann, 1998).

Eish: An expression used in South Africa to express disbelief, surprise, disapproval or agreement (Collins English Dictionary, 2014).

Employer: This term may refer to the patient themselves, the patient's family, or both the patient and their family.

Home: Refers to a private home and not to an institution or old age home.

Ja: South African expression for "yes".

Loved one: Referred to, and used interchangeably, within the dissertation with "patient"- refers to the employer's ill family member.

Maid: Term used by South African society, and the participants within this study, when referring to a domestic worker.

Mummy: Term used in an African language as a form of respect when communicating with an older person.

Muti: A traditional African magical charm or medicine (Oxford University Press, 2014)

PEG tube: Percutaneous endoscopic gastrostomy (PEG) tube is a method of feeding directly into the stomach and is considered as a long term solution to swallowing disorders as it eliminates pharyngeal or nasal irritation (Logemann, 1998).

Veranda: Patio or porch in a home.

GLOSSARY FOR TRANSCRIPTIONS

To assist understanding for the results chapter, a glossary for the presented transcriptions is as follows:

P: *Participant*. A number will represent each participant.

G: The researcher, *Gina*.

FG1: *Focus Group 1*.

FG2: *Focus Group 2*.

Please note:

Transcriptions included throughout the dissertation may contain phonetic or semantic errors. These are not typing errors but rather are present as a result of English not being the participants' first language. Inserts have been included to assist in understanding the context where necessary.

Chapter 1

INTRODUCTION

1.1. RESEARCH RATIONALE

Throughout my studies and work experiences within speech therapy, I have always felt a pull towards adult neuro-rehabilitation. After working in a neuro-rehabilitation hospital during my year of community service in 2011, I was reassured that neuro-rehabilitation was my passion within the profession, and I am currently working at a private neuro-rehabilitation centre. Within neuro-rehabilitation, stroke has always been a leading interest of mine.

The effects of stroke are not isolated and its resulting impairments affect the person who has suffered from the stroke as well as the family unit (Thomas & Greenop, 2008). Many people who have suffered from a neurological condition, including stroke, have a caregiver who cares for them within their home environment. An increase in stroke prevalence (Adeloye, 2014) develops into an increased need for stroke caregivers.

While my experience has changed from the inpatient to the outpatient therapy setting and back again within the past two years, it was within the outpatient therapy setting that my attention shifted from the people who had suffered from a stroke towards the caregiver who accompanied the patient to therapy. While I have always had an interest in the patient who suffered from a stroke, and how their speech or language impairment may impact on their communication within the home or workplace, I began to pay attention to the usually quiet, unassuming, and tolerant caregivers who accompanied the patient to therapy sessions.

Greeting and speaking to the caregivers, asking for their feedback about patients, and including them as a communication partner within therapy sessions, was an interesting and eye-opening experience for me as a speech-language therapist. The shock and surprise present on the caregivers' faces when I had asked for *their* opinion about the patient, when asked to participate in the session as a communication partner, or when asked "how are *you*?" was intriguing. Despite these women often taking the role of primary caregiver and communication partner in the patient's life, it did not seem that their day was often inquired about nor had they been invited to join in conversations with the patient to whom they often dedicate their day. A sense and feeling of invisibility was felt to exist among these employed caregivers.

Not only were these caregivers more often than not friendly and caring, but they also took every opportunity to join in the therapy sessions rather than to have a break outside while waiting for the patient to finish their therapy session. The passion they presented with in wanting to learn more about stroke, its impairments, and strategies to assist the patients that they cared for amazed me. These

caregivers spent their day caring for a patient, assisting the patient with daily activities and therapy homework, and yet, they did not seem to know basic stroke information (for example, a stroke occurring on the left side of the brain would result in weakness on the right side of the body). While many of the caregivers I had met had achieved a caregiving certificate, and were exceptionally proud of it, they remained unaware of foundational stroke information.

The lives and experiences of these caregivers began to intrigue me and lead me to develop the research question that resulted in this dissertation. As a speech-language therapist, I have the best intentions for the patients I treat and I often find that the caregivers present within the therapy sessions allow for optimal carry-over of therapy to occur. Overall, therapeutically, I began to notice that the patients who had a strong relationship with the caregiver were typically happier and more driven patients, which resulted in increased participation, resulting in greater potential for progress. The patients that had a caregiver who they trusted and had developed a friendship with seemed to have stimulated conversations throughout the day. The caregivers seemed to serve numerous roles for the patient including providing the patient's therapists with feedback on the patient within the home setting, as they were the patient's primary caregiver.

Realizing the important role that these caregivers have in the lives of others, who are not their own family members and are typically people with very different backgrounds and lives, I began to wonder what the life was like of an employed caregiver caring for a patient who had suffered from a stroke within the private home setting. The interest in discovering the caregiver's feelings and perceptions about the role they played as a caregiver for a non-family member, within the patient's home setting, attracted me.

The frequently employed caregivers in this role were black African female caregivers with seemingly poor socio-economic backgrounds and circumstances. Due to its past inequalities, poverty and decreased economic growth are a reality in South Africa (Makiwane & Berry, 2013). In order to support themselves and their families financially, many females in South Africa with limited opportunities may become caregivers (Patel, 2009). As South Africa presents with diverse cultures and large racial inequalities, employing a caregiver of different culture and socio-economic status to the employer seems highly prevalent. The possibility of this racial and power dynamic influencing the caregivers' experiences and needs, working as employed caregivers in private homes, was sought after in this study.

The South African literature on stroke seems to focus on the neurological and medical features of stroke rather than on the caregivers and the psychosocial impact that caregivers may experience (Thomas & Greenop, 2008). While there is a large body of literature which explores various theoretical frameworks of caregiving as well as the experiences of caregivers who are related to the patient, limited research and theoretical frameworks exist which are applicable to the experiences of

employed caregivers that work for patients who have suffered from a stroke, particularly within developing contexts.

After reading about the caregiving burden that is so apparent and acknowledged for family caregivers, I began to wonder if the experiences would be similar for employed caregivers, and how the South African context might influence these experiences. Thomas and Greenop (2008) set out to investigate the psychosocial aspects and effects that caregiving can have on a family member, as the primary caregiver, caring for their loved one who suffered from a stroke. They made use of a qualitative design in order to gain in-depth experiences and information. While their qualitative study investigated the psychosocial aspects associated with stroke caregivers, the focus remained on family caregivers and not on employed caregivers.

Further investigations within the South African context lead to the realization that many studies have been completed on caregivers caring for patients with human immunodeficiency virus infection (HIV) and acquired immune deficiency syndrome (AIDS) (Evans & Thomas, 2009), home-based carers (HBCs), social workers and nurses (Lund, 2010; Lund & Budlender, 2009), and caregivers for mental illness in rural communities (Mavundla, Toth & Mphelane, 2009). While HIV/AIDS is South Africa's most prevalent disease (AIDS Foundation South Africa, 2013), therefore justifying the amount of research it has received, the experiences of employed caregivers, specifically caring for patients who have suffered from a stroke within the patient's private home, seemed to present with a gap in the caregiving literature. Within South Africa, volunteer caregivers also seem to have received attention as culturally, many rural areas and communities care for one another suffering from HIV/AIDS, tuberculosis (TB) and other infectious diseases (Mavundla et al., 2009).

Abroad, caregiving literature increasingly focuses on informal family caregivers caring for elderly or ill family members. Literature on informal family caregivers and their negative caregiving experiences seem prominent in the caregiving literature. These family caregivers often experience many emotional, psychological, and physical burdens such as anxiety, depression, and stress (Pierce, Steiner, Govoni, Cervantez & Friedemann, 2007). Advice and support for family caregivers seems to be effective in decreasing these negative emotions (Rigby, Gubitz & Phillips, 2009). Literature on African American caregivers is present within the United States (US) investigating the experiences and employment responsibilities, while taking on the role of informal caregiver for a loved one within the private home setting (Bullock, Crawford & Tennstedt, 2003).

As a result of the gap that caregiving literature has on employed stroke caregivers working specifically within private South African homes, most of the literature used in this study reflects the large body of literature on informal caregivers, most frequently referring to spouses and children taking on the caregiving role. Although caregiving literature is expanding within the disciplines of

nurses, long-term care facilities, and rural caregivers (Williams & Crooks, 2008), limited literature exists for employed caregivers working within private homes.

Swartz (2012) wrote an insightful article regarding his personal experiences as a family member who employed caregivers to care for his ill mother within the private home setting. He described how various perspectives were present between himself and the caregivers with regards to his fairness as an employer within the home. He discusses the challenges of engaging with care workers, of different racial and professional status from him, without exposing them to exploitation and exclusion that is common within care work, and offers valuable insight into the power relations that still seem present within private homes in South Africa. His article provides a valuable contribution to the current study as it references South African caregiving experiences from the view of the employer rather than from the employee.

It was necessary to develop research in the area of employed caregivers within South Africa as the well-being and support for employed stroke caregivers seems neglected. As South Africa presents with a rich history of diversity, the context of this caregiving situation may bring about unique experiences and needs for employed caregivers. It is unknown whether employed caregivers suffer from the same psychological and physical burdens that informal family caregivers experience.

Speech-language therapists can assist by providing support, guidance, and strategies for increased communication to occur not only between patient and family, but also between patient and caregiver. The researcher has observed that caregivers play an important role when carry-over of therapy is to be completed from therapy session-to-session, and from the therapy session into the patient's daily life. Therapists are therefore able to assist not only the patients, but also have the potential to positively influence and train employed caregivers. I feel that as a speech-language therapist, exposed to and working with employed caregivers, I wanted to learn more about these dedicated and inspiring women.

1.2. OUTLINE OF THE FOLLOWING CHAPTERS

There are two literature review chapters within this dissertation. **Chapter two** will present literature on the background and context of South Africa which is required to gain an understanding of this study. It will provide background information of the effects of Apartheid on the economy and employment opportunities for women. The chapter will then present information on stroke by defining the neurological condition, discussing the prevalence of stroke within the global and South African context, as well as discuss common stroke related impairments.

Chapter three, the second literature chapter, will provide literature on caregiving. Caregiving definitions will be explored globally and within South Africa. The influence of gender within the caregiving role will be discussed. Literature exploring caregiver burden, ethics in caregiving, and support for caregivers will be provided. A theoretical framework on caregiving, that seemed applicable to the current study, will be presented and discussed at the end of the chapter.

Chapter four will provide the methodology of the study. This chapter will describe the rationale behind the study being of a qualitative nature, and will discuss the semi-structured interviews and focus groups that were used to collect the research data. The measures used to ensure triangulated results and rigour will be explained. The chapter will highlight the participant criteria as well as the ethical considerations implemented throughout the study. The methods used for analysis of the collected data will likewise be explained.

Chapter five will present the results of the study. The chapter will be divided into three main themes that were discovered throughout the data analysis process, namely: relationships, lack of voice, and support. This chapter will present the findings of the study and make use of existing literature to interpret the study's findings.

Chapter six will present the discussion of the study. This chapter will discuss and analyse the leading themes of the study in relation to current caregiving literature and theories. This chapter will further discuss the proposed theoretical model in relation to the study's findings and as a result, propose a new model describing the factors that influence employed caregivers' experiences working within private South African homes.

The final chapter, **chapter seven**, will present the conclusion of the study. This chapter will provide the implications and limitations of the study, and will lastly include reflections of the research process.

Chapter 2

BACKGROUND

OVERVIEW

In order to gain an understanding of this research study, the context in which this study occurs needs to be explored. This chapter will describe the impact of historical legacies on the employment of black African females working within South African homes. This chapter will further provide literature on the medical condition – stroke. The chapter will explore the prevalence of stroke globally and within the South African context. A description of stroke and its most associated impairments will be included in order to gain an understanding of the type of care these patients may require.

2.1. THE SOUTH AFRICAN CONTEXT

Apartheid came into existence after the Dutch and British colonialism ended, changing numerous aspects of the country including political, economic, and social day-to-day life when the National Party gained power in 1948. During Apartheid (1948-1994), the introduction of segregation caused many people to be left without appropriate health, education, and welfare services (Lund, 2010). The country was divided not only by race, but also by the services and opportunities available to certain populations. Wealthier people, most commonly the white population, were provided with the option of private education and health care, while the remaining poorer populations received public health and education, often that was of a lower standard. Living space was also separated and varying races were secluded to specific living areas resulting in black populations living in the more rural areas (Lund, 2010), leading to significant inequalities remaining within the country between various classes, racial, and gender groups (Makiwane & Berry, 2013).

When the African National Congress (ANC) was elected through a democratic vote in 1994 (Lund, 2010), bringing an end to the Apartheid era, a policy was established based on a liberal constitution. The policy allowed the rights of each and every individual, no matter their race or gender, to be heard and respected, as seen in the Bill of Rights, which stood for equal rights among all (Lund, 2010). The Reconstruction and Development Programme, built on various developmental approaches, was developed to bring balance to the previously unbalanced society (Patel, 2009). Free health care as well as education became more readily available however, difficulties and poverty were, and still are, a reality for some populations (Lund, 2010), resulting in current employment and economical struggles.

2.1.1. Economy and Employment

Patel (2009) classified South Africa as a lower middle-class society. Despite this, the rate of human development performance has decreased as a result of the HIV/AIDS pandemic, resulting in low levels of economic growth (Patel, 2009). Social assistance to the underprivileged populations has

grown as grants and pensions have become available. Institutional care for children, people with disabilities, and the elderly, has reduced since the change towards developing social welfare saw a significant increase among home caregivers' responsibilities (Lund, 2010).

South Africa presents with high levels of poverty and income inequality among populations that contributes to its decline in human development. Poor income and opportunities affect overall quality of life and personal development including poor health, and limited education, as well as an increase in violence (Makiwane & Berry, 2013). While both males and females present with high levels of unemployment, females present with greater unemployment rates (Patel, 2009). Women are burdened with great levels of poverty as previously during Apartheid, and within current times, men leave the townships in search of industrial work, while women stay at home to care for the family (children and elderly) as well as community members (Makiwane & Berry, 2013). Black African women find employment more difficult to attain than white women and have therefore turned to domestic and care work in order to earn an income with their low-skilled experiences and opportunities (Patel, 2009).

Numerous studies have been conducted in South Africa with domestic workers including their background, race and gender, as well as their rights, legislation, and work environments (Bradfield, 2012; Fish, 2006). Domestic work in private homes is the product of vast differences among class, race, and gender separations within society. Feminine tasks performed in private homes by female domestic workers working for female employers, highlights the inequality among races and classes. Fish (2006, p.113) describes the oppression by gender, race, and class as a "triple oppression", which is commonly found to exist within households where a power imbalance between employer and employee exists. The "triple oppression" found within households between domestic workers and employees in South Africa seemed to exist within a broader social hierarchy during Apartheid rule (Fish, 2006) however, the oppression may still be present in some South African homes at present, not only between domestic workers, but also between employed caregivers and employees. Inequalities that existed under Apartheid rule against class, race and gender for domestic workers, may be applicable and occurring within present times with employed caregivers of similar race, gender and class as domestic workers within South Africa. The participants in this study were all black South African females of a lower economic class.

South Africa can present with power inequalities and power relations within the private home setting. All races employ domestic workers however traditionally they have been employed by both the rich and poorer white populations as well as by wealthier Indian and coloured populations (Budlender, 2009). As a result of their minimal skill sets and poor income, domestic workers have poor contact to social protection, training, and skill-development opportunities (Razavi & Staab, 2010). Typically, the homes in which they work are culturally different to their own (Woolard, 2002) adding to the

possibility of unique challenges and experiences occurring. These unique challenges were explored through this study to assess whether or not they also apply to employed caregivers.

As domestic work occurs in private homes and does not always carry with it a clear definition within its job description, domestic workers may need to take on a caregiver role when required to take care of the children, elderly, or the sick within the home. Therefore, excluding housework, the domestic worker may be required to work as a caregiver, baby-sitter, and cook (Budlender, 2009). Despite the relationship between domestic workers and employees within private homes potentially presenting with a negative power dynamic, the possibility of a strong positive relationship developing within the home seems possible as evident by the support provided by employers to domestic workers (Budlender, 2009).

HBC work is vastly different to employed caregivers working within the private home setting. While employed caregivers often work for a family of differing race and class, HBCs are volunteer care workers and often share the same backgrounds as the people that they care for, therefore eliminating the power inequalities within the relationship. HBCs do not have an established job description or curriculum. They do however have the National Aids Convention of South Africa (NACOSA) with assistance from the Joint Primary Health Care Forum (JPHCF) that is developing a curriculum for HBCs with assistance from the Department of Health (National Aids Convention of South Africa, 2013). NACOSA is a national civil society, networking the HIV/AIDS community in South Africa and works with HIV/AIDS, TB, as well as other connected social development aspects (National Aids Convention of South Africa, 2013).

2.2. STROKE

2.2.1. Definition of Stroke

Stroke is a neurological heterogeneous condition that results in sudden and frequently devastating injuries, which occur due to insufficient blood supply to an area of the brain (Rombough, Howse & Bartfay, 2006). Stroke can be divided into three sub-types, namely, cerebral haemorrhage, cerebral infarction, and subarachnoid haemorrhage. The cause, outcome, and treatment will vary according to the type and sub-type of stroke that is experienced (Connor & Bryer, 2006). High blood pressure is the leading cause of stroke and while developing countries are reducing the incidence of stroke by lowering blood pressure, the overall stroke statistics still remain high (Stroke Centre, 2014).

Worldwide, fifteen million people suffer from stroke annually, while five million people lose their lives, another five million are left with permanent disabilities (Stroke Centre, 2014). In the US, stroke is the third highest cause of death (Stroke Centre, 2014). Stroke is the leading source of long-term

disability within the US with numbers as high as 795 000 people suffering from stroke every year (Stroke Centre, 2014).

2.2.2. Stroke in South Africa

The prevalence of stroke is on the rise in South Africa (Adeloye, 2014). In South Africa, an estimated 25 000 deaths occur annually from stroke. The number of people affected by stroke annually has increased since 1990 and it is estimated that 20 million people will suffer from stroke related deaths by 2030 globally (Maredza, Bertram, & Tollman, 2015). Stroke is the second most common cause of death worldwide with two-thirds of these recorded deaths occurring within developing countries of the world such as Sub-Saharan Africa. While South Africa presents with a lower prevalence of stroke compared to other poverty-related illnesses, it is on the increase due to the HIV/AIDS epidemic (Connor & Bryer, 2006). The risk factors of stroke are divided into modifiable factors and non-modifiable factors, such as gender and age. Modifiable factors prevalent in South Africa include hypertension, diabetes mellitus, alcohol abuse, and smoking (Connor & Bryer, 2006).

Stroke results in personal, social, physical, and economic stressors (Thomas & Greenop, 2008). Patients are often discharged into their home environment, rather than into an institution or rehabilitation facility, which results in the need for a caregiver to be present for facilitation of daily functioning. The patient is able to reduce hospital costs and lower the risks of further infections being caught in the hospitals (Hilton, 2011). Access to resources and health opportunities may be limited for populations with poor living and working opportunities, as found within many rural areas in South Africa. Despite stroke occurring in greater numbers in more developed countries, the level of assistance required for South African patients who suffered from a stroke in completing activities of daily living (ADLs), is higher than high-income based countries. Stroke is therefore adding substantially to levels of disease-related burden within the South African health system (Connor & Bryer, 2006).

2.2.3 Impairments resulting from stroke

As stroke is a severe medical health condition, it often has a life-changing impact on the person who has suffered from the stroke and on their family and friends (Thomas & Greenop, 2008). Stroke can result in physical, psychological, cognitive, language, and motor impairments. Stroke may further result in emotional disturbances including anger, apathy, poor self-esteem and frustration (Thomas & Greenop, 2008).

The World Health Organization (WHO) developed the International Classification of Functioning, Disability and Health (ICF). The ICF makes use of a standard framework when relating to health, and places the person suffering from a disorder within a context (World Health Organization, 2013). The ICF is divided between part one, functioning and disability, which includes body functions and body

structures with activity and participation. Part two, contextual factors, includes the environmental and personal factors of the individual. Disability and functioning result from the interactions between the conditions of health with the person and their environment (Word Health Organization, 2013).

With reference to the ICF, the health condition of stroke results in impairments in body function and structure. The WHO (2001, p. 212-213; as cited in World Health Organization, 2013), defines impairments as a problem in body structure or function such as a substantial loss or deviation. These impairments as well as contextual factors (environment and personal factors) impact the person's activity and participation (World Health Organization, 2013).

Stroke can lead to long term physical disabilities such as hemiparesis, joint contractures, spasticity, as well as motor impairments that affect balance, standing, and walking. These impairments can lead to limited physical activity and participation (Waldman et al., 2013). Impairments resulting from stroke include paralysis or motor impairments (National Institute of Neurological Disorders and Stroke, 2014). Paralysis is a common stroke-related disability and typically occurs on the opposite side of the brain that is injured by the stroke. Paralysis can occur on the leg, arm or face of the body, or can affect the whole side of the body, i.e. hemiplegia. Hemiplegia can negatively affect the patient's ability to complete ADLs independently. Sensory impairments, such as an inability to feel temperature, touch, or pain may also occur as a result of stroke (National Institute of Neurological Disorders and Stroke, 2014).

Aphasia can occur after a stroke. Aphasia is the loss of ability to communicate verbally or non-verbally, affecting receptive and/or expressive functioning (Rombough, Howse, Bagg & Bartfay, 2007). Approximately 30% of people who have suffered from a stroke will be affected with aphasia (American Speech-Language Hearing Association, 2014). Most commonly, strokes that occur on the left hemisphere of the brain can result in aphasia for right-handed people and for an estimated half of left-handed people. Additional communication impairments may be seen in a person who has suffered from a stroke such as apraxia of speech, dysarthria, or dysphagia (American Speech-Language Hearing Association, 2014).

Aphasia does not only affect the stroke survivor but also the family members, friends, and caregivers that are related to the patient. Aphasia leads to daily challenges and lifestyle adjustments and therefore, this impairment becomes life-altering for the patient, their loved ones, and for the caregivers involved (Lyon et al., 1997). Managing aphasia within the rehabilitation process involves numerous factors such as belief systems, modes of support and coping, expectations, previous illnesses, and adjustments to the illness (Herrmann & Wallesch, 1999).

Cognitive impairments can also occur and include difficulties with memory, attention, and planning skills. Emotional disturbances including anxiety, fear, and anger may be experienced as a result of the

psychological trauma of surviving a stroke (National Institute of Neurological Disorders and Stroke, 2014). Among all the challenging cognitive, physical, and emotional impairments that occur after stroke, family caregivers have described the communication impairments as the most stressful stroke related impairment to manage (Thomas & Greenop, 2008).

CONCLUSION

This chapter provided background information on the effects that South Africa's history currently plays on the economy and employment, specifically for females of a low socio-economic status. Due to the potential power inequalities and relationships found within private homes between employers and employees, it is understood why challenges may arise within the private home settings. This chapter further provided insight into the health condition of stroke including its prevalence and definition. It provided insight as to why a patient who suffered from a stroke may need the assistance of a caregiver for assistance in functioning due to their stroke-related impairments. The following chapter will explore caregiving including various types of caregivers, burden associated with care work, and the role caregivers play with patients who have suffered from a stroke.

Chapter 3

CAREGIVING

OVERVIEW

As a large body of literature exists for numerous types of caregivers (Evans & Thomas, 2009; Razavi & Staab, 2010; Rigby et al., 2009; Thomas & Greenop, 2008; White et al., 2003; Williams & Crooks, 2008), a closer look into the world of caregiving, within various contexts and situations, is required to understand the targeted population of caregivers within this study. The types of caregivers within the South African context will be described, with a focus applied to caregiving and stroke. As there is a wide array of literature on caregiving burden, this will be discussed, as gaining insight into the experiences and potential burden of employed stroke caregivers is an aim of this study. Ethical considerations within care work and the association between gender and caregiving will further be explored.

3.1. CARE WORK

England, Bugid, and Folbre (2002) define care work in the following way:

> 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. (England et al., 2002, p. 455)

"Care" is commonly referred to as the unpaid activities required in physical or emotional needs of adults and children, and are structured according to relationships within the family and community (Razavi & Staab, 2010). Care work has been described as "invisible" as care workers are undervalued by care-recipients and communities, despite the essential role that they play (Razavi & Staab, 2010). "Caring for the caregivers" by acknowledging their needs and rights, began to receive recognition in the 1980s. The combination of working from love, responsibility as well as at times from a lack of choice, in the case of family caregivers, began to raise attention for numerous caregiving research studies (Keith, 2007).

3.2. CAREGIVER DEFINITIONS

According to the Merriam-Webster Dictionary, a caregiver is defined as "a person who gives help and protection to someone (such as a child, an old person, or someone who is sick)", and caregiving is defined as "a person who provides direct care (as for children, elderly people, or the chronically ill)" (Merriam-Webster, 2014). Caregiving can take many forms and can be classified as paid or unpaid, formal, or informal, however, the boundaries separating these variations can be unclear (Williams & Crooks, 2008). While the terms "carer," "assistant" and "caregiver" have been found within various studies referring to the same concept, the term "caregiver" will be used to describe the targeted population of employed caregivers within this study.

3.2.1. Informal Caregivers

Informal family caregivers care for a family member or loved one. These caregivers are typically unpaid and unemployed. This form of caregiving can take place either over a short or long-term period, on a part-time or full-time basis. This form of caregiving may take place in a hospital or home setting and may involve both physical and emotional care (Williams & Crooks, 2008). Williams and Crooks (2008) described this type of caregiving as an ethical obligation. While unpaid care work is a fundamental component of the care economy (Razavi & Staab, 2010), the levels of burnout and burden experienced by these caregivers have been researched in numerous settings and reveal serious difficulties in numerous areas of well-being (Williams & Crooks, 2008).

Quality of life of the family member assuming the role of caregiver is challenged as various emotions including guilt, anger, anxiety and depression may be experienced due to the various impairments, and implications post-stroke (Thomas & Greenop, 2008). Spousal caregivers in the US experience numerous caregiving difficulties, as they need to learn new skills as well as adapt to a change in their relationships, often with the additional stress of limited resources. Families may also struggle with social isolation, sleeping difficulties as well as financial pressures (Thomas & Greenop, 2008). In a study completed by Hartke & King (2003), 88 caregivers of spouses of stroke within the USA revealed that depression and loneliness are often present in the caregiving role with depression occurring in 34%-52% of the 88 caregivers, more so than for patients who have suffered from a stroke (Thomas & Greenop, 2008). Family caregivers have reportedly experienced similar characteristics as patients who have suffered from a stroke, such as poor self-esteem and depression. Poor emotional states have been linked to the patient's level of disability as the more independent the patient previously was, the less resentment was experienced on both sides (Thomas & Greenop, 2008).

3.2.2. Formal Caregivers

Unlike informal caregivers, formal caregivers are employed and are usually practitioners, nurses, therapists, or social workers that practice across many care environments. These caregivers have usually received some form of formal caregiver training (Williams & Crooks, 2008). The caregiver in this situation has willingly dedicated their time to be a caregiver. As the demands of caregivers have increased, the care provided by these practitioners has decreased due to limited time constraints and greater caregiver demands and responsibilities (Williams & Crooks, 2008).

Paid caregiver work is receiving increased attention within policy and research domains (Razavi & Staab, 2010). Across numerous countries, the number of paid caregivers is on the increase due to changes in social, economic, and demographic systems. The labour force in South Africa and other countries is expanding, and as a result the demand for women taking on paid caregiving roles has increased internationally (Razavi & Staab, 2010).

Razavi and Staab (2010) identified three reasons as to why paid care work is on the rise in South Africa. Firstly, women are increasingly being found within the labour work force globally, while continuing to be the primary providers in unpaid care work. Secondly, the need for increased care is found specifically within areas of high HIV/AIDS prevalence. Lastly, family structures are experiencing a change in migration and relational patterns, resulting in caregiving being moved outside of the home setting. Different policies and frameworks that are influenced by the country's regulations and social policies (Razavi & Staab, 2010) influence paid caregiving work.

There seems to be a spectrum of care workers included into the definition of formal care work. This spectrum includes highly educated and well-earning professionals on one end, with poorly educated and poor-earning religious and health workers on the other end. Razavi and Staab (2010) adopted a different care work definition to include domestic workers, as these workers form a vital role in the employment sector and contribute to a large majority of female work found in developing or disadvantaged countries, where race negatively influences their backgrounds and opportunities. Despite being employed as domestic workers, some level of relational care within the home usually occurs (Razavi & Staab, 2010).

The type of caregiver investigated in the current study was a formal employed caregiver. The boundaries between these caregivers being formal versus informal is unclear (Swartz, 2012) as some have achieved an element of education or training in the field, some may not have received formal caregiver training. Despite the caregivers in the study being defined as employed, it was not investigated whether or not these caregivers were registered employees. In this study, the focus was on the experiences that employed caregivers have while working within the private home setting, and not on the amount of training they had received.

3.2.3. Home-Based Caregivers

In South Africa, HIV/AIDS is a constant and relevant health concern as it has the highest prevalence of HIV/AIDS when compared to other countries worldwide (AIDS Foundation South Africa, 2013). In South Africa, 5.6 million people are living with HIV, with a record of 270 000 deaths related to HIV documented in 2011 according to Joint United Nations Programme on HIV/AIDS (UNAIDS) (AIDS Foundation South Africa, 2013). With the HIV/AIDS pandemic growing rapidly in South Africa, more caregivers are required to care for the needs of the HIV/AIDS population (Lund & Budlender, 2009).

HBCs including Community Based Health Workers (CBHWs) and Community Health Workers (CHWs) are found most commonly within the health division of care work. Non-governmental organizations (NGOs) seem to run HBC programmes commonly subsidized by the government (Budlender, 2009). HBC varies according to its needs however includes counselling, training family members in nursing tasks, management of medication, medical treatment, nutritional needs and household chores, as well as playing a leading role in caring for patients with end stage AIDS (Budlender, 2009). Despite the highly significant role that these workers play in South Africa, many have received minimal or no training (Lund & Budlender, 2009).

HBCs seem to mirror the opposite of the nursing system, as they often do not have various levels of authority or clear employment structures (Budlender, 2009). Working descriptions and conditions are not always known to HBCs, including dispute resolution systems. Those who do receive a wage or income seem to have a more established relationship with their supervisors (Budlender, 2009). In Sub-Saharan Africa, HBC is a vital part of informal home-based HIV/AIDS care completed by women (Campbell, Nair, Maimane & Sibiya, 2008). HBCs provide care on an individual and community based-level to terminally ill patients with TB, HIV/AIDS, and other chronic illnesses. They promote healthy living, referring to appropriate health services, as well as providing minimal health interventions and psychosocial support (National Aids Convention of South Africa, 2013).

While Western culture emphasizes individualism, ethnic groups from African cultures places a larger emphasis on collectivism and the well-being of one's family i.e. familism (Pinquart & Sö rensen, 2005). Within the South African context, many people also care for the ill or elderly within their community. Mavundla et al. (2009) investigated the experiences of family caregivers caring for loved ones with mental illness within rural South Africa. As a result of Apartheid, poor care was provided to the racially segregated which formed the majority of people within the country.

As a result of the poor basic care, i.e. minimal health care/clean water/sanitation, post-Apartheid South Africa saw the development of Primary Health Care (PHC) services integrated into the system. As mental health care became integrated into the PHC system, resulting in deinstitutionalization of

mental health care, patients were required to return home to be cared for primarily by their family members with assistance from health care providers (Mavundla et al., 2009). Within rural South Africa, the experiences of caregiving for mentally ill family members has been conceptualized as negative due to numerous factors including cultural influences (Mavundla et al., 2009).

Therefore, it can be seen that various definitions and types of caregivers exist for numerous illness and situations. Within South Africa, a range of care workers is found formally within private homes and informally within communities.

3.3. GENDER AND CAREGIVING

Patel (2009) defines gender as:

> Socially constructed and is based on socially acquired notions of what are appropriate expectations and responsibilities for men and women in a society in relation to, among others, the provision of care of families, children, older persons, people with physical and mental disabilities and chronic illnesses. (Patel, 2009, p. 8)

Care work is highly feminized, whether paid or unpaid in nature (Razavi & Staab, 2010). Internationally, women hold the highest form of responsibility with regards to care work. Caregiving by girls and women, i.e. the nurturers within the home, is seemingly expected geographically, historically and culturally as seen within numerous societies (Evans & Thomas, 2009). Among minority groups, females are also more likely to take on caregiving roles when compared to men, i.e. daughters will care for family members more frequently than sons (Pinquart & Sö rensen, 2005). This may be as a result of the women's association within the home or because of expectations formed by society and family structures (Williams & Crooks, 2008). Women also dominate in the professions of HBCs, social workers, and nurses (Lund, 2010). Despite gender policies coming into place, gender segregation provides the rationale as to why care work is devalued. As women fulfil roles such as midwifery, domestic work and care work, they automatically fall into a lower wage bracket and fall victim to receiving minimal rewards or recognition within their role (Razavi & Staab, 2010).

Taking on dual roles as breadwinner, caregiver and homemaker, places a large burden on women and can create many challenges for their families and for society. Poor women present with fewer financial opportunities available to them, resulting in the need to work in order to provide for their children and families. These women often have limited support available to them due to their busy schedules (Steiner, 1997). White, Mayo, Hanley, and Wood-Dauphinee (2003) discuss various theoretical perspectives on how gender differences influence the type and volume of care as well as the availability of social resources that may be beneficial in lifting caregiver burden.

Within South Africa, the burden of care seems to fall primarily on the women's responsibility across various organizations and Non-Profit Organizations (NPOs). Despite women not always being acknowledged within NPOs roles, there is space for women to provide developmental opportunities such as empowering women within communities (Patel, 2009). Numerous studies have differentiated the male versus female roles in caregiving and have found three main areas of differences. Firstly, women seem to provide the majority of care required for the elderly populations. Secondly, women and men care in different ways as based on their already gender-specific roles. While a man will provide more organizational care, women provide more hands-on care. Finally, women seem to experience higher levels of caregiver burden and strain when compared to men (Neal, Ingersoll-Dayton & Starrels, 1997).

Due to globalization, the burden women experience as a result of care work has increased (Robinson, 2006) and changes have occurred within the nature of work especially within developing countries. These changes have influenced the woman's role in various ways. Women entering into the paid working field do not seem to always receive working rights and gender equality, while trying to manage their households in current economic difficulties, as found within developing countries. As described by Gillian Youngs (2000), cited within Robinson (2006), women are entering society to meet the need for cheap labour that requires low-skilled work. Therefore, women are not only completing domestic and family-related tasks but are also contributing to the wage-earning population, often with unequal social status (Robinson, 2006).

Concerning safety at work, Zeller, Dassen, Kok, Needham, and Halfens (2012) highlight how female caregivers are increasingly exposed to and experience physical aggression towards them when compared to male caregivers. Women are at greater risk of experiencing assault and aggression against them (Zeller et al., 2012). While it is unknown why gender differentiation exists, it may be due to patients having higher levels of respect for male caregivers. Male caregivers are usually more involved in the management tasks involved in caregiving and therefore, the more intimate tasks performed by females may explain why they are exposed to higher levels of aggression (Zeller et al., 2012).

Despite reproductive labour historically being connected to women, there is an interdependent connection and hierarchy that links class, status, and race of women to the distribution of formal versus informal labour work (Parrenas, 2000). Women who are class-privileged are able to free themselves from emotional, manual, and mental labour, as well as from gender subordination. In the US, African American and Latina mothers who work as domestic workers, both turn to family members to care for their loved one when they are unable to (Parrenas, 2000). The family members who take the role as caregiver are typically women (Bullock et al., 2003).

Filipina migrant women are frequently employed as domestic workers and are found working in over 130 countries. While some of these women occupy middle-class working roles such as nurses, two-thirds work as domestic workers. There is a large demand for domestic workers to work in homes in order to allow the family members to be able to continue working in their jobs, i.e. the productive labour force (Parrenas, 2000). The reproductive labour (work of domestic workers) includes care for adults, children and the elderly, household work, as well as maintaining social relations within families. Primarily, reproductive labour has been found in class-privileged homes, often resulting in a racial division, causing an automatic hierarchy occurring which dominant employers want to maintain. This study by Parrenas (2000) relates to the current study as within South Africa, an automatic hierarchy may also be found among female workers, i.e. domestic and care workers within class-privileged homes.

As the literature reveals, gender and the role of caregiving are closely connected both globally and within South Africa. Domestic workers and care workers in South Africa are typically females. This may occur as a result of their cultural and gender-based nurturing roles.

3.4. OVERVIEW OF TYPES OF CARE WORK

3.4.1. Care for children and elderly populations

In South Africa numerous types of care work are found among various populations. Care work includes tasks such as caring for the young, elderly, sick or underprivileged. Care work for children may be required due to abandonment or health needs (Patel, 2009). When viewing care work in relation to caring for children, childcare refers to someone excluding the guardian or parent of the child and includes foster parents, caregivers in shelters or centres, or any caregiver caring for the child with attained parental permission (Patel, 2009). Caregivers of children may also be family relations or people who have a connection to the child without any blood relation. This allows legislation to include a non-typical family form that recognizes significant family members or others as playing an important role in the lives of children (Patel, 2009).

The Expanded Public Works Programme (EPWP) focuses on care provided in two areas: early childhood education, and home-based care. As women with HIV/AIDS present with high death rates while still young, their children are left needing care (Lund, 2010). This responsibility may fall onto more elderly populations, i.e. grandparents caring for their grandchildren. As the elderly have their own challenges living in South Africa, the demand to maintain their own livelihood as well as their grandchildren's brings high levels of pressure and burden (Lund, 2010).

Care and protection of the elderly and ill populations requires care work in numerous situations. Among care for the ill, mental health caregivers have been investigated with specific reference to dementia (Zeller et al., 2012). Caregivers caring for patients with dementia are at highest risk for

experiencing aggression towards them within nursing homes. Aggressive behaviour is linked to physical distress, cognitive impairments and neuroleptic drugs. Furthermore, younger caregivers seem to experience an increase in aggressive behaviours towards them when compared to caregivers above 30 years of age (Zeller et al., 2012). Patients who have suffered from a stroke may suffer from similar impairments when compared to patients with dementia and therefore this information may be applicable to the current study.

3.4.2. Care Work and Stroke

As described in the study conducted in Australia by Gustafsson & Bootle (2013), the transition from leaving an inpatient rehabilitation centre and progressing back into the home and community is a challenging time for both stroke survivor and caregiver. Despite having outpatient therapy available, the transition back into reality presents with challenges (Gustafsson & Bootle, 2013). On discharge into a home setting, patients are often not yet independent in function, therefore the care of these patients can be more physically demanding on caregivers (Kalra et al., 2004).

Primary informal caregivers are typically female spouses who carry the responsibility of integrating their spouse back into the home and community (Rombough, Howse, Bagg & Bartfay, 2007). Caregivers report the first month home as being the most difficult time within this transition, however, with adequate mobility and support from therapy services, this transition becomes easier. A poor transition within this time is a reflection of minimal support and poor information provided to the patient by the medical or therapy team (Gustafsson & Bootle, 2013).

Caregivers of patients who suffered from a stroke play an important role in facilitating daily functioning and participation, providing assistance with daily needs, as well as assisting with the patient's rehabilitation and long-term improvements (Hilton, 2001). Within the first month home, informal family caregivers also have challenges with becoming used to the caregiving role including changing their own routine, providing practical care, and implementing safety requirements (Gustafsson & Bootle, 2013). Caregivers are often responsible for understanding and communicating with patients through both verbal and nonverbal communication methods. Support of the primary caregiver is important and essential in the patient's rehabilitation to ensure the successful transition of the patient back into the community (Rombough, Howse, Bagg & Bartfay, 2007). Within South Africa, some families employ a caregiver to care for their loved one within the home, rather than a family member taking the role as primary caregiver.

3.5. CAREGIVER BURDEN

Caregiver burden is used to describe the load that is carried by caregivers as a result of assuming the caregiving role. Montgomery, Gonyea, and Hooyman (1985) differentiate between objective and subjective caregiver burdens. Objective caregiver burden is described as the physical cost that the caregiver faces when caring for the patient, related to the physical aspects that are required by caregivers during caregiving tasks. Subjective burden describes the caregiver's perception of their responsibility and role of caring for the patient, which can be demanding both emotionally and physically. Subjective burden is experienced as a result of objective burden (Rigby et al., 2009). Despite numerous studies being conducted on both subjective and objective forms of burden, these studies' primary focus has been on the burden that informal or family members experience, while there seems to be a lack of research exploring the potential burden experienced by employed caregivers who are not a family member.

While earlier research has primarily focused on the negative aspects of caregiving, i.e. caregiver burden, more current research has investigated the positive aspects of caregiving such as caregiver satisfaction, esteem, and the rewards of caregiving (Mavundla et al., 2009). Caregiving has been linked to associations including stress, making it seem that negative aspects involved in the caregiving process exceed the positive caregiving aspects. Both subjective and objective burdens have been discussed as having an impact on the emotional well-being of caregivers (Mavundla et al., 2009).

Not only has caregiving been described as an independent risk factor for morality, but it is a risk factor towards health (Pioli, 2010). The psychological, physical and cognitive impairments of patients, together with the amount of limited support available to caregivers, contributes to caregiver depression and burden. Reversibly, caregivers who experience positive caregiving experiences and feel a sense of closeness to the care-recipient may experience greater levels of mental health. Caregivers who have external stressors within their personal lives, i.e. live in poverty and have poor access to formal support services, seem to experience higher levels of caregiver stress and burden (Pinquart & Sö rensen, 2005). The ability to manage levels of stress is often undermined by other factors including levels of poverty, lack of social assistance, stigma, as well as social exclusions of females. Other factors include poor physical health and burnout, emotional disturbances, and family disturbances such as relationship and economic breakdowns (Campbell et al., 2008).

A study of employed immigrant caregivers in Spain found that they have a similar burden to family caregivers and that their level varies according to contextual factors such as the support they receive from social systems, the level of dependency of the person cared for, and the working conditions (de la Cuesta-Benjumea, Donet-Montagut & Galiana-Gómez de Cádiz, 2012). In terms of the burden of care, immigrant caregivers are even more vulnerable than family caregivers are, however, their need for rest and support is not recognized. In contrast to this, numerous studies in the past have spent their

time and attention focusing on the demands of family members and providing them with strategies to prevent stress, anxiety, depression and problem-solving techniques (de la Cuesta-Benjumea et al., 2012).

Akalin (2007) investigated the challenges in care work in Turkey. Caregivers who are employed within a home are often task-shifted and taken advantage of as they are required to complete domestic work tasks that fall outside of their original obligations. Migrant workers are employed rather than local caregivers not purely for their skills as caregivers, but rather for their obedient and submissive traits, that allow them to be task-shifted into various household tasks. The assumption in hiring a worker would be that their skill sets are impressive, however, in the case of hiring a care worker in Turkey, their personality type is more important to the employer in order for an unequal power relationship to be formed between the two (Akalin, 2007).

Pinquart and Sö rensen (2005) found poorer physical health with better psychological health among minority ethnic caregivers in the US when compared to white caregivers. Ethnic caregiving groups may have poor medical insurance available to them and therefore despite caregiving usually having a greater impact on psychological well-being, this may explain why their physical health is affected. African-American caregivers experience lower psychological burden indicators, which could be explained by their motivation to care for others based on familism values as well as the use of coping strategies. Even further, it seems that African American caregivers are more positive in their caregiving role when compared to white caregivers (Pinquart & Sö rensen, 2005).

Caregivers working in institutions such as old-age homes have reported experiencing aggressive behaviour towards them by the population residing within the homes (Zeller et al., 2012). In German nursing homes, over 90% of the caregivers have experienced some form of verbal aggression while many have experienced physical aggression, as found within a study with a sample size of 123 individuals by Franz, Zeh, Schablon, Kuhnert, & Nienhaus (2010). In the US, 34% of nursing assistances reported having physical injuries as a result of aggressive behaviour towards them by the residents in nursing homes (Zeller et al., 2012) in a study completed using telephone interviews from 3017 nursing assistants from 582 nursing homes (Tak, Sweeney, Alterman, Baron, & Calvert, 2010). Within the European setting, nurses working in clinical settings experienced the highest levels of abuse from residents, followed by the psychiatric and emergency units. It can therefore be seen that within nursing homes, caregivers are at high risk of experiencing acts of aggression and abuse towards them. The rationale behind this seems to be multifaceted and includes the resident, the caregiver, as well as the environment in which they are situated in (Zeller et al., 2012).

Caregivers who experience greater levels of abuse or aggression are at greater risk for burnout (Zeller et al., 2012). Minimal information is available regarding the influence of the environment that leads to

aggression, however, it is known for patients with dementia a change in their environment triggers aggression, as they are highly sensitive to environmental changes. It is assumed that environmental factors and caregiver characteristics are connected as the caregiver ultimately shapes the environment for the patient, influencing the patient's daily tasks (Zeller et al., 2012). As caregiver burden exists within numerous caregiving situations, an aim of this study was to explore if employed stroke caregivers working in private homes in South Africa experience similar caregiver burdens to other caregiving populations.

3.6. CAREGIVER SUPPORT

"Coping" is a broad term and therefore coping should be evaluated within specific or stressful situations (Le Dorze & Brassard, 1995; Michallet, Tetrault, & Le Dorze, 2003). Among the most difficult challenges faced by the family of the brain injured/patient who suffered from a stroke are communication breakdowns and role changes. Compared to other caregivers, caregivers of patients with communication impairments experience higher levels of psychological distress (Oddy, 2010). Caring for a patient who suffered from a stroke is comparable to the stress related to caring for a patient with dementia (Draper, 2007).

Communication impairments are a leading cause of stress that family caregivers experience as well as high levels of loneliness, depression and other emotional disturbances (Draper, 2007). Caregivers are frequently responsible for interpreting the stroke sufferer's communication attempts, which leads to frustration for both the stroke survivor and caregiver (Rombough, Howse, Bagg & Bartfay, 2007). The Department of Health in the UK (2007), as cited in McGurk, Kneebone, and Pit ten Cate (2011), found that caregivers often lack coping skills, and therefore it was recommended that caregivers receive training for coping mechanisms when dealing with patients with communication disorders.

"Long-term care of stroke patients should include the identification and assessment of vulnerable caregivers in need of support so that appropriate interventions can be implemented*"* (Rigby et al., 2009, p. 291). The most beneficial and cost-effective way to support family caregivers may be via support groups. These groups provide education as well as emotional support and skill training to assist caregivers in their caregiving duties (Oddy, 2010). As seen within Gustaffson and Bootle (2013), in relation to family caregivers, the development of intervention programmes providing psychosocial and educational information and support has led to the prevention of caregiver depression and strain.

As seen by Kalra et al. (2004), training programmes for caregivers of patients who suffered from a stroke decreased the caregiver burden as well as reduced caregiver and patient depression and anxiety. Tronto (1993) recognizes that due to limited resources and availability of time, the ideal state of care is not easy to obtain. Difficulties in providing care occur as care is needed not only for the care-

recipients, but also applies to the caregivers caring for themselves (Tronto, 1993). Formal support services in the US are less readily available to ethnic minorities (Pinquart & Sö rensen, 2005).

The emotional components of caregiving must be viewed in relation to both caregiver and care recipient (Williams & Crooks, 2008). In South Africa, many domestic workers live on or near to the property of their employers, away from their families, causing many of them to feel isolated (Budlender, 2009). Many employed caregivers working for families also move away from their families and homes to stay near or on the property of their patients, in order to be able to provide the support required. This may result in caregivers having limited support systems being available to them, which was investigated in this study.

Within numerous countries, caring for people affected by HIV/AIDS, children, and the elderly, present with challenges in wages and working conditions (Razavi & Staab, 2010). Income and working conditions for care workers are influenced by the labour market of the economy and environment within a country. As the economy in South Africa has been affected by Apartheid, care workers within South Africa experience related repercussions. This situation is not limited to South Africa, as globally Argentina, Tanzania and India seem to present with large disparities within the care worker field (Razavi & Staab, 2010).

Within South Africa, there seems to be a wide discrepancy between various support systems available to nurses and social workers when compared to HBCs (Lund, 2010). In theory, all three have free health care access through public health services, however, nurses seem to have enhanced health care insurance as many belong to contributory schemes, and social workers commonly have additional health insurance. Despite health services, both nurses and social workers have access to retirement schemes, whether they work in the private or public sector (Lund, 2010).

HBCs receive assistance in their care work in various ways by society (Budlender, 2009). The assistance includes being provided with a project manager, being given the opportunity to discuss their work with others, and visits from a psychologist. It further assists by providing church volunteering services to allow the HBCs to complete their administrative tasks and to give them an opportunity to meet and speak with one another (Budlender, 2009).

Nurses and domestic workers within South Africa seem to have numerous unions available to them. Within South Africa there is a high degree of unionization that occurs within the work force (Budlender, 2009), which may assist in increased support and assistance when required within the workplace. The National Education, Health and Allied Workers Union (NEHAWU) is a trade union within South Africa and is the biggest public sector union in the country. It arranges welfare, education, state and health workers within the country. NEHAWU is associated with the Congress of

South African Trade Unions (COSATU), the biggest federation within South Africa (National Education, Health and Allied Workers Union, 2014).

The Domestic Workers Act was established to make the rights of domestic workers known and to allow for improved and fairer working conditions to occur. The Act stipulates working hours, minimum wage, various forms of leave, accommodation conditions, as well as the ability to register for unemployment insurance (Bradfield, 2012). However, despite the Act coming into existence, the drastic contrast between cultural and economic status between employer and employee still seems to have a significant influence over their work environment. Despite the legislation provided and legal protection acts implemented, dignity is still missing among domestic workers in South Africa as power asymmetries are still present and empower the workplace (Fish, 2006).

The Unemployment Insurance Fund is also available to those nurses and social workers working in private practice. HBCs however are not provided with the same benefits as nurses and social workers in both health and retirement funds. Despite having access to public health care, many HBCs rely on their family or friends for support (Lund, 2010). Razavi and Staab (2010) describe that respect, rights and equal wage distribution for care workers remains a problem that needs to be confronted in order for paid care workers and care-recipients to reap the benefits of care work. Social policy makers and services need to attend to and understand the needs of the care labour market (Razavi & Staab, 2010).

HBCs who care for HIV/AIDS patients within the patient's home setting have reported feeling unrecognized and are concerned about the unclear future that the Home-Based Care Policy offers them. Organizations and leadership for these caregivers is sparse (National Aids Convention of South Africa, 2013), however awareness of them seems to be present, as evidenced by the NACOSA Position Papers. The concerns of HIV/AIDS caregivers have been raised and include: to obtain a clear role where they fit within the health systems, to be treated with respect and recognition, to receive standard and fair employment conditions, as well as professional and training opportunities to attain a qualification through a structured curriculum (National Aids Convention of South Africa, 2013).

Care workers do not always receive minimum wages, rights, or benefits when compared to nurses with highly regulated formal professional councils. Within the EPWP, care workers typically have an ambiguous employment status (Razavi & Staab, 2010). While HBCs for children affected by HIV/AIDS is included within the public workers scope, it is evident that within the EPWP, care workers still receive lower wages when compared to workers hired to complete cultural, environmental or infrastructure projects (Razavi & Staab, 2010). It seems that a hierarchy may exist among the types of care workers present within South Africa. The amount of awareness, benefits, rights and support provided to various care groups seems to vary, as seen by the amount of unions, legislation and opportunities available to some of the care groups.

3.7. ETHICS IN CAREGIVING

Besides the negative aspects, the positive benefits and moral rewards of caring for another is of high importance (Tronto, 2002). Diemut Bubeck (1995), as cited in Tronto (2002), states that care workers are vulnerable to a specific type of exploitation. She describes that as women are socially constructed into the role of caregiver, they therefore often provide the service of unpaid labour to society. As the care worker develops a relationship with the employer, it becomes difficult for them to fight back if exploitation is occurring, especially if the relationship has been one of providing care. This results in the workers losing their moral dignity. So too, domestic workers are highly vulnerable to abuse as they receive low pay, have poor working conditions, and are commonly task-shifted between roles (Tronto, 2002).

Tronto (2002) discusses the "nanny" question in relation to feminism. Within a home, a nanny employed to care for one's children is working in a private and intimate environment as a quasi-family member, and therefore certain ethical questions with regard to caring and feminism are discussed. Domestic workers are paid minimal wages and despite this the most degrading aspect to their work is the lack of dignity and respect that they receive within the home. A sense of powerlessness and anger is experienced as within someone else's home, their own value and worth are often lost or are not seen to be of value. This is seen with live-in workers as even their food and leisure time is not to their discretion. Live-in workers may be further exposed to abuse or harassment within the home, and may have limited resources to turn to for assistance (Tronto, 2002). While there are laws for domestic workers in the US and within South Africa, they are not always adhered to.

Female employers may be increasingly more difficult to work for as the employer may view the worker as her competition (Tronto, 2002). With regards to caring for a child, as mothers may feel a sense of guilt leaving their children in the care of another, a mother may take their feelings out through actions towards the carer positively or negatively. The sense of guilt may make them act negatively towards the workers or may positively result in the form of gift giving as a sense of gratitude towards their care. Busy mothers may be too busy to learn about the workers they employ and do not spend time getting to know them or learning about their lives. This results in poor reciprocity of care being provided back to the workers (Tronto, 2002).

3.8. THEORETICAL FRAMEWORK OF CAREGIVING

While there were numerous caregiving theoretical frameworks that seemed to apply to the study, the multidimensional model (Raina et al., 2004) seemed most applicable. However, as assessing employed stroke caregivers' burden was not the main aim of the research study, the multidimensional model (Raina et al., 2004) served rather as an initial guide and model application, rather than the model used to collect and interpret the research results.

3.8.1. Multidimensional Model

The multidimensional model by Raina et al. (2004) is based on previous caregiving theories and literature, and was developed to guide future research on caregiver health. The model was based on the current caregiving literature on geriatric and paediatric populations that require care. These aspects of caregiving were included in the development of the model in order to expand the caregiving framework to form one caregiving representation (Raina et al., 2004). The multidimensional model focuses on various aspects of caregiving, including: direct and indirect relationships within care work, characteristics of the caregiver, the caregiver's background and social interactions, as well as focuses on coping methods within caregiving, as all of these aspects play a part in the caregiving process (Raina et al., 2004).

One of the comprehensive caregiver theories that influenced the development of the multidimensional model was the caregiving stress process model (Pearlin, Menaghan, Lieberman & Mullan, 1981; Pearlin, Mullan, Semple, & Skaff, 1990). The caregiving stress process model assesses informal caregiving stress factors that may negatively affect the caregiver's health. These caregiving stressors can change with time and can be grouped into primary (physical demands from disability) and secondary stressors (demands from the caregiver role) (Raina et al., 2004). It links the micro and macro-levels of stressors, resources and outcomes within a socio-structural process. It focuses on three main sources of stress including the source of stress, the intervention of the stress (i.e. support), and thirdly the manifestation of stress (Pioli, 2010).

The caregiving stress process model, as described in Raina et al. (2004), describes how negative life events can lead to negative consequences experienced by the caregiver within their personal life and within their caregiving role. Social support and coping strategies may benefit and positively support the process of change therefore positively influencing the outcomes (Raina et al., 2004). The need for the multidimensional model was developed for the guidance of future caregiver research, specifically research investigating caregiver well-being and health. This model includes not only direct sources of caregiver stress but also indirect sources. The multidimensional model comprises six steps. It seemed that the multidimensional model was applicable and relevant to the current study as it was anticipated that multiple factors could affect the caregiver burden of the employed caregivers investigated within the study, i.e. relationships and background characteristics (Raina et al., 2004).

Children with Cerebral Palsy (CP) were used as the prototype when developing the multidimensional model (Raina et al., 2004). Despite the model using caregivers of children with CP, the model still seemed applicable to the current study as the model makes use of various factors that seemed influential over the levels of caregiver burden experienced by employed caregivers in South Africa. As the background and context of employed caregivers in South Africa may differ significantly from their employers, this factor seemed important when considering caregiver burden. Patient

characteristics (i.e. patient who has suffered from a stroke), caregiver strain, and caregiver coping strategies further seemed applicable to the caregivers investigated in the current study. As the primary caregiver within this model refers to an informal caregiver, i.e. family member, it was anticipated that the model would have an influence on the current study, however, some steps and aspects may not be applicable to employed stroke caregivers as investigated within the current study.

Figure 1: The conceptual model of the caregiving process and burden found among the paediatric population – multidimensional model

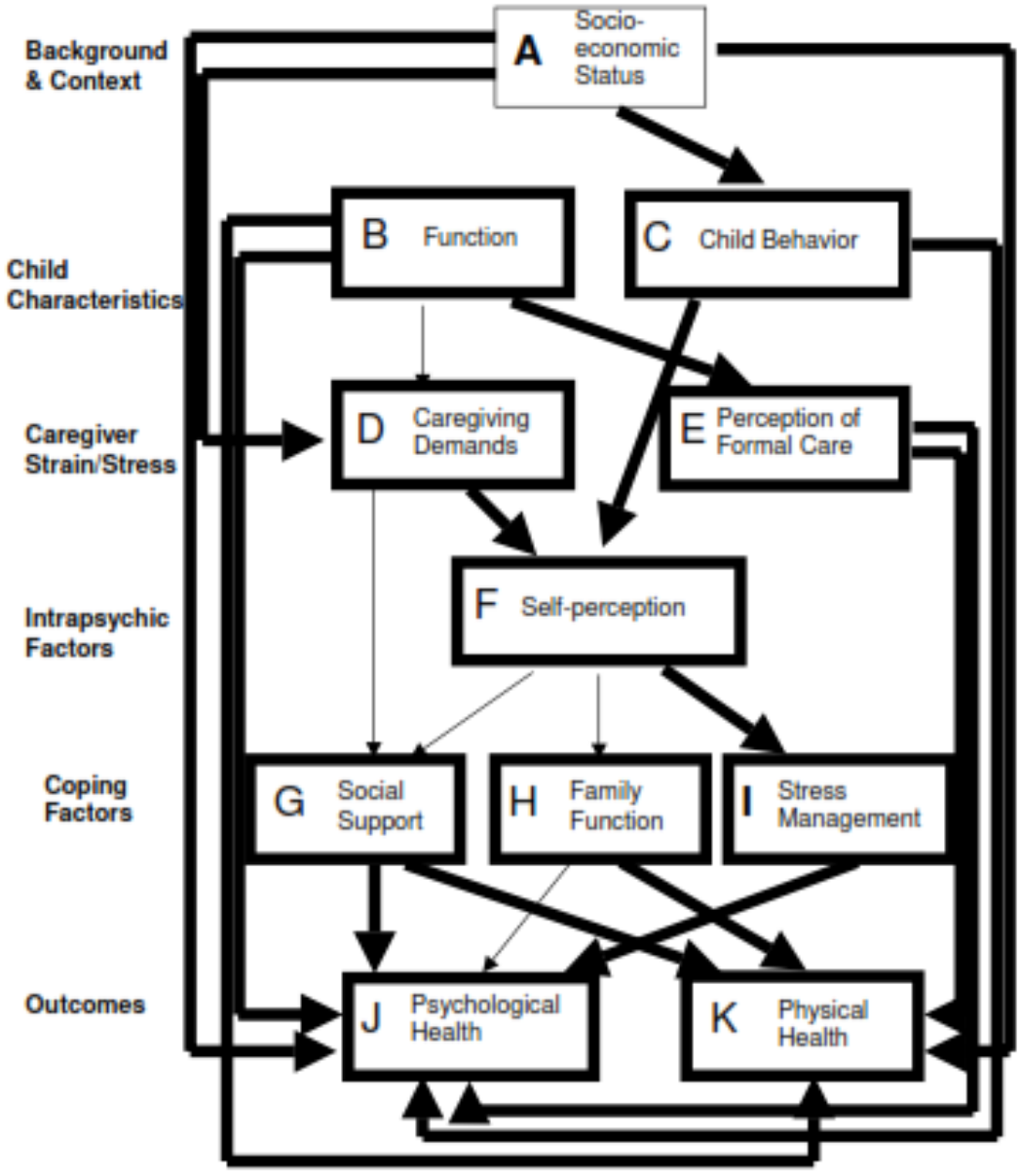


Figure 1
Conceptual Model of Caregiving Process and Caregiver Burden Among Pediatric Population

(Raina et al., 2004)

The original six steps of the study seemed to have application to the current study in the following ways:

1. Background, context, and socio-economic status: The background of the caregiver needs to be considered, as caregiving does not occur in isolation from one's experiences. The economic and social structure of the family and patient further needs to be considered as socio-economic status may impact the amount of care resources available, which may influence caregiver burden (Raina et al., 2004).

2. Patient characteristics: This step describes how the patient's characteristics and impairments will impact on the caregivers' demands. The patient's cognitive abilities, dependence on ADLs, general medical status, and behaviour may affect the caregiver's demands (Raina et al., 2004).

3. Caregiver stress and strain: Included in this step are caregiving perceptions and demands that occur with formal care. Caregiver demands include conflict between caregiver and occupational roles. Perception of care is dependent on the formal care services being family-centred (Raina et al., 2004).

4. Intra-psychic factors: The intra-psychic factors relate to the caregiver's internal state and refer to how the caregivers manage their feelings. Self-perception and evaluation occurs when a new role is taken on, i.e. primary caregiver. Self-perception can be evaluated by the mastery of a situation as well as with self-esteem (Raina et al., 2004).

5. Coping factors: The coping factors include elements such as social support, family function, and stress management. Social support includes support from family or friends while family function refers to the functionality of the family unit. Stress management refers to the way in which the caregiver responds to stressful situations (Raina et al., 2004).

6. Outcomes: Two health outcomes were used within this model, namely physical health and psychological health, referring to levels of distress and depression of the caregiver (Raina et al., 2004).

CONCLUSION

Current literature on informal caregiving is extensive, while literature, especially within the South African context, on formal employed caregivers, remains small. Various types of caregiving burden have been identified among informal family caregivers, however the experiences of employed caregivers, caring for patients who have suffered from stroke, needs to be investigated. While current theoretical frameworks exist for informal caregiver burden, a theoretical framework investigating the factors influential to employed caregivers' experiences in South Africa is required. The following chapter will describe the methods applied throughout this study.

Chapter 4

METHODOLOGY

OVERVIEW

This chapter will describe the methods used within the research study. The chapter will state the research question, the research aims, and will provide a description of the methods applied throughout the study. It will review the data management and the methods of data analysis, as well as the trustworthiness of the study. The chapter will further include the participant criteria as well as the ethical considerations applied throughout the study.

4.1. RESEARCH QUESTION

What are the experiences and needs of employed caregivers, caring for patients who have suffered from a stroke, within a home environment in the South African context?

4.2. RESEARCH AIMS

The primary aim of this research study was to explore the experiences of employed caregivers, caring for patients who have suffered from a stroke, within a home setting in South Africa. A sub-aim of the study was to explore the perceived needs of these caregivers within the South African context.

The research study had further objectives including:

- To investigate barriers and facilitators, stressors and resources involved in being employed as a caregiver of a patient who has suffered from stroke.
- To explore the unique aspects of caregiving in the private home environment which may be present within the South African context. For example, the different backgrounds, cultures, traditions, and socio-economic situations that may exist between the employed caregivers and the patients and families with which they work.

4.3. METHODOLOGICAL FRAMEWORKS

4.3.1. Epistemology

The epistemology of a research study has a significant influence on the methods and analysis that will be made use of in the study. As this study followed a qualitative design, the paradigm of the study followed an interpretivist approach (Banister, Burman, Parker, Taylor & Tindall, 1994). The interpretivist paradigm implies a continuously changing reality and relies on subjective experiences. Meanings and knowledge of the world are formed as a result of the individual's interpretations of their experiences (Banister et al., 1994). The participants in this study were required to share

information on caregiving in private homes from their personal subjective experiences. The study wanted to gain information with regards to caregiving in private South African homes, not from the interpretations of experiences from the employers but rather from the caregivers, i.e. the employees. The interpretations of the employed caregivers' experiences while working in private South African homes was sought after, and therefore the interpretivist paradigm was selected to allow for the relevant influence over the methodology to occur.

Interpretivist models of human behaviour suggest that individuals have free choice and free will and they are therefore able to control and monitor their behaviour. Individuals are purposeful and actively involved in life (Cohen & Manion, 1985). Interpretations of the world and of individuals are based on previous knowledge or social constructs and therefore individuals are able to understand people's actions based on their understanding of the world (Schwandt, 2000). Therefore, subjectivity and interpretivism are highly correlated. Interpretivists make use of methods to collect data that allow the researcher to gain subjective information, i.e. interviews, as completed in this research study (Schwandt, 2000).

4.3.2. Theoretical Perspective

A social constructivist perspective influenced the methodology of this research study based on the work of Crotty (1998), Lincoln and Guba (2000), Mannheim, Berger, and Luckmann (1967), and Schwandt (2000), as cited in Creswell (2003). Their work described how individuals seek knowledge about the world in which they live and develop subjective meanings of their daily experiences. As the meanings experienced are numerous and varied, the researcher searches for the complexity of the views rather than boxing ideas into fewer categories, allowing for a broader viewpoint of the meanings they may hold (Creswell, 2003).

The experiences of each participant are formed from social and historical events that have occurred within their life and therefore their cultural norms and daily interactions with others may have an effect on their social construct (Creswell, 2003). The focus of the researcher therefore becomes the participants' way of interaction as well as the context whereby they work and live. The constructivist aims to interpret the meanings that others construct about the world around them (Creswell, 2003).

4.4. RESEARCH DESIGN

It was felt that using a qualitative research design would be the most appropriate method to collect and interpret the findings for this study, given that many health related studies that assess human behaviour and health services use qualitative research designs to achieve their goal (Flick, 2006; Green & Thorogood, 2009). The use of qualitative methods allowed for real descriptions and

explanations from the participants to be captured. This allowed for in-depth information to be obtained in order to answer the research question and aims in detail.

Making use of the social constructivist perspective relies greatly on various participants' viewpoints of the situation being investigated (Creswell, 2003), i.e. the caregivers. Discussions with the participants throughout the interview process allowed for the collection of the participants' experiences of the researched area, caregiving within South African homes, through means of open-ended, broad questions, i.e. through in-depth interviews and focus groups.

An exploratory research design was implemented via semi-structured interviews and focus groups (Maxwell, 2009). The use of exploratory research allowed for a descriptive and in-depth understanding about each participant's experiences in their caregiving role to be captured.

4.5. PARTICIPANTS

4.5.1. Sampling Strategy

Purposive sampling was applied as the participants were selected purposefully to ensure that a pre-determined range was selected according to the selection criteria for the study (Green & Thorogood, 2009). This method of sampling allowed for the selection of participants to take place according to the shared common features that the study set out to investigate (Silverman, 2011). The participants were selected from a previously defined sub-group (i.e. employed caregivers) (Liamputtong & Ezzy, 2007).

The participants were recruited from organizations in Johannesburg, such as Stroke Aid in Norwood and Headway Hyde Park. Recruitment further took place through stroke rehabilitation centres within the Johannesburg region including Rehab Matters (Rivonia and Rosebank) and Netcare Auckland Park. The participants were not recruited from caregiving agencies as the aim was not to identify which agencies do or do not provide training and counselling for caregivers. Therefore, caregiver agencies were not contacted directly as the focus of the study was on the caregivers' experiences within the private home setting.

4.5.2. Selection Criteria

The participants in the study were required to meet the following criteria:

Qualification: The participants were not required to have a formal diploma or degree in nursing or caregiving in order to participate. The experiences of all caregivers, whether trained formally or not, were valued.

Experience: The participants needed to have at least one year's worth of caregiving experience, in the South African context, in order to be able to provide details of past caregiving experiences. They were

further required to have previously or currently cared for a patient who had suffered from a stroke. As this study focused primarily on stroke caregivers, caregivers' experiences with other neurological impairments without experiences working with patients who suffered from a stroke, were excluded from the study to allow for the experiences collected to be correlated to a specific impairment. The experiences of caregivers caring for other neurological conditions in isolation may differ and therefore to avoid this variable, only caregivers who had cared for a stroke sufferer were included. However, the experiences of working with other neurological impairments were valued as many of the interview questions were applicable to various neurological impairments, which allowed for further insight into the caregivers' experiences and needs.

Context: As the study intended to gain information from caregivers working within the South African context, the participants were required to have had experience working as a caregiver within South Africa. The participants could be live-in or live-out caregivers provided that they had worked within a patient's home rather than only in institutions. This was required as the dynamics within a private home environment between caregiver and the patient and patient's family were being investigated. Caregiving experiences that were limited to one patient at a time, without receiving assistance from other workers including caregivers or nurses, were investigated.

Language proficiency: The participants were required to have a good command of English in order to understand the questions and discourse that took place during the semi-structured interviews and focus groups as an interpreter was not used during the study.

Gender: This study was open to both male and female caregivers, however, only females participated in the study. Two male caregivers were contacted, however; they were unable to attend the interviews and focus groups due to busy schedules.

Age: The participants were required to be any age over 18 years.

4.5.3. Sample Size

The sample size consisted of fifteen participants in total for the study, all of whom met the prescribed inclusion criteria. Qualitative research makes use of two factors when selecting the sample size of a research study - adequacy and appropriateness (O'Reilly & Parker, 2012). These factors require the researcher to be flexible in selecting a sufficient sample size in order to allow for saturation to be reached, therefore indicating that no further themes or information are expected to emerge from additional participants (O'Reilly & Parker, 2012).

The study consisted of two focus groups, each consisting of five participants per group. de Vos, Strydom, Fouche, and Delport (2011) suggest that the optimal number of participants for focus groups is between six to ten participants. Despite all fifteen participants being grouped into one of the two

focus groups, not all of the participants could attend on the designated day due to various responsibilities. However, the small size of the group allowed for each participant to speak openly about their experiences and needs, ultimately resulting in rich and detailed data. During the focus groups, the participants were interviewed in a group setting. A randomised grouping system was used as due to the busy caregiving schedule of the participants, numerous dates were proposed to each participant for their convenience.

4.5.4. Demographic Information

All fifteen participants were black African female South Africans. Their ages ranged from 29-59 years, with the majority of the participants being in their 40's, and an average age of 43 years. Further demographic information is represented in Table 1 below:

Table 1: Demographic information of the participants within the research study

Participant	Gender	Age (Years)	Race	Nationality	Someone was cared for at home while growing up	Caregiving training course	Experience (Years)	Most experience with	Number of stroke patients	Currently self-employed vs. agency	Number of employers (Private homes worked in)
1	Female	40	Black African	South African	No	6 month course	8	Alzheimer's disease	1	Agency	8
2	Female	35	Black African	South African	Grandfather	6 month course	8	Alzheimer's disease	1	Self employed	5
3	Female	42	Black African	South African	Niece	3 month Home-Based Care course	4	Traumatic Brain Injury / Diabetic	1	Self employed (previously agency)	6
4	Female	29	Black African	South African	No	6 month course	5	Stroke	2	Self employed	2
5	Female	49	Black African	South African	Mother	6 month course	15	Stroke	4	Self employed	4
6	Female	47	Black African	South African	No	Volunteered at Baragwaneth Hospital as nurse and then became a caregiver	4	Stroke	2	Self employed	4
7	Female	47	Black African	South African	No	3 month course	12	Alzheimer's disease	2	Self-employed (previously agency)	7
8	Female	32	Black African	South African	No	6 month course	3	Stroke	Many	Agency (previously self-employed)	5
9	Female	48	Black African	South African	Grandmother	3 month course	7	Alzheimer's disease	1	Agency	4
10	Female	33	Black African	South African	Uncle	6 month course	5	Stroke	2	Self employed (previously agency)	3
11	Female	46	Black African	South African	Many children and pensioners	6 month course	3	Stroke	10+	Agency	Many
12	Female	44	Black African	South African	Grandmother	Domestic worker trained to become caregiver by family and neuro-rehabilitation centre	2	Stroke	1	Agency	1
13	Female	59	Black African	South African	Grandmother	6 month course	36	Alzheimer's disease	6	Self-employed	3
14	Female	43	Black African	South African	No	Basic Caregiver course at Hospice 3 month course	24	Stroke	Many	Self-employed	Many
15	Female	48	Black African	South African	Children	6 month course	13	Stroke	5	Self-employed (previously agency)	2

4.6. PILOT STUDY

Pilot studies serve as an important guide before completing research studies. The pilot study conducted prior to the main research study allowed me to become familiar with my interviewing design and to gain experience as an interviewer (de Vos et al., 2011).

The pilot study took place with an employed caregiver of a patient with a traumatic brain injury (TBI) within a private home setting in South Africa. A caregiver caring for a patient who has suffered from a TBI was selected as these patients may present with similar impairments to that of a patient who has suffered from a stroke. The semi-structured interview was conducted for the pilot study without a focus group taking place as pilot studies on focus groups are found to be a difficult task because each focus group has its own environment and dynamics (de Vos et al., 2011).

Piloting the semi-structured interview questions was found to be beneficial as I was able to assess which style of questioning was best suited for the research study (Silverman, 2011). It further allowed me to assess my questionnaire and make the necessary adjustments and changes before using it for the research study.

4.7. METHODS OF DATA COLLECTION

The data for this study was collected using two methods. A semi-structured interview with each participant as well as focus groups made up of the same participants. Two methods were employed to allow for triangulation to occur, resulting in increased rigour of results as possibly different information would be collected through each method, allowing for the truth of the study to be more accurately identified (Green & Thorogood, 2009).

In order for increased information to be elicited, the completion of the focus groups was planned to occur prior to all the individual interviews. Practically, with the restricted time that caregivers have, this was not a possibility for all of the participants. However, this seemed to be favourable as information shared within the initial interviews was used as a catalyst for topics of discussion within the focus groups, allowing me to gain more information about seemingly relevant themes.

4.7.1. Research Equipment and Location

My research tools included a semi-structured interview schedule of questions as well as a guideline of scheduled questions for discussion in the focus groups (Appendices D and E). The semi-structured interviews and focus groups were recorded by use of an audio-recorder, a cell phone audio-recorder as a backup recorder, and by use of researcher notes.

The participants were interviewed in a location away from their place of employment in an attempt to increase the reliability of the information obtained. It was felt that participants may be apprehensive

about participating if they felt it might jeopardize their job (as per guidelines suggested by Silverman, 2011). The individual interviews took place in a public area (i.e. coffee shop/restaurant in a shopping centre) most conveniently planned for the participants, or they occurred at the location of the focus groups. Each individual interview was conducted face to face.

Both focus groups and several interviews took place at a business office that was in a central area in Johannesburg, on a main road, to ensure that the participants' transport (public minibus-taxi service) could drop them at ease, without the participants needing to walk to the location. The focus groups took place on two Sundays, when the business office was closed. When an individual interview took place on the same day as the focus group, the participant was taken to a separate room in order to allow for privacy between the participant and myself to be present. I reimbursed all travelling expenses to the participants on the day of their interview/focus group.

4.7.2. Focus Groups

Focus groups are a useful and effective method of collecting data for qualitative studies as they assist the researcher in finding the social norms and range of perspectives that are present among the targeted subgroup (Mack, Woodsong, Macqueen, Guest & Namey, 2005). Information that may not be shared within an interview may be shared in a focus group as the group dynamic may serve as a catalyst in additional information and topics being shared within the focus groups, as well as within the personal interviews (de Vos et al., 2011).

An advantage of utilizing focus groups for this research study was the ability to collect a large amount of information within a short period of time from multiple participants. The focus groups and individual interviews took place within a two-month data collection period. Some of the participants had met with me for their individual interview before they participated in a focus group, while others met with me after they had participated in a focus group.

The guidelines proposed by Silverman (2011) were followed as I conducted and led the group discussions, as the moderator, by conversing and asking open-ended questions to the participants. Open-ended questions were used to obtain in-depth responses and information from the participants in order for their experiences and needs to be expressed freely (Appendix E). Seemingly relevant information and possible themes that had emerged in the individual interviews were included throughout each focus group (and will therefore not be found in Appendix E). The additional questions and themes of discussion allowed for member checking to be implemented. Often used in qualitative studies, member checking allows the researcher to increase validity and accuracy of information collected throughout the interviewing process (Harper & Cole, 2012).

4.7.3. Semi-Structured Interviews

Interviews are commonly used in gathering data for qualitative studies (Irwin, Pannbacker & Lass, 2008). Interviews range from very structured to free flowing, however, for the needs of this study the interviews conducted were semi-structured (Holstein & Gubrium, 1998). Semi-structured interviews are beneficial when the aim of the researcher is to determine the individual participant's perspectives rather than to investigate a group norm for which focus groups were used. The semi-structured interviews allowed for me to obtain socially sensitive information that the participants may not have felt comfortable to discuss within the focus group that they had attended (Mack et al., 2005).

The questions were based on my clinical experiences as well as from current literature in the field with reference to formal caregivers, caregiving in South Africa, as well as caregiver burden and support (Evans & Thomas, 2009; Razavi & Staab, 2010; Rigby et al., 2009; Thomas & Greenop, 2008; White et al., 2003; Williams & Crooks, 2008). As the study progressed, possible themes emerged that were not anticipated, and therefore member checking was applied where new questions were added for further investigation.

The questions within the interview were derived from the research questions and objectives (Appendix D). The semi-structured interview was structured in three categories as described in table 2:

Table 2: Structure of the semi-structured interviews

Structure of the semi-structured interview	
1. Background information	The initial set of questions were used to: • Build rapport between the participants and myself. • Obtain background information from the participants including their demographical information (Grbich, 2003).
2. Caregiver experiences	This section allowed me to: • Investigate the level of training of the participants. • Investigate how the caregivers felt about their role. • Gain an understanding of the positive or negative experiences that occur within the private home care setting. • Investigate whether the participants received any additional training once employed that would assist them with their understanding of stroke and stroke impairments. • Gain insight into how many participants live within the homes of their patients, and how this may impact on their well-being both emotionally and physically. • Gain insight into the potential emotional consequences that participants may face when they have worked for numerous patients. • Gain insight into the experiences of working in a personal home where other employees may be working. • Investigate any coping skills that the participants may have adapted as well as what systems would be most beneficial, if available to them, in order to receive debriefing, counselling or guidance should they require it.
3. Needs of the caregivers	This section of the interview addressed: • The possible needs that the participants may have, working as employed stroke caregivers in South Africa, and if so, which elements of support are most desired.

4.8. ETHICAL CONSIDERATIONS

Ethical clearance to complete the study was obtained from the University of the Witwatersrand Human Research Ethics Committee (Non-Medical), protocol number: H13/06/36 (Appendix A). The participants were invited to participate in the study and written consent was obtained. An additional consent form allowing for the interviews to be audio-recorded was signed by each participant (Appendices B and C).

The study was explained to the participants and an information sheet containing all relevant research details was made available to them (Appendix B). A description was provided of the relevance and rationale for the study, as well as the procedures that it involved. The participants were given the opportunity to read through the information and consent sheets both alone and with me. This was completed to ensure that the participants did not feel pressured to participate in the study and to allow them time to gain an understanding of all the information provided.

As stipulated by the HPCSA Guidelines, Booklet 6 (2008), information given to research participants needs to take place in a language understood by the participants. As the participants and I most commonly did not share the same first language, it was ensured that before being selected as a participant in the study, the participants had a good command of English (able to engage in a mutual conversation) in order to understand the study in its totality as an interpreter was not available (Lubinski & Frattali, 2001). As the caregivers work for patients who mostly speak English, it was assumed that the participants had a good command of English, and therefore, the data was collected in English without the use of an interpreter. It seldom occurred during the interviews that a participant did not understand or misunderstood a question, and in these situations the question was rephrased to ensure that the participant understood what was being asked. Questions or misunderstandings were clarified throughout the data collection process.

Further steps were taken to ensure the participants did not feel obligated to participate in the study, as stated in HPCSA Guidelines, Booklet 6 (2008). I was aware of the potential power and cultural differences that existed between the participants and myself, and therefore efforts were made to ensure that these potential differences did not influence the participants' decision or information shared within the study. The principles of confidentiality found in the HPCSA Guidelines, Booklet 6 (2008), were established as the participants' confidentiality was protected throughout the research process.

The information and guidelines stipulated in the Helsinki Declaration and the Medical Research Council of South Africa (MRC) ethics guidelines were taken into consideration throughout the study. According to the MRC ethics guidelines (1996), participants have the right to privacy and confidentiality including autonomy over personal details. Therefore, the researcher is required to

ensure that any information regarding the participants stays confidential. The Helsinki declaration, as found in the Bulletin of the World Health Organization (2001), further explains that the integrity of each participant within a research study needs to be continuously respected. This includes ensuring confidentiality of information is maintained.

It was explained to the participants that all identifiable information would be kept confidential and each participant would be assigned and referred to by a participation number throughout the data collection and reporting processes. Additional ethical principles were adhered to throughout the research study including autonomy, beneficence, and non-maleficence.

Autonomy, the right to make your own decision and to have your own views, refers to a set of diverse notions that include privacy, liberty, rights, self-governance, and individual choice making (Beauchamp & Childress, 1989). Autonomy was upheld as the participants independently decided whether or not they wanted to participate in the study and their individual free choice was respected. The participants were informed that that their participation in the study was voluntary and should they feel that they did not want to continue with the study for any reason, they would be permitted to withdraw at any time without consequence. Each participant reportedly felt comfortable to participate in both the interview and focus group and each participant decided to stay and participate in the research study.

Being moral refers not only to treat people with autonomy and refraining from harm, but also to contribute to safety and wellbeing (Beauchamp & Childress, 1989). Beneficence was upheld as this study was conducted to discover the experiences and needs of the employed caregiver population in South Africa. Beneficence was implemented through completion of the study, as an implication of the study was to provide support and training opportunities to the targeted population.

Non-maleficence has been associated with "primum non nocere"– above all do no harm (Beauchamp & Childress, 1989). I ensured that if any questions had the potential of upsetting the participants, that discussion would be discontinued. A social worker was available to the participants throughout and after the interviewing process should they have been upset or required counselling from the interviewing process. None of the participants in the study required this service.

4.9. DATA ANALYSIS

4.9.1. Transcriptions

All of the collected data was transferred from the audio-recorder onto a laptop in a digital MP3 format, in order to allow for each interview to be transcribed. Personal notes with regards to my impressions of each interview were added to each transcription for assistance in later analysis. Any additional information that was shared throughout the interaction but was not captured on the audio-

recorder (non-verbal information/stories shared outside of the structured interview) was noted and added to my personal notes, which were considered and included when analysis of the data began.

During the transcription process, rigour occurred by use of two audio-recording sources (audio-recorder and cell phone recorder) to ensure that when a word or phrase was misheard, a second source was available for increased transcription accuracy. After each interview was transcribed, I listened to the audio-recordings while reading the interviews to ensure that the information shared and captured on the audio-recorder matched the written transcription.

4.9.2. Thematic Analysis

As guided by principles outlined by Rapley (2011), thematic analysis was implemented inductively in order to analyse the collected data (Patton, 2002). An inductive approach allows the researcher to utilize the collected data to create a thought, unlike deductive reasoning that uses the collected data to confirm an existing thought (Thorne, 2000). Thematic analysis was used to identify, analyse, and document themes within the collected data. This allowed data to be organised and interpreted in rich detail as well as to allow for interpretation of a range of aspects related to the research topic to occur (Braun & Clarke, 2006). Rapley (2011) breaks down thematic analysis into five steps, which were followed while the data was collected, transcribed and analysed. The analysis incorporated guidance from Silverman (2011), Rapley (2011) and Booth, Colomb, and Williams (2008) as follows:

1. Familiarize yourself with the collected data
    - During the transcription process, I familiarized myself with the data as I transcribed each interview and focus group.
    - After the transcriptions were completed, each interview and focus group was read numerous times to allow for familiarity of the data to occur.
2. Create initial codes throughout the data
    - As the data was being collected, I began to informally code the data into possible themes.
    - Initial codes were created with the use of colour coding and mind-maps. I continuously reviewed my personal notes and added to them when information was repeated or seemed of interest or relevance to the study before the central themes were identified.
3. Search and gather data into potential themes
    - The initial codes were used to establish themes and sub-themes throughout the data.
    - Patterns of results were compared and interpreted from both the semi-structured interviews and focus groups and were further crosschecked and triangulated to allow for increased rigour of results (Green & Thorogood, 2009; Silverman, 2011).

4. Reviewing the themes
    - After analysis of the collected data, information was divided into themes to allow for interpretation to occur.
    - Once all of the information was grouped and analysed, I began to identify the main results and arranged a structured format of how each theme connected and influenced the other.
5. Refining the themes by looking for associations
    - I needed to "remove myself" from the intricacies involved in transcriptions and analysis in order to view the data holistically. Data reduction occurred by grouping information and separating relevant versus irrelevant information in order for the most prominent and relevant themes to be established (Rapley, 2011).
    - As suggested by Booth et al. (2008), I stripped away all information from my laptop and notebook, and using a pen and paper I began to write the claims, evidence, and support that seemed most important. This allowed the relevant information to be viewed in its totality allowing for repeated, insignificant, or unrelated information to be removed.
    - Obtaining the thoughts and suggestions of my supervisors further allowed me to analyse the research results from a less subjective view.

4.10. RIGOUR

Qualitative research makes use of the concept of rigour instead of the quantitative research concepts of reliability and validity (Liamputtong & Ezzy, 2007). Rigour can be strengthened through triangulation or through various research methods, theories and sources. As different results may be discovered using various methods, researchers and theoretical frameworks, triangulation addresses this dilemma (Liamputtong & Ezzy, 2007). Throughout the study I made use of a pure qualitative strategy using naturalistic inquiry, qualitative data and thematic analysis. Data triangulation as described in Patton (2002) was employed through making use of a selection of data sources. Various research methods were applied as they allowed for numerous findings to emerge (Patton, 2002). Therefore, a triangulation method was applied as both the semi-structured interviews and focus groups were used when the leading themes of the study were identified (Creswell, 2003).

To ensure rigour of the study, a reflective journal was kept throughout the data collection process. Reflection is an important element of qualitative research. In addition, peer debriefing occurred by my supervisors reviewing the analysed data to ensure and confirm that no biased analysis of data had occurred in the presented information (Long & Johnson, 2000).

CONCLUSION

This chapter described the research question and aims of the study. In order to ensure rigour and replicability of the study, a detailed outline of the methods used throughout data collection and analysis was provided. The ethical considerations applied throughout the study were also described.

Chapter 5

RESULTS

OVERVIEW

Throughout the data collection process, three leading themes emerged from the individual interviews and focus groups. As each interview concluded and new data was collected, the prominent findings became more refined and were divided into three main themes, as represented below in table 3.

As many of the participants' experiences with caregiving within private homes were centred on the relationships that were and were not formed, the first theme **- relationships -** will be presented at the beginning of the results chapter. The participants' experiences working as employed caregivers in private homes, revealed relationship dynamics within the home, both directly with the patient and patient's family, as well as indirectly, with domestic workers and other caregivers working within the same home.

When challenges arose within the home and relationships became strained, the caregivers felt unheard and uncared for, leading to the second theme of the results chapter, **lack of voice**. A commonality revealed throughout the interviewing process, was the participants' descriptions of how they feel they are undervalued and unheard, both within the homes in which they work and within South African society. The lack of voice expressed by the caregivers seemed to occur due to numerous contextual factors that occur within South African society. When the caregivers are required to continue working through difficulties without acknowledgement or assistance from employers, caregiver agencies, and society, emotional or physical caregiver burden may increase.

This leads to the third and final section of the results chapter **- support**. This theme includes the various aspects of support that this caregiving population feel are necessary as a result of their caregiving burden working in private South African homes. Despite the participants describing the support they had received from various people, greater emphasis was placed on the support they do not receive within the home and within South African society.

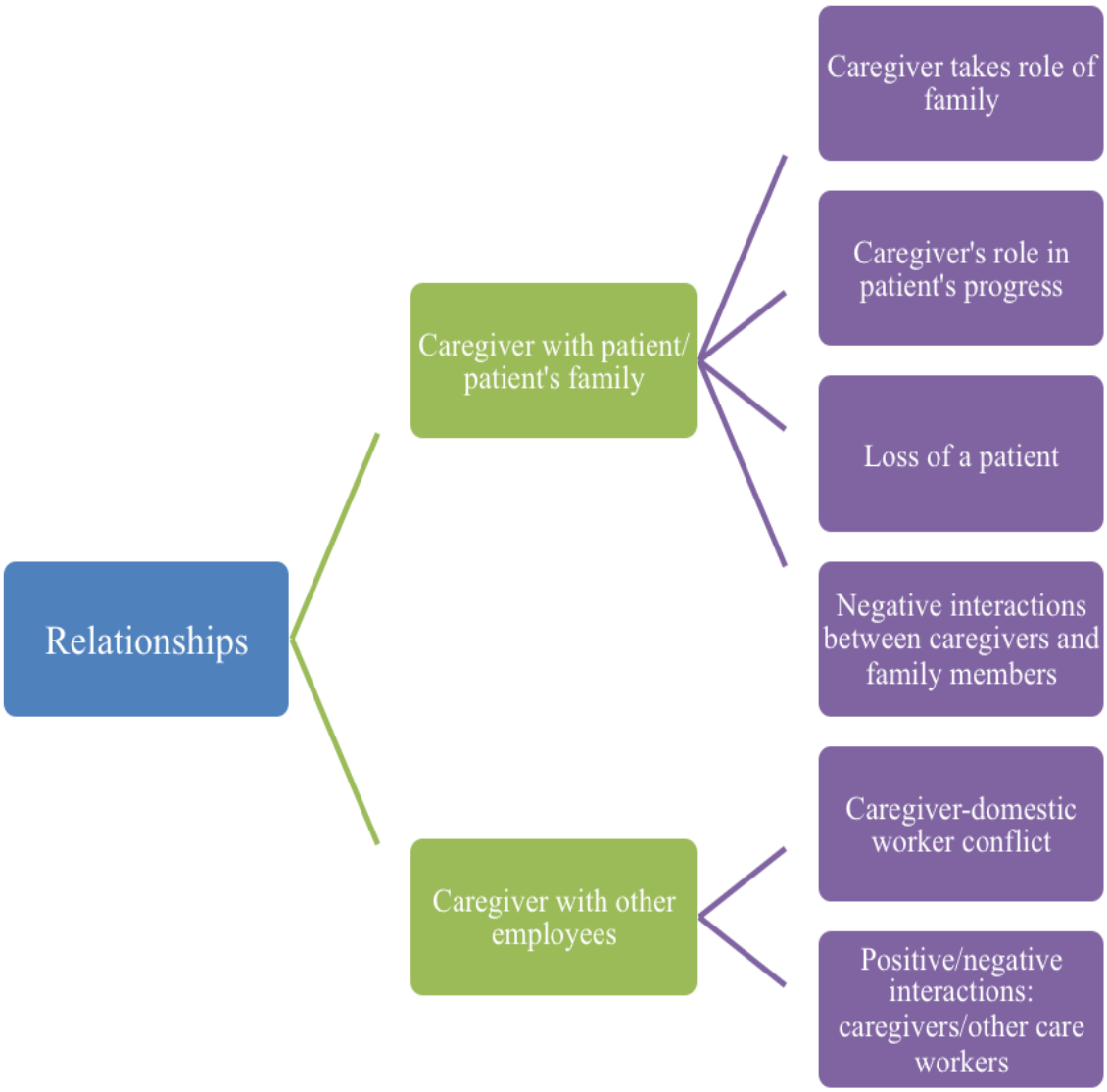
Table 3: Overview of codes, sub-categories, categories and themes

Data / Codes	Sub-categories	Categories	Themes
• **Compliments** • **Secrets** • **Gifts** • **Friendship** • **Quasi-family member** • **Religious holidays** • **Taxis/meeting places** • **Inheritance** • **Patient's progress** • **Despair/sadness - patient passes away** • **No greetings/concern** • **No development of relationship** • **Jealousy and competitiveness** • **Fear losing job** • **Unkind – domestic workers** • **Lies – caregivers**	Relationships with • Patient • Patient's family members/employers	Positive interactions	**Relationships**
	Relationships with other workers • Domestic workers • Other caregivers • Nurses	Negative interactions	
• **Poor safety** • **Basic food/drink** • **Poor leave/uniform/transport benefits** • **Nowhere to complain** • **Unheard population** • **Unknown challenges** • **Asked to complete tasks outside work description** • **Stereotyped roles in home** • **Therapy/nursing tasks outside work description**	• Lack of basic rights • Income instability • Task-shifting between roles	Contextual factors/cultural influences	**Lack of voice**
• **Poor training** • **Emotional burden** • **Loss of a patient through death/losing job** • **Conflict within home** • **Physical burden – injuries** • **Financial insecurity** • **No voice/assistance from union/legislation** • **Poor rights/benefits/voice in society** • **Therapists provide support/training** • **Social workers/organizations** • **Support one another** • **Family support – not consistent** • **Patient support – financial and emotional**	• Therapists • Support groups • Union/legislation • Professional services • One another (caregivers) • Employers	Support within home and society	**Support**

THEME 1: RELATIONSHIPS

The theme of relationships recurred throughout the individual interview and focus group data. The participants discussed various types of relationships that form within the home setting. The types of relationships developed seem to have had an effect on the participants' overall levels of happiness and emotional burden within the home. The relationships between the caregivers with their employers and with other employees within the home will be discussed in this section of the results chapter.

Figure 2: Overview of the relationships caregivers may form within the South African home setting



5.1. RELATIONSHIP BETWEEN CAREGIVER AND PATIENT/PATIENT'S FAMILY

The findings suggest that within South Africa, an employed caregiver in a home setting may fulfil a role greater than what the job presents on the surface. Family members of the patient are often required to leave their loved one at home with an employed caregiver, in order to continue with their regular daily or work routines. This in turn seems to result in a strong bond and relationship being formed between the employed caregiver and the patient. Caregivers that live on the property of the patients may form an even stronger connection with the patient and patient's family as is the case with live-in domestic workers (Stiell & England, 1997).

As the demands and workload placed on caregivers increase, increased levels of burnout may be experienced (Williams & Crooks, 2008). However, it seems that other factors such as friendship, support, and trust, between the caregiver and patient/patient's family, can influence the caregiver's happiness and well-being, reducing the overall levels of caregiver burden experienced. Many participants described that caregiving for them is an easy task, as despite the patient presenting with various stroke-related impairments, the positive relationships that exists within the home setting allows the possible caregiving challenges to be met with ease. It seems that the lack of emotional burden that could form from poor relationships within the home has an influence on the physical burdens of caregiving.

Numerous participants that developed a good relationship between themselves and the patient/patient's family described their job with positive connotations. Participants shared examples displaying the positive relationships they developed within the home setting as seen in table 4:

Table 4: Extracts depicting positive relationships formed between caregivers and patients

Examples	Quotes
Complimenting each other	P3: *I liked to work with you because when I get into the house I used to say 'hi mummy, how are you, oh today you are looking so gorgeous!'* G: *She used to say to you or you said to her?* P3: *I used to say to her and she would say back to me 'ah you too are also gorgeous.'*
Working over-time by choice	P6: *I didn't even want to go home if it was my turn to go home… You know what, I think it's, when you are working somewhere and you are*

	happy about what you do. It's like me when I started looking after that person who had a stroke. I end up being, even when I'm off I will say 'I don't want to be off, I'd rather be with you' then it all changes automatically that you people are bond now together.
Strong relationships over-power physical impairments	P15: *You know when you get used to a patient now it's not any difficulties anymore that you getting and then you see that when you are not there you miss a person, and you get easily attached to each and every patient that you get around as long as you are happy to work with that person. So as soon as you see that it's weekend off I'm not there and wherever you are you thinking of the patient. And even the patient too he'll be thinking that even if you* (caregiver) *not there then who's going to help me because the children can't do what we* (caregivers) *are doing.*
Becoming close friends	P11: *I can tell you one thing, if there's people who know our pain as caregivers, it's the patients, because you get so close to the patient, then you become open, you tell them things that we can't even tell our pastors in church, you know. I always tell my patient, I always say to her 'you know you are becoming my best friend, I'm telling you like deep secrets, I don't know anyone to know but you know', and the patient trusts you. Everything goes smooth because there is understanding between the two of you, then they recover as well, things go well.*
Importance of establishing a good relationship	P9: *Ja, its good relationship* (be)*cause it's very important for us.*

	G: *To have a good relationship?* P9: *As a care worker yes.*
Open communication with employers	P6: *If I got problems with the patient I'll talk to them* (employers)*, you see this and this about the patient... they will always come with me to the patient, we talk to her until we come to an agreement.*
Energized to work when relationships are positive	P15: *Yes if the relationship is good you know in the morning when you go there you are very active, you are very happy to go there.*

These examples seem to reveal that caregivers, who have a positive relationship with the patient/patient's family, enjoy their work as primary caregiver, as the relationships that develop within the home influence their overall happiness in the caregiving role. These relationships are described and seen in various situations:

5.1.1. Caregivers taking on the role of family member

Many of the caregivers felt that they had an additional role and that not only had they become the patient's caregiver, but they had also become a member of the patient's family. This was seen in both happy and less fortunate circumstances as some caregivers are brought into the family unit and are treated like a member of the family, while others become the patient's family by default as the patient's own family is no longer present to care for them, either because they have passed away or moved away. Stroke often occurs in older age when support systems may already be limited, as family has moved away and friends have passed on (Oddy, 2010).

Participant 2 shared that she felt like a part of the patient's family as the family trusted her with the care of their loved one. Having the responsibility of caring for someone's loved one, made her feel like a part of the family as her role was one of importance. Further extracts depicting the role caregivers felt they acquired within the home, as a quasi-family member, are presented in table 5:

Table 5: Extracts depicting caregivers as taking the role of a family member of their patient

Examples	Quotes
Caregiver replaces the patient's family	P5*: Sometimes it's good to work for them to know that you helping them but it's also sad sometimes because some of the stroke patients, their family is not there for them, then you have to be there looking after them all the time.* G: *Are they not taking care of them because they are away or just because they don't care…?* P5*: They just don't care for them, ja they there.*
A part of the family	P2: C*aring can make you to feel like that friendship is getting to be like family...*
Relationship similar to parent and baby	P6: *It is so difficult because sometimes you find a person who's house is double story, you have to take her up and down and it's so difficult and you have to make sure that you trying to help him or her to walk, or to touch, you have to do lots of things, all the exercise, all those things, carrying them with your hands like teaching them how to walk like a baby, a person with a stroke is like a baby. Always learning to walk.*
Choosing to spend Christmas with the caregiver	P13: *… In 2006 we were going to go, December 2006, I was ready to go, got someone to come and stay with my patient and my children were already in the car waiting for me... And she called me, and said 'how are your children going to feel if I say I want to go with you to have Christmas with you?' and I say to her 'no, my children won't mind, what about your children?' and she pick up the phone and she phoned… 'I want to go and have Christmas at my caregiver's house and the (her) children'… So I pack her*

	bags and off we go! G: *So she chose to have Christmas with you?* P13: *Yes at my home in the village. We stay*(ed) *for three days, we were going to stay for longer but she was a diabetic and I forgot the insulin….When we get there I got the house with a veranda and lots of food, mangos and things so she phone her children and said 'you won't believe what I've got' my house is a village but it's got everything. Everybody in the village came to see a white lady! It was really fun to me and my children.*
Sharing in religious festivities	P12: *…on Friday I say 'I'm going I'll see you on Tuesday', like she's India* (Indian – Hindu religion), *and Sunday it was their Christmas, and I came, I dress her, I choose nice clothes for her and match everything so she was dressed and* (she) *said 'are you not coming?' and I said 'no I'm off'…* G: *Was she upset?* P12*: Ja {nods head}.*

Participant 13 (FG2) shared a story depicting the important role she played in the life of a patient that extended beyond her duties as a caregiver. She shared how she took care of a patient in her home as the patient's family had moved away. The patient used to confide in the participant and discussed how she knew that her children were waiting to inherit her money when she passed away. As the participant cared for, and built up a strong relationship with the patient, when the patient passed away, the participant unexpectedly was included in her will and inherited a part of what would have been the children's inheritance. The participant felt that she cared for the patient as if she was her own mother, and therefore that she deserved the inheritance despite the patient's family becoming angered by it:

P13: *My previous boss who died in 2008, before she died she made a certain will, her children are billionaires they couldn't care less, but she gave me a car, everything in the house. The children came*

and took there and there, I didn't mind, but after I left, they wanted those who were given to me through the will and they went and spread to rumours that I took their mothers furniture. I couldn't care because I had the proof with me, those children, the daughter she stays in (X-place) and she will come and say to her mother, she will say to me 'where is that horrible vicious woman?' her mother was always in tears when she came, she couldn't care less that her mother was sick, they were waiting for the day, they were waiting for the phone when I said 'your mother passed away.'

She continued to share that not only did she care for the patient, who she referred to as her mother but that the patient ensured the participant that her children would be taken care of:

P13: … *My children are well educated because of that. Because one hand washes the other, I was looking after her, she was looking after me.*

The participants who had described stories of being taken care of by their employers were called "lucky" by the other participants, as not all of them had been fortunate enough to work for a family that cared so deeply for them and who were treated as a member of the family. The two-way relationship that caregivers build with their patients provides them with dignity as they develop a close constant relationship (Stacey, 2005), as described by the extracts above.

5.1.2. Caregiver's role in the patient's progress

Besides taking on the role of a family member or friend, the findings of the study reveal that employed caregivers also seem to take on the role of therapist or counsellor when required. The relationship and bond that develops between patient and caregiver seems to affect the patient's recovery process as well as their overall happiness and well-being. A good relationship between caregiver and patient seems to result in reduced stressors within the home and allows for full support and energy to be provided towards the patient.

Participant 12 described the biggest challenge when working with a patient who suffered from a stroke was the patient's ability to use the toilet. The participant recognized this and tried to assist the patient in making the activity of using the toilet a less anxious time for her by adding humour to the situation. This situation displays how caregivers, who have a good relationship with the patients, may experience greater job satisfaction, which has the potential of influencing their overall caregiving experiences. Being a caregiver comes with completing the "dirty work" associated with the job including cleaning and toileting responsibilities. Caregivers learn how to provide dignity to their patients and how to value these more difficult jobs (Stacey, 2005). Caregivers play an important role in allowing these and other required daily acts to occur in a dignified way, which has the potential to influence the patient's overall recovery. Further examples depicting the role caregivers play in the patient's recovery are presented in table 6:

Table 6: Extracts depicting the role caregivers play in the patient's recovery

Examples	Quotes
Happiness when a patient makes progress	P11: *You know, talking from one time, there the patient is recovering very well and you have that hope as well that tomorrow the patient will be much better than today, only to find out the healing is just progressive. That is the pain to you also, because especially when you looking after a patient, your own goal, is to see that patient recovery* (recover), *getting better. So if that doesn't happen, no, then it's a pain for you… I'll tell you I found this patient in (X- hospital). The patient was not communicating with anybody, the patient was not eating. Could move a little bit, was not talking, not eating, was using a tube to eat. Day when I arrived there the patient talked to me*! ... *I was so happy for that, I'm so proud of that. And I make that patient eat that day normally, not through the tube, and I was happy, the patient over-ate, so the doctor was so pleased so I was so happy to see that happening. And what makes me happy more is that the patient recovered, completely!*
Family recognizes impact of caregiver	P12: *…I was naughty and left them. I ran away for a month because of the* {using hand to gesture money} *you know, and I went away and then they look for someone to work there and their mother, they didn't tell me exactly what happened, then they phoned me I was working at a crèche, then they said 'that person* (another caregiver) *has gone so can you come and help our mother? Our mother depends on you, she misses you' all those things 'and when you left we thought she would be sick again and go to the hospital' then I said*

	since I went there, to look for a job as a domestic worker, then I got the caregiving (job) *and this* (these) *are the people who taught me how to do* (caregiving), *let me go back, and let me not worry about money anyway.*
Sadness experienced over poor progress	P1: *You know, taking from one time, there the patient is recovering very well and you have that hope as well that tomorrow the patient will be much better than today, only to find out the healing is just progressive. That is the pain to you also, because especially when you looking after a patient, your own goal, is to see that patient recovery, getting better. So if that doesn't happen, no, then it's a pain for you.*
Supportive role	P14: *No I never get frustrated, I always laugh at them to make them feel better of themselves, always laugh, I always enjoy and make sure they do.*

After the transition from inpatient neuro-rehabilitation into the home setting occurs, the patients require additional support, especially in the first month, in assuming their role back into the household and community (Gustaffson and Bootle, 2013). The participants within this study describe their desire to assist the patients, as if they were their own family members, to make this transition as easy as possible. The role that the family caregivers take, as seen in Gustaffson and Bootle (2013), seems similar to those of the employed caregivers in the current study. When discussing family members as caregivers, Gustaffson and Bootle (2013) explain that the caregivers feel they play a vital role in the patient's progress as they take the role of informal therapist and motivator in difficult situations.

5.1.3. Loss of a patient

The findings of the study seem to imply that the feelings and strong connections that develop between employed caregivers and patients/patients' families can be seen in the stories and descriptions of the hurt they experience when a patient they had been caring for passes away.

A patient passing away can result, for the caregiver, in the loss of both the patient and patient's family, i.e. the caregiver's "new family." As the findings reveal, when a patient passes away, the

emotional connection between patient and caregiver no longer exists, resulting in significant feelings of hurt, loss and increased emotional responses (Stacey, 2005). The loss includes the end of a friendship as well as a loss of the financial security the job had provided them. As a result of the strong friendship and bond that forms between the caregiver and patient, the loss of a patient is greater than initially assumed. Participant 15 shared her story depicting this loss:

G: *Have you ever cared for a patient that passed away?*

P15*: Yes… I've never spoken to anybody about that but I had patients who passed away. Like the lady* (patient), *she had a stroke, I was sitting with her in the morning and I said 'you know today you are different' I didn't know whether she was going to die or not, I said 'why are you so heavy?', and she* (patient) *said 'I don't know but all I need is for you to prepare my breakfast' and I said 'I gave you the breakfast, your cousin is here from London so I'm going to leave you with your cousin for lunch… she* (patient) *said 'no I'm not going to have lunch with her I'm going to have lunch with you as always so you going to prepare lunch for me as always'… During lunch time I gave her* (patient) *soup she ate soup and afterwards she* (patient) *was looking at the mirror and I said 'I told you there is something wrong what is happening?... and I don't know if a person is going to die or not… and then I looked at her and later I saw the neck* (of the patient) *just go on the side.*

G*: How did you feel after that?*

P15: *It was so sad. I was crying a lot. I cried because I didn't think that a person can die just like that. And when I call the family outside they were very cross with her* (patient) *because she* (had) *chase*(d) *them out… She knew that she's dying so she wanted me to be with her in the room.*

The loss of a patient was further discussed among the participants in focus group 2:

G*: Do you think sometimes, that you have a better relationship with the patient than their family does?*

P13*: Most of the time, you usually click with the patient, you know each other, the patient trusts you because long hours you with the patient, you land up knowing secrets of the family and some of the things the patient can't tell them and you know if you just spread the word, they will kill you.*

G: *So then, when that patient passes away…what's it like when someone like that who you've been working for passes away, and then there's nowhere for you to turn to speak to…*

P15: *You just in tears.*

P3*: It's traumatizing.*

P15*: It's traumatising and you been in tears, because you won't say anything to anybody, but they'll just see you that you crying because of that person, and it is deep down.*

G*: Is it difficult being a caregiver when a patient who you really have loved and cared for passes away, that the first thing is that you need to find another job, because you need an income, so you don't even have time to mourn for that patient?*

P15: *It does, and nobody cares how you feel.*

This loss and hurt experienced by some of the participants was evident as many of them explained that they had not spoken about the loss of patients until the interviews for this study took place. Realizing the loss and pain experienced by this population of caregivers encourages the idea of support systems to become more accessible and available to this caregiving population, as such services do not seem to have been made use of previously by the participants within this study.

5.1.4. Negative family interactions

Not only were there positive stories depicting the relationships with the caregivers' patients/patient's families, but negative experiences were also shared describing the effects that a negative relationship within the home can have on the caregiving role. The findings reveal that challenges associated with caregiving can occur within the home, more commonly with the patient's family members. As mentioned in Stiell and England (1997), as the caregiver is working in a private home, the line between family and employer can be easily shifted. Some participants were treated as members of the family and were cared for accordingly, while others believed that they had become a part of the family, expected care from the employer, and became disappointed when it was not provided. The participants described their job as difficult when the relationships were not reciprocal and when they were not treated well by the patient or patient's family:

Table 7: Extracts describing negative family interactions within the home

Examples	Quotes
Caregiving: *easy* versus *difficult*	P1: *It is difficult, it's not easy. It's not easy at all. It has some challenges. Sometimes if the patient is accommodating then the challenge is always with the family.*
Encouraged to stay when treated well	P13 during FG2: *In homes it's really not a joke because you dealing with your patient and everyone in the family, it's really not easy... The*

	other thing that make you to stay to look after the patient, it's when the family support you, yes.
Negative interactions between caregiver and family members	P11: *You get in*(side) *in the morning, you supposed to change and bath the patient, give medication and all that, and then the wife was there and she will always say to you 'no, leave my husband alone!', and then the son will come to the house and he will just sit on the chair like this* {cross arms} *to you. They always fighting and shouting so, no, that wasn't good...*
Caregivers have minimal expectations	P11: *No it has to be a one-way relationship, I'm not expecting much from them, at least a 'thank you' you see it means a lot.*
Treatment influences happiness	G: *Tell me about the feelings you have when you working for patients who suffered from a stroke?* P8: *I'm feeling happy, if you looking someone and the person treats you nicely.*
G*ood* and *ugly* families	P11 during FG2: *It's not always ugly for all the families, some are different, they really treat you like you are a human being and they respect your professional worth, yes they do, so they will treat you, you know really when I'm at work I'm appreciated, and that gives you more power to want to be more helpful to the patient.*

Participant 8 described the "good" families as the ones who talk to you while the other families just say "hello" and greet caregivers without any further conversation. She expressed that she has not had a good relationship with the family that she currently works for and does not feel supported by them. After the interview, the participant shared a recent event that had occurred a few days earlier:

The patient had suffered a seizure during a therapy session at an outpatient neuro-rehabilitation centre. The participant waited with the patient for over an hour until the ambulance arrived and took the patient to a hospital. As the event occurred on a Friday, she left for her home for the weekend and

anticipated a phone call from her patient's family to inform her of the patient's medical status. This did not occur and she only discovered what had happened to the patient on the Monday when she returned to work. She explained that the family had not contacted her to update her, despite her being with the patient when he had fallen ill. The family had not phoned her to see how she was doing after the incident or to thank her for taking care of him until the ambulance had arrived. This upset her deeply as over the weekend, she did not know whether the patient was medically stable.

While some caregivers described the negative relationships between themselves and the employers, describing the potential power difference that exists between them (feeling personally offended and hurt when they are not greeted or spoken to with care and respect), many participants described the positive relationships they built with the patients and patients' families, becoming a quasi-family member or friend, as described above. The relationships that caregivers develop within the home setting in South Africa are not restricted to the patient and patient's family, as daily interactions with other employees within the home occur. These relationships also seem influential over the caregiver's happiness within their job.

5.2. RELATIONSHIPS WITH OTHER EMPLOYEES WITHIN THE HOME

The findings seem to reveal that despite difficulties arising between employed caregivers and the patient or patient's family, many participants developed and maintained good relationships with the employers, despite the obvious cultural and racial differences present between them. While some of the participants felt that a power difference existed between themselves and the employers, resulting in poor treatment within the home with minimal reciprocal care being provided towards them, an additional stress factor seems to exist within the home setting within a different relationship. This stress factor seems to exist between caregivers and other workers, of similar background, race and culture. The relationship that exists between caregivers and domestic workers, other caregivers, and nurses, has the potential to result in strain, negativity and caregiver burden, as described by the participants.

5.2.1. Relationship between caregivers and domestic workers

The relationship and dynamic between caregivers and domestic workers working within South African homes was a prominent theme within the findings. The information and responses from the participants on this topic were highly emotive and descriptive. The relationship between caregiver and domestic worker can be one of jealousy, strain and competitiveness as supported by the stories shared by many of the participants. One possible factor contributing to the strained relationships is that domestic workers may feel threatened that they may lose their job to the caregivers and therefore a competitive nature develops between the two parties, as seen in table 8:

Table 8: Extracts illustrating the relationships between caregivers and domestic workers

Examples	Quotes
Role delineation	P3 during FG2: *No! Huh! I don't want to clean the toilets, and the ironing! I'm a caregiver, I have a diploma for this job.*
Stress within the home from domestic workers	P1: *…Because another thing that is difficult to work in a home, if there's a lady* (domestic worker) *who's been working there, who's been a madam or a master, so you come, they see you as someone who's going to take your job.* G: *A domestic worker in the home? They give you a hard time?* P1*: Yes, they are worse than a family! So that's what we* (other caregivers) *always talk about {laughs}.*
Domestic workers feel threatened by caregivers	G: *What's the relationship like with the domestic workers in the home when you are there?* FG2: (Laugher in background) All: *Horrible!* P15: *It's like a disease, as a carer! Somehow they don't like you, because they have that mind that I'm going to steal your job, even though we not doing the same thing…Some they will be nice to you because they want to use you. They want you to do their jobs! That's what happens.* G*: So it's not a good dynamic?* All: *No.* P3*: One of the ladies she told me 'if you coming to steal my job' she didn't tell me that you coming to steal my job, she said 'oh if somebody*

	coming to steal my job, oh, they'll see!'
Suspicion towards caregivers	P3: *Always, always these people will say, 'the boss likes you too much, I don't know what muti you using?'* FG2: (Laughter in background) P3: *I say I don't use muti, this is my job! Because she told me one day that this woman did not introduce anyone* (the domestic worker is not introduced to visitors) *but when it's me then she* (employer) *say 'hey this is (name of caregiver), she comes from (X-Place), she is working so hard.'*
Domestic workers feel jealous of caregivers	P6: *And another thing, if you looking after a patient, you become closer to them and you know when he's doing this, he doesn't like thing, so you become closer. Every time when he or she has something got something to give, they will give you first, the caregiver, because you are taking care. They say 'you bathing me, you are feeding me, you are doing what you doing' and then the domestic workers become jealous.* *… And then the domestic worker will say to you 'since I've been here for 14 years, they've never given me a bra! But you getting everything, the pair of shoes, shirts, everything!'* FG2: (Others laugh in background, look at each other and agree) *Then I always ask the lady that I'm looking* (after) *'why don't you give the same?* (to domestic worker)*' and she* (employer) *says 'but you are the one that I'm close to, she never bath me, she never asked me or cared or what so you*

	are my favourite', just like that so they become scared that you'll take her job.
Feeling unsafe	P5 during FG1: *It's just that feel unsafe when you getting there. It's another story, they (domestic workers) funny* (strange) *with you.*

Participant 6 described how a possible reason why jealousy develops within the caregiver and domestic worker relationship is that the caregiver is employed to care and work for only one family member, the patient. Despite this being a strenuous and demanding job, emotionally and physically, the domestic workers may feel jealous that they are required to work for all of the family members and complete many household jobs, when it seems that the caregiver is not carrying out as many demands as the domestic worker completes. It further seems that role delineation, various responsibilities, and the possible hierarchy that exists between caregivers and domestic workers may contribute to the tension that is experienced within the home. As described by participant 6:

G*: Is it not only the patient who needs to be taken care of? Do they want you to care for everyone?*

P6: *It's only the patient, and then sometimes you find it difficult because you have the contract that you are signing with the patient and they'll tell you everything that is concerning the patient you must do it and you end up being an enemy to the domestic worker like maybe the domestic worker was doing the washing, everything, cooking, now they give you the contract that you need to do all these things just to the patient and you end up being an enemy to the domestic worker.*

The risks associated with home care go beyond losing a job or bringing harm to the patient. Rather, the most common risks are those associated with the caregiver (Stacey, 2005), i.e. emotional and physical strain and burden. Despite this, the participants feel that the domestic workers view domestic work as more difficult than caregiving tasks. Participant 10 shared that domestic workers act unkindly towards caregivers when a salary discrepancy is present. She further explained how she feels that domestic workers do not like to see the patient progress as that indicates that the caregiver is completing her job well and may receive increased benefits as a result:

P10: *Ja sometimes, when the salary is not the same then, and (s)he's getting jealous when she sees her boss is getting better.*

In South Africa, many domestic workers will live on the same premises as the family members that employ them. Depending on the needs of the patient, the employed caregiver may be required to live

on the premises of the employer, with the domestic worker. The strenuous relationship between the domestic worker and caregiver seems to extend to their living space. As seen in focus group 1:

G: Have any of you stayed in the home with the domestic worker also staying in the home, and is that even worse if you both living there?

All*: Yes, worse.*

G: So what happens after work? Are they nice to you in your room or is it still bad?

P6*: Sometimes they don't even talk to you, in the mornings they don't even greet… good morning... silence...I'm ok!*

(Laughter in background)

The participants further discussed honesty and deception in the workplace. The caregivers felt that what influences the strained relationship between themselves and the domestic workers is an attempt to make one seem "worse" than the other. The participants shared that at times, when they enter the home and are the new worker, the domestic worker will plan a scenario to make the caregiver seem as if they have stolen from the employer, resulting in the caregiver being fired on the grounds of theft. As the caregiver is the new employee, and a relationship of trust has not yet been established between themselves and the employer, the domestic worker will accuse the caregiver of theft. This may occur as the domestic worker feels threatened of losing their job should the caregiver be asked to take over the domestic duties within the home, as seen in focus group 1:

G*: … Stealing?*

All*: Yes!*

G*: They blame you because you are the new one?*

All*: Yes!*

P6*: And you (the) one who is closer to that person* (patient)…

P2*: And even through communication with the family- you are getting more communication than her* (domestic worker) *and she* (domestic worker) *will still think maybe that you* (caregiver) *are gossiping, about her to the family.*

The above extracts depict the strain and tension that seems to develop between employed caregivers and domestic workers working within the same South African home. Role delineation seems to contribute to this situation without the employers possibly being aware of it. Competitiveness and jealousy seems to result in nastiness within the caregiver-domestic worker relationship, negatively

affecting the caregivers' work experiences and contributing to their caregiver burden. This dynamic seems to be a significant finding within the South African context as households that employ a domestic worker, caregiver, or other worker, may present with similar difficulties as described by the participants within this study.

Further, a hierarchy of employees seems to exist within the private home setting in South Africa. It seems that employers and domestic workers view caregivers on a higher hierarchal level when compared to domestic workers, as depicted by caregivers receiving gifts and establishing closer relationships with the patient/patient's family. The caregivers also seem to view themselves on a higher hierarchal level when compared to domestic workers as seen by them feeling insulted when they are task shifted into domestic roles.

5.2.2. Relationships with other caregivers and nurses

The caregiver and domestic worker relationship does not seem to be the only relationship associated with strenuous tension. The relationships between caregiver-caregiver and caregiver-nurse also seem to be significant and influential relationships, contributing to caregiver burden for employed caregivers working in private South African homes. The participants discussed both of these relationships within the interviews and focus groups:

5.2.2.1. Relationships between caregivers

As caregivers often encounter one another, between shift changes or within the same caregiving agency, the relationship that forms between the two is significant and seems to influence their overall caregiving experience. The findings from this study imply that competitiveness, fearfulness, and jealousy seem to be present among caregivers and not only between caregivers and domestic workers, as was discussed by participant 11 in focus group 2:

P11*: But you know apart from the maids* (domestic workers), *us, amongst the carers, if you there to relieve someone* (a caregiver)*, that person is not pleased with you, I don't know why, they will show you wrong things deliberately, so you can be in trouble.*

G*: With your agency?*

All*: Yes.*

G*: So even to each other, caregivers are not nice?*

P11: *It happens, some are so jealous of each other, they don't even know you, you are there to relieve but the person* (other caregiver) *won't be nice to you at all, I don't know why.*

Participant 9 shared that her biggest challenge within caregiving was to work with a caregiver from the same caregiving agency. Another caregiver from the agency asked her to lie and to tell the agency that she had missed her caregiving shift. This would result in the other caregiver receiving additional payment for a shift that she did not complete. During focus group 1, participant 7 expressed that for her, the biggest challenge of being an employed caregiver in South African homes, is the caregiver-caregiver feud that exists. In her situation, she worked for a patient where there was another caregiver working within the same home and was stealing from the patient. Despite being aware of the other caregiver's wrongdoing, participant 7 felt too scared to report it, as she did not want the caregiver to lose her job on account of her.

The fear of losing their job seems to be experienced not only by domestic workers when a caregiver is employed to work within the home, but also by caregivers when more than one caregiver is hired to care for the same patient. Poor job stability and fear of losing their income seems to be a recurring theme among domestic workers and caregivers working in private South African homes. The job insecurity described by the participants in this study may occur as it seems their work and role within the home is easily replaceable. Power difficulties and historical inequalities seem to exacerbate the situation as labour laws to protect domestic workers from exploitation are relatively new within the context, resulting in many employed females working in private homes to feel that their jobs are at risk.

Caregivers who work in the home setting are required to give of themselves physically and emotionally despite the job providing an inadequate income and poor job stability (Stacey, 2005). The carers in the study conducted by Stacey (2005), felt that they deserved a higher income for the work they completed as a caregiver, and most felt that they needed to complete numerous jobs to be able to cover their minimal expenses, which caused them additional stress. Many of the participants in her study were immigrants or people of different cultures (Stacey, 2005). The participants in the current study seem to present with similarities as they reported earning low salaries and therefore, struggle to support their families, which seems to result in competitiveness and fear developing among one another.

Another possible factor contributing to the caregiver-caregiver relationship is the employer, i.e. the patient or patient's family. Participant 14 explained that the family is often to blame when tension develops among caregivers as a family member will tell one caregiver that they are better than the other is, and that they are liked more than the other caregiver working in the same home. Jealousy and fearfulness of losing their job seems to arise should the other caregivers find out. This contributes to feelings of job insecurity within a home where possible power dynamics already exist:

P14: *You know I never find myself in a corner except my last patient, it was mixed because if you working all together, maybe there's one* (caregiver) *at night and one in the day, like if its three of you*

or four of you, if the family doesn't… I don't know how I can put this… they in between you four girls or three girls or two girls, like if somebody is going to say 'I love you, you know you better than the other one (caregiver)' *then the problem comes.*

Swartz (2012) describes that the caregivers who worked within his home would fight to work for him as his family treated caregivers well:

> The carers told us that they fought among themselves to come and work in our house because we were nice people, because the food was good and because that whenever my mother was well enough we took them on outings with us to nice places. (Swartz, 2012, p. 35)

As employers may not always be "nice people," competitiveness to work for a caring family may exist among caregivers. The desire to receive reciprocal care from employers seems important to employed caregivers, and therefore, if more than one caregiver is employed within a home, competitiveness for reciprocal care may occur between the caregivers.

5.2.2.2. Relationship between caregivers and nurses

In addition to the caregiver-caregiver dynamic, a strained relationship seems to take place between caregivers and nurses within a hospital or old-age home setting. When a patient is receiving inpatient neuro-rehabilitation, caregivers are often employed while the patient is still in hospital or at the neuro-rehabilitation centre, in order for training to be completed by the treating therapists. Within this setting, hospital nursing staff and caregivers are present and may encounter the newly employed caregiver.

Contact with nursing staff may also occur if a patient falls ill and is admitted to hospital for treatment. The employed caregiver may be asked by the family members to continue caring for the patient within the hospital setting. Within this situation, caregivers will encounter nursing staff and, as reported by the participants within this study, are sometimes mistreated and judged poorly by the nursing staff due to their comparative knowledge and training level:

P11: *And the staff in the hospitals, they don't even want you to check the file, you know I don't know what they think, they don't value us they don't recognize us as people who would like to learn more, some of them they think that we don't have schooling, that we've never been educated. I have my matric, I have my diplomas for other things and I'm doing this job because I have passion for it, I love it, not for money. I've been for families who don't have enough money to pay and you check the condition of the patient and you just say 'no, I can't leave this patient like this, they need me', then you help.*

P15 (FG2)*: And the nurses in the hospital, they don't treat us nice, you know, some of them... There are really horrible ones who are after you!*

As seen in the study by Stacey (2005) completed in the US with a sample size of 33 participants, home care workers in the US are often ignored and disrespected by nurses and doctors. The participants in the current study feel that professionals on a seemingly higher hierarchical level ignore caregivers and are looked down upon for their levels of education and training. Stacey (2005) described how home care providers are at the bottom of the medical hierarchy and are often unrecognized or disrespected by medical professionals in higher authoritative positions.

Despite negative relationships potentially forming between caregivers with domestic workers, other caregivers, and nurses, positive relationships do seem to develop within these relationships, specifically among caregivers, as the findings will present later, in relation to the support and guidance that they provide to one another through caregiving challenges.

SUMMARY

The theme of relationships discovered within this study reflects both the positive and negative interactions that employed caregivers experience within private South African homes. These relationships seem specific not only to the home setting but also to the South African context. The role that caregivers seem to take on can extend further than originally anticipated, as strong relationships seem to develop among caregivers and patients. However, negative relationships have the potential to form among caregivers and patients, and more commonly, with the patient's family. The relationships between caregivers and domestic workers and other caregivers, of similar culture, race, and opportunities, have the potential of being strained and negative due to fear of losing their jobs, poor role delineation, and competitiveness.

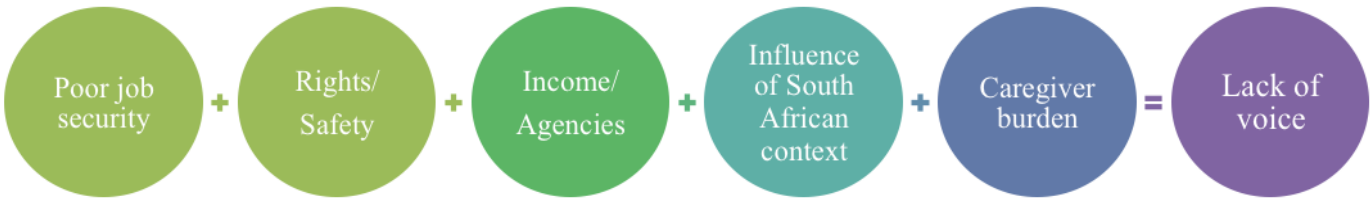
THEME 2: LACK OF VOICE

Despite employed caregivers feeling that they play an important role in South African homes, the findings from this study reveal that employed caregivers feel voiceless and unheard. Factors residing both within the home setting and within South African society seem to contribute to the lack of voice experienced by this caregiving population.

This theme of the results chapter will describe the participants' perception of their poor rights, income, and safety while working as employed caregivers in private homes. Caregiver agencies seem to contribute to employed caregivers feeling unprotected and uncared for while working in South African homes. Throughout caregiving work, employed caregivers seem to experience emotional and physical burdens that influence their overall happiness within their job. The lack of a recognized organization or union that can assist these caregivers in times of need further influences their feelings of loneliness within South African society. Job instability, poor transport and safety benefits, as well as feeling alone in their burden, contribute towards employed caregivers feeling voiceless. Figure 3 and the description below by participant 11 describe the following section of the results chapter.

P11: *I'm telling you in South Africa, caregivers are not noticed at all and they* (people) *don't value them! Even our agencies, they don't value us, all they do they are making money out of us. Working hours here…they are really killing you, I mean for caregivers, it's not like you are in hospitals, in hospitals they pay you well. Caregivers are not paid well at all! And there's nowhere to complain.*

Figure 3: Factors that contribute to caregivers' lack of voice within the South African context



5.3. BASIC RIGHTS, SAFETY, AND INCOME

Many participants felt that they do not have a voice due to the lack of necessities and assistance granted to them within their job, both by employers and by society. The participants shared stories depicting how they felt their safety and well-being was not a priority by caregiving agencies or by families that employed them. Necessities that the participants seem to have expected, i.e. safety within the home, transport and uniform benefits, are not provided.

Numerous participants explained that the income received while working as a caregiver in a home setting is significantly lower than the income received when working in an institution such as a hospital or frail care facility. Further, receiving employment through caregiving agencies does not seem to improve the lack of voice experienced by this caregiving population. The findings seem to indicate that the participants who receive employment through an agency felt that their voice within society was weaker than the voice of self-employed caregivers. The participants who found employment through an agency explained that they earn a lower income than self-employed caregivers do as their salary is unequally divided between the caregiver and the agency, with caregivers receiving a minimal amount of the caregiving rate. These caregivers further reported that they do not receive leave or employment benefits, i.e. transport and uniform allowances, despite belonging to a caregiver agency.

Included in their basic rights is safety within the workplace. The findings reveal that some participants have been exposed to robberies in the homes of the patients that they work for, however, they have not been offered or been given the opportunity to receive debriefing or trauma counselling after such potentially traumatic events have occurred. This was an important contextual finding within the study and reflects the unique challenges that seem to exist within South Africa. Receiving counselling after traumatic events in South Africa is not equivalent elsewhere as the people, culture and availability of resources and experiences of those in Africa differ comparably to the Western world (Goss & Adebowale, 2014). Therefore, employed caregivers may not have the resources available to receive counselling after such events have occurred.

As presented in the table below, participant 11 described how during robberies, caregivers could possibly be beaten or raped, yet no psychological assistance is provided to them. Post-traumatic stress disorder (PTSD) is a syndrome that results from an experience of dangerous trauma. Its characteristics include hyper-arousal, avoidance, functional impairment, and severe distress that continue for over one month (American Psychiatric Association, 2013). The participants may have experienced PTSD within the situations described and are yet to receive assistance in dealing with their traumatic experiences from employers, agencies, and society. Further examples depicting the participants' perception of exploitation within their job are presented in table 9:

Table 9: Extracts depicting caregivers' perceptions of exploitation within caregiving in the home setting

Examples	Quotes
Lack of basic necessities	P15: *…Food is expensive it's what they saying, yes its true it's expensive but they must offer you bread, butter and tea. So it's what they are doing instead of giving you bread, they say bread is expensive so you just get tea, just tea and coffee…*
Lack of basic safety	G: *Is there anything besides stroke that you would want* (support) *groups to focus on?* P11*: Living conditions, you know.* *G: What do you mean?* P11*: Of the carers who are doing live in. And the safety of the carers where they are going to work.* G*: Do you mean safety from the family? What do you mean by safety?* P11*: Okay. I was once exposed to this um, robbery. In (X-Town), you see its far from my home in Johannesburg there I was doing live-in, so, the family was careless, there was no yard, it was just a small hedge, like that, it's so short like it goes to your knees, and the yard was a corner house, next to the minibus-taxi rank… that is not acceptable, you get nothing, you get robbed there, you get beaten there, sometimes you can get raped {emphasised}, you don't get nothing, they don't care about that and if you were asking the agency, 'have you checked the place before, do you know how safe it is?' 'no I don't know that', those places where they sending carers they*

	don't even check them.
Lack of concern post traumatic events	G: *And none of you have been for counselling before?* All (FG2)*: No.* P13*: You know sometimes, even if you got mugged there, on duty, they will go by themselves individually for the counselling, not you, they don't care about you, you still traumatized until I don't know.* G: *Does the family not say to you 'come you need to have counselling with us' if you've had the robbery.* P13*: No, they just offer you money, you know money isn't everything, money can't heal you inside, and if you died there money can't help you. They don't care about such things… money isn't everything.*
Poor income	P11: *You don't have unions like other people like nurses, nurses have unions but caregivers you have nowhere to go, mostly you work for so long and you not even registered, you see, so anything happens to you, nothing! There's no benefits, that's it. Uniform is yours, transport in many agencies is yours, it's the first time I see an agency with the transport, it's the family that gives you the transport… There's no company, there's no CV, there's nothing if you work you get paid, if you don't work there's no pay, it's like that and you have nowhere to go and complain.*

As described in the theme of relationships, the caregivers who were listened to, acknowledged, treated with respect, and received seemingly reciprocal care from employers and patients, described their role as a caregiver as easy and enjoyable. However, being heard and recognized does not seem to occur within every home, as described by Swartz (2012):

> Early on in their relationship with us, many of the carers told us that we were different from others in whose homes they worked. We spoke to them and we always invited them to eat with us when we had meals... It was important to us and to our sense of ourselves to treat these women with respect and dignity (Swartz, 2012, p. 35).

Treated with respect and dignity, as well as receiving necessities and safety, seems to affect the caregiver's perception of their voice and worth within the homes they work in and within society. If treated poorly, it seems caregivers feel disrespected and unacknowledged, influencing their caregiving burden.

5.4. CAREGIVER BURDEN EXPERIENCED WITHIN A PRIVATE HOME SETTING

The participants in this study shared stories describing both physical and emotional caregiver burden they had experienced while working within private homes. The lack of support and unavailability of family members within the home setting contributes to the lack of voice experienced by employed caregivers. It seems that when family members are present in the home, many are not willing to assist in caregiving tasks, and therefore, the patient's well-being is dependent on the caregiver alone. As described by Stacey (2005), nursing and home caregivers present with the highest levels of musculoskeletal conditions when compared to all occupational groups. The physical burden of caring for a patient in a private home setting brings with it strenuous physical tasks as the caregivers are frequently unassisted throughout the day, and have nowhere to turn when and if they suffer from a work-related injury. As discussed by participant 2:

P2: *Exercise is most important thing. As you do to the patient you must also do to you to your own, before you go to work and thereafter work you must exercise, just to take that pain off otherwise you feel like you are paralysed. Some days you feel exhausted, you can feel pain; otherwise you can take medication tablets every day, you sleeping with pain tablets.*

The participants within this study seem to suggest that the amount of stress and pressure that is placed on them working in private homes, is greater than the amount of stress that is experienced by caregivers working within institutions. Working individually within private homes seems to come with increased physical and emotional burden, as only one caregiver is available to complete all caregiving related tasks for the patient. Participant 12 described the stress associated with the job:

P12: *It is stressing truly speaking, it's not an easy job. Cause you have to take care of this person, she mustn't fall, she mustn't do* (anything), *you must be next to her each and every move, ja.*

In South Africa, as employment is difficult to obtain in many instances, especially for women from lower socio-economic groups (Budlender, 2009), caregivers who may sustain an injury during work usually continue to work despite putting themselves at increased physical harm, in order to avoid unemployment. Stacey (2005) described similar occurrences with the carers in her study as a caregiver working for an over-weight patient did not have adequate training or skills to transfer the patient and sustained an injury. Due to the financial pressure these women experience, many seem to remain working despite any emotional or physical burden they may experience within the job.

5.5. INFLUENCE OF THE SOUTH AFRICAN CONTEXT

Many employed caregivers feel that working in South Africa contributes to their caregiving challenges. Many participants felt that in South Africa, the salaries are poor and working hours are more demanding than elsewhere. As seen in table 10 below, participant 13 shared how her friend, working as a caregiver, was recruited to work in the United Kingdom (UK), and receives a higher income while working better hours, and is treated with greater respect and dignity when compared to her caregiving experiences in South Africa. Working within the context of South Africa, where past inequalities resulted in poor opportunities for some, seems to influence employed caregivers' experiences within private homes, as described below:

Table 10: Caregivers' perceptions of working in South Africa

Examples	Quotes
South Africa versus UK	P13: *My home-girl* (friend) *is working there* (UK) *now. What's going on there is they* (caregiver) *are there for that specific person* (patient)... (Caregivers) *Don't pay for accommodation, you don't stay anywhere, you stay for them* (patient). *They* (employer) *do give you off-days, they* (employer) *do give you some days where you don't touch nothing* (anything), *that you are off. Others* (caregivers) *can go out, have some fresh air or still* (stay) *in the house and do whatever you want to do, but if you go to the kitchen to wash dishes, you check time and report it and you get paid for it. The house* (in the UK) *they*

	appreciate carers, unlike here.
Poor benefits in South Africa	G: *Do you think being a caregiver in South Africa is different to other places in the world?* P11: *Yes it is… they don't value us… They just make money out of you, you sick, you don't go to work, they will replace you with someone, you don't get paid. There's no medical aid for you. They don't care how sick you get you go to the doctor, and the longer it takes for you to get better you are replaced.*
Taken advantage of within the home	P3 during FG2: *Sometimes they don't even give you time for breakfast and lunch, then when the patient is sleeping, they say 'make the bed, do like this, do like this', you don't have time for rest because there is tea time and lunch time so even that.* P15 during FG2: *Maybe I say something wrong...* (pause) *It's a pain, because people in the houses they feel when you are working they are safe, so they take us for granted. They don't respect us at all. Even if you show them that you are here for this, they will tell you what they want from you, not us telling them what we are there for.*

During focus group 2, participant 6 shared that when a patient is upset, the patient will release their anger towards the caregiver, even when the caregiver is not the cause. She further described how her patient was upset one day and responded by throwing water in the caregiver's face. In response to the potential abuse that could occur between employers and caregivers, they cannot react as this may result in them losing their job, "*No you must always give a smile."*

As discussed in theme one, the fear of losing their job seems to be an ongoing anxiety within the home setting for caregivers. Many of the participants indicated that they choose not to complain, even when they have a reason to do so, due to fear of losing their job and income. Besides the potential power-dynamics that may exist within the home, other stressors such as being task shifted between

roles seems to occur within South Africa. As the caregiver and domestic worker within the home may have similarities in their background, opportunities, culture, and race, both may be placed at risk for being task shifted as role delineations and expectations may be unclear.

5.5.1. Role delineation and the risk of being task-shifted

As mentioned in the introductory chapters, black African females within South Africa who may have limited education opportunities, may become nannies, domestic workers, or caregivers within private homes. Women are trying to enter the market place to provide cheap labour with low-levels of skills; however, instead of improving and increasing their status, many women globally are adding income earnings to family and domestic needs and are therefore suffering from poor social equality publically and privately (Robinson, 2006).

As a result of the low-skilled work being provided by women with similar cultures and backgrounds, if job descriptions and roles are not clarified on employment, task shifting seems to be at risk of occurring within the home setting, as described by the participants. As the findings reveal, employed caregivers are at risk of being task-shifted into other roles within the home. Task shifting seems to result in caregivers feeling unheard and unrecognized as caregivers. Due to fear of losing their jobs, it seems that caregivers are voiceless when trying to avoid such situations.

Numerous participants shared that they are told to complete housework, which would usually fall under the responsibility of the domestic worker, including washing the dishes and cleaning the house when it was not agreed upon or discussed before employment occurred. The participants feel that they are grouped into the same field of work as domestic workers as a result of their background and culture being similar (Budlender, 2009). Many of the participants felt insulted that they had been asked to complete housework when they had worked hard to achieve a caregiving certificate.

Participant 13 shared that she gives more than she is expected to and in return does not gain respect from her employers. While she is able, when requested, to take on the roles of caregiver, domestic worker and driver (beneficial for outpatient therapy and other appointments), she is still paid only one salary, for essentially completing three roles:

P13: *... I always call myself the "three-*in*-one". Yes, the caregiver, I'm a driver and I'm* (a) *maid. Cause when you got me you've got those three things.*

These findings are echoed in the study by Stacey (2005) who reports on carers who felt loyalty to their employees and therefore would comply with additional job requests such as being a maid, nurse, companion and family member, "We're Maids Plus, you know?" (p. 839).

Besides domestic tasks, the participants expressed how they are asked to complete nursing or medical procedures that they have not received training in. When the participants do not complete such tasks and are told by employers that they are being lazy, the caregivers comply and complete the medical tasks due to fear of losing their job. Another example of caregivers being asked to fulfil roles outside of their duties is the completion of therapy-related exercises, when they have not been trained to do so by the treating therapist. Participant 13 explained that when travelling with her patient and their family to their holiday home, the patient required physiotherapy. The pain experienced by the patient was new and therefore the caregiver had not been trained by the treating physiotherapist on how to assist the patient in that situation. The participant did not feel comfortable or capable to treat the patient with their current discomfort and suggested that a professional physiotherapist in the area be contacted, which they did.

Stacey (2005) described similar examples in her study, as many carers were completing medical responsibilities outside of their training; however, their agencies shifted responsibility onto the carer for such actions. Some carers maintained their boundaries and did not complete the tasks. This situation still seems unfair to the caregivers, as some regard their patients as family, they do not want to see them suffer and go without the required medical care. Therefore, the carers would complete duties outside of their role, placing them at risk of losing their job if harm is brought to the patient (Stacey, 2005), as would happen to the participants in the current study.

As seen below, participant 15 shared that she was asked to complete wound care despite observing how to do so only once before and was unaware that she was going to be continuing the task within the home. She did not feel confident to do so alone. Other examples describing caregivers being task shifted between roles are presented in table 11:

Table 11: Extracts depicting caregivers being task-shifted across various roles

Examples	Quotes
Expected to complete domestic work tasks	P15 during FG2: *So they need us to clean the house and I said 'no I'm not here for the house and I'm not going to do it.'*
	P11 during FG2: *Like she doesn't want someone to sit* (still), *if the patient is sleeping they want you to do what is not your job!*
Perceived as rude	P15 during FG2: …T*hey think I'm rude when I'm*

	saying I'm not going to clean the house.
Medical tasks outside their training	P15: *Now, I'm a wound specialist… I was helping them, I said 'I can only help once', but now it's my job, every day, when the wound is there they don't want to pay professional peoples they want to use us… I was forced with a catheter and I said 'no I'm not a trained nurse' and they said 'no you know' and I said 'yes they showed me but I'm not allowed to do it, can you please take her to the doctor'… I said 'no I'm not allowed and I'm not going to do it' but when you say 'no'* (to) *the wife, they think you are rude to say 'no.'*
Therapy-related tasks	P13: *I said to the husband 'that is not going to happen, I'm sure there are some physio*(therapists) *around here, you got to phone the physio*(therapist) *and do the right thing, I'm just a caregiver.'*

It seems that there may be miscommunication or mismatched expectations occurring between employers and caregivers working within the home setting. Employers may request employed caregivers to complete medical related tasks, such as nursing duties, with the expectation that the caregivers have received training in the specific area, which does not always occur. As the caregivers seem to experience high levels of unemployment stress when asked to complete duties outside of their role (domestic/nursing/therapy), they may feel that they are obligated to comply and complete the task in fear of losing their job. The findings reveal that the caregivers were hesitant to argue against doing domestic related tasks, in fear of seeming rude, and were more easily able to express their voice and concerns with medically related tasks, which bring greater potential of bringing harm to the patients they were employed to care for.

SUMMARY

The lack of voice expressed by the participants in this study comprises of various aspects, many of which seem to be influenced by the South African context. The described lack of basic rights and safety provided to employed caregivers, both by agencies and employers, results in caregivers feeling alone and uncared for. Caregivers completing demanding tasks alone, without assistance, influence the amount of caregiver burden experienced within private homes. The lack of voice and caregiver burden experienced by these caregivers seems exacerbated further when they are required to complete tasks that fall outside of their job descriptions, especially as an increase in income does not reflect their additional work.

The final factor influencing the lack of voice experienced by caregivers seems to be the unavailability of a union that could assist or represent employed caregivers when they need to voice complaints or concerns that occur within the private home setting. The data reveals that if caregivers feel they are treated poorly, without rights and dignity, they feel alone and unsupported. This will be discussed in greater detail below, in the third theme of the results chapter, support. The final section of the results chapter will describe the various elements of support that are and are not currently available to employed caregivers working in private South African homes.

THEME 3: SUPPORT

The final section in this chapter discusses the theme of support. This theme links the previous themes with the discussion and conclusion chapters to follow. Due to the relationships formed within the home and lack of voice perceived by the caregivers, various support systems are required for employed caregivers working in private South African homes. This section discusses the support that caregivers feel they have and do not have available to them within South African society. Support for employed caregivers seems to be an important requirement and finding of the study.

Support within this section has been separated into various categories according to the information reported by the participants. Support can be provided by various people who come into contact with employed caregivers. The support ranges from receiving support from one another, professional services, and the governmental sector. Support that may be beneficial to one caregiver may not be considered a support system to another. Support may be dependent on each caregiver's personal circumstances and experiences, and therefore, various aspects of support have been investigated in relation to the information provided by the participants in this study. The categories that will be discussed in this chapter are displayed in figure 4 below:

Figure 4: Areas of potential support for employed caregivers in South Africa



5.6. SUPPORT FROM OTHER CAREGIVERS

As some caregivers do not have a driver's licence or their own cars, many rely on the minibus-taxi services for their daily transportation needs. Within South Africa, public transport is dominated by the minibus-taxi industry. Minibus-taxis run throughout the days and evenings and travel within and from city to city. There is a need for public transportation in South Africa, and the minibus-taxi service predominantly satisfies this (Oosthuizen, 2002). These mini-bus taxis become a location where caregivers meet and discuss their jobs, the difficulties surrounding them, and they have the opportunity to provide support to one another.

Minibus-taxis were not the only places mentioned where support is found among caregivers. Other places included changing over of shifts, within caregiving agencies, and at therapy or neuro-rehabilitation centres. Neuro-rehabilitation and therapy centres seem to be a location for informal support among caregivers. At these various locations, caregivers get the opportunity to speak with each other, share advice, and provide emotional support to one another. The participants revealed that advice shared among caregivers includes strategies on how to improve communication between themselves and their patient, transferring techniques, and how to assist in the patient's activities of daily living, as seen in table 12:

Table 12: Examples of informal meeting places where support is provided between caregivers

Examples	Quotes
Neuro-rehabilitation therapy centres/institutions	P7: *We discussing the difficulties we having with our patients, and then we can give the other one the plans, just like my patient was not feeling to go to the bath, so sometimes I don't understand that sometimes I have to say, no I have to* (become) *cross if I want her to go there, but if I talk with the other ones they say 'no don't be cross, just sometimes it's like a little baby, you have to do this and this and this' and then after that you see they happy, don't be cross with her so that she can scare.*
	P11: *Only meet when exchanging the duty and we meet there, like when in hospital we usually sit and talk when exchanging duties and then you*

	have time to sit and talk then you talks… It does help you feel better because sometimes you feeling like you the only one who is feeling this load on your shoulders and facing dangers in different places and only to find out when you listen to others that they've been exposed to worse.
Support exchanged in minibus-taxis	G*: Do you ever meet up with other caregivers to discuss difficulties in caring?* P1: *Only in taxis.*
	P3: *The others sometimes they complain they say I can't handle this person maybe if I'm doing the job they say 'no, maybe I can't handle this one he looks like he's heavy', something like that… Just around or in the taxi they ask me what type of job are you doing but they tell me 'eish, I have this certificate but maybe I can't handle this job.'*
Support exchanged in caregiver's home	P13: *We support each other because someone says 'no I'm going I can't anymore I can't take it anymore' then well say 'no hang in there' I'll say, 'look me, 36 years it's not a joke'. And then they hang in there.* G: *Where do you meet up?* P13*: Mostly we will go to someone's when she got, when we are off at the same time, we will go to someone's house.* G: *How often do you do it?* P13*: Once a month.* G: *And it helps?* P13: *It does help. We support and love each other because someone will say 'thank you guys I*

	almost leave my job.'
Optimal location for support groups	P13: *Somewhere quiet, so we can, cause, some of us end up crying when you hear what other have been through we end up crying a lot of us so we want to be in a quiet place.*

Common risks associated with home care go beyond bringing harm to the patient. Rather the most common risks are associated with bringing harm to the caregiver of the patient (Stacey, 2005). Some participants described the physically demanding tasks that caregiving requires of them. Not only is there a need to provide support and strategies to each other in managing patients, it is also essential to provide support, advice, and strategies to caregivers, as burnout and fatigue are often a consequence of the job. As seen within the literature, numerous studies conducted on family caregivers reveal that they may suffer from mental, psychological, and physical difficulties (Rombough, Howse, Bagg & Bartfay, 2007). One participant shared how after the death of a patient, she found it difficult to move past the event. Speaking to a fellow caregiver assisted her in dealing with and accepting the loss and allowed her to move on. The benefits of caregivers providing support to one another can be found in the extracts shown in table 13:

Table 13: Extracts from individual interviews describing the benefits of supporting one another

Examples	Quotes
Comfort after the death of a patient	P13: *…On my hand, she was screaming and I was comforting her you know 'please … don't cry, don't cry.'* G: *And you never had any counselling after that?* P13: *No, no.* G: *Did you speak to anyone about it?* P13: *I did.* G: *Who did you speak to?* P13: I *speak to the other sister* (nurse) *at (X-hospital).* G: *And did it help?*

	P13: *Ja it did because she also said to me that she told me about someone who had the same experience. She did mention that we really should have counselling.*
Speaking to another helps to heal	P14: *I hope I help them because I was always telling them about my views with the patients, there's nothing that makes you laugh, if you home you feel sad, if the person dies you feel sad so you need another one to make you laugh, because it's you, it's like something that is helping your soul actually to have them around you.*

The desire for caregivers to receive support from one another seems to be a practical requirement within South Africa. A professional can facilitate this support; however, it seems that the caregivers themselves have the potential of being a great support system to one another, as they share common caregiving experiences and needs. It also seems that more experienced caregivers may be able to provide guidance and assistance to caregivers with less experience.

5.7. SUPPORT FROM PROFESSIONAL SERVICES

Besides receiving support from each other, the findings suggest that some caregivers would benefit from support from professional services such as social workers, counsellors, or psychologists. Support from such services may be required after the loss of a patient or after a traumatic event. Advice on how to manage difficult relationships that develop within the home may also require professional guidance.

Professional support, after a patient passed away, was sought by only a few of the participants in the study and seemed dependent on their caregiving situation, emotional connection to the patient, as well as the participant's cultural viewpoints. As mentioned previously, caregivers do not seem to be given the opportunity to mourn for patients who have passed away, often who have become like a close friend or family member, as they need to focus on finding a new job as soon as possible in order to be financially stable. Participant 2 initiated going for formal counselling at a clinic after her patient had passed away. She expressed that the counselling assisted her in dealing with the loss:

P2: *I wasn't forgetting about* (be)*cause I feel like I was seeing it every day… because that thing of feeling strange it went away, I've been feeling free. From that time that I started to go for my*

counselling. It was difficult I felt like I'm starting to know about it, I felt more painful and sad, thereafter I felt relieved and just forgot about it.

Participant 1 also shared:

P1: *The patient can be fine and then tomorrow you don't know it changes, and the other thing, you get so attached to the patient, and then if anything happens to that patient, you also feel that pain and nobody teaches you how to separate yourself from that, you carry that with yourself all these years… No and you don't hear from people, but I am telling you, if you don't have passion for this you can't do it.*

Some employed caregivers often accompany patients to group therapy sessions. Once a month at one of the organizations, the employed caregivers are provided with the opportunity to meet with a social worker. While some of the participants found this opportunity beneficial as an opportunity to be heard, others felt that the sessions with the social worker did not benefit or assist them in their caregiving related difficulties. Focus group 1 discussed that despite expressing their concerns to the social worker, specifically with regard to being treated like a domestic worker within the home, no changes occurred despite the social worker passing on the concerns to the caregivers' employers. Despite providing the caregivers with an opportunity to be heard and a forum to express their concerns, the opportunity may be increasingly beneficial should they receive practical advice that could assist them in managing caregiving related issues, rather than only a forum to express these issues.

The findings seem to reveal that employed caregivers require the assistance of others. Whether they choose to discuss it with a professional or with fellow caregivers, it seems that both options need to become more readily available and beneficial for employed caregivers in these settings. Receiving caregiving advice and support from one another seems beneficial to the caregivers, while receiving professional counselling or trauma counselling after the loss of a patient/traumatic event has occurred, seems to be a requirement for employed caregivers.

5.8. SUPPORT FROM THERAPISTS AND THERAPY CENTRES

As caregivers are exposed to therapists, both at an inpatient and outpatient level, this seems to be an opportunity for caregivers to gain additional information regarding stroke-related impairments and how to carry over treatment into the home environment. Despite some caregivers receiving additional training from neuro-rehabilitation centres and treating therapists, many caregivers do not feel that they know enough about stroke and stroke impairments. Therapists involved in a patient's neuro-rehabilitation could play a significant role in the training, education, motivation, and support towards caregivers in South Africa however they may not be aware of the responsibility and role that they

hold. The extracts below in table 14 reveal the benefits of therapists providing support to employed caregivers:

Table 14: Extracts of therapists providing support to caregivers

Examples	Quotes
Therapists engaging with caregivers	P11: *No, nobody cares, no body, sometimes if you take them to therapists, it's the therapists that has time, I mean it depends on you if you an easy person you are… easy to reach, you are open, you are communicating with therapists. Some will ask you, 'how are things there?', 'how are you working?' you see, and then sometimes you get by, you get open to talk.*
Benefits of neuro-rehabilitation centres	P11 during FG2: *Most of the time you are called to get the patient from hospital, let's say it's their last day the person is there, you are there the whole day with the therapists, you see what the patient is going through, you see the exercises, what is this what is that, medication, know how to give medication because we can read, so it is not wise to go the last day, its better if they call me three days before so you can learn the patient, you see. The patient gets used to get to know you better, you get to know the patient better, then you get to know the needs of the patient.*
Training at neuro-rehabilitation centres	P12: *And to teach her how to walk, they* (employers) *are the ones who taught me before going to the rehab, ja then at the rehab they show me more things… It was the physio, those me showed me how to move and how to take care of her, ja. They showed me how to like, when she's sitting, when she's standing up, how to dress her, all those things… Speech therapy also taught me*

	how to do the sound, 'aa' 'ee' all those things.

Participant 12, as found in the above table, previously worked as a domestic worker before being employed as a caregiver for a patient who suffered from a stroke. Her knowledge and skills regarding caregiving was developed at a neuro-rehabilitation centre by the treating therapists. She specifically mentioned the physiotherapists and occupational therapists who taught her how to take care of the patient with regards to sitting, standing, and dressing, as well as the speech-language therapists who taught her how to make sounds with the patient to assist in their expressive language skills.

In this situation, and in many other cases where the domestic worker takes the role of caregiver, without the therapist training and education, the caregiver would not have received training, potentially affecting the patient's long-term recovery. As seen in Rombough, Howse, Bagg & Bartfay (2007), caregivers who receive training, present with lower levels of anxiety, burnout, and depression and therefore have a higher quality of life when assessed one year after stroke. Based on these results, the input that therapists can provide to employed caregivers seems highly motivated. The participants referred specifically to speech-language therapists and physiotherapists when describing emotional and physical support they had received, as well as support through education and training on how to care for patients who suffered from a stroke.

Speech-language therapists can provide insight, tips, and communication strategies, towards caregivers in order to allow improved communication to occur between the caregiver and the patient. Many participants shared that working with patients who suffer from aphasia is their biggest challenge within caregiving. Aphasia can contribute to poor communication developing between caregivers and patients, possibly resulting in emotional burden. Participant 2 shared how she finds her work emotionally challenging and becomes upset when the patient she cares for is able to understand language, however, is unable to express herself through language. As seen with family caregivers, caregivers of patients with aphasia do not experience more psychological stress than patients without aphasia, however, they do experience more difficulties surrounding their caregiving duty (Oddy, 2010).

The data reveals that speech-language therapists have already had an influential role in assisting communication between caregivers and patients. Servaes, Draper, Conroy, and Bowring (1999) describe how role changes and communication impairments are two most commonly mentioned areas of difficulty found within a home after a brain injury occurs. As a caregiver may spend a considerable amount of time caring for the patient, it is important for them to be able to communicate with each other (Tronto, 1993). Some of the participants also mentioned swallowing and choking difficulties (dysphagia) as their biggest stress within the job. Speech-language therapists can further assist

caregivers on how to assist the patient in swallowing safety of various consistencies, as described in table 15:

Table 15: Extracts describing the important role speech-language therapists play in facilitating communication and dysphagia strategies between caregivers and patients

Examples	Quotes
Challenges in caring when patients have communication impairments	P8: *The biggest challenge is if somebody doesn't know to talk because you think that the person she want something and they doesn't* (don't) *talk, that's the challenge… Sometimes when I talk but he doesn't know to talk but when you talk he hear you.* G: *Do you think he understands you when you talk to him?* P8: *Ja he understand*(s) *but he doesn't talk.*
	P2: *…It's not easy {pause) you know cause, they understanding, you can see he or she can understand but he can't, it's difficult for them to talk at the same time, the mind is like getting dull, and he will be always crying all the time, the more he or she thinks, the more when he's thinks of active or doing something, they want to help themselves but they can't or she can't, some others they can manage to help themselves but they find out others someway, somehow, it's getting difficult to continue afterwards to what he wants to do.*
Communication develops relationships	P2: *And also I can add on that, especially on the bond between you and the patient, some others, when she's already being used to her, she can't communicate with the another person, she can't agree for another person to take her to bath or*

	maybe to the toilet.
Communication leads to progress	P5: *And also what's nicer for you if you want a friendship, communicate and then the patient knows exactly what you saying and then there's a lot of improvement going on and then you for yourself can see it. Then at least you know you can see that at least here I'm doing something right… Or even just communication, because some of them they don't get the communication, even from their own.*
Benefits of learning communication strategies	P13: *It is not that easy, it's a hard job, very hard. People think it's easy. First of all, you* (are) *going to a person who's all together changed. Coming to their language, you have to start learning the strange language and you must know it, yes.* G: *Do you mean they speak another language?* P13: *Yes, a different language!* G*: After the stroke?* P13: *Yes like (patient's name), you can't hear what she's saying. You make up, sometimes you win, sometimes you know and she get so cross… I think the language is the most difficult because they will say 'close the door' when she want water.* G*: And you need to be the one to figure it out?* P13: *Yes, and if you don't, sometimes they will cry! Shouted at you because you don't know what they wanted to tell you to do.* G*: Have you learnt any strategies, anything that you do to help you out with this problem of the language?*

	P13*: I learn that sometimes I'm taking the wheelchair because she will keep pointing, I will take her to the direction that and I ask her to show me exactly what she want.*
Difficult to care for patients who cannot communicate	P11: *You know what happened mostly, I learnt something about stroke. Patients with the stroke who are still walking you see, and that can still talk, they easier to look after than the patients that have that eh, {pause} the one that destroys the brain and then the patient becomes mute. It's really difficult.*
Poor communication makes job challenging	P15: *For me it's not challenging as long as the patient can speak to you…*
Limited education on dysphagia	P1: *For me, it was, I felt bad for her because she couldn't eat for herself, she couldn't feed herself, you had to feed her and they had to out a PEG cube* (tube) *so that, for about 6 months she was using the PEG cube to feed her though it because she couldn't chew, she forget how to chew... And also it was difficult...also she was a very active person so when the second stroke, the second stroke happened she couldn't do anything and you could see she wanted to do things but she couldn't so it wasn't a nice thing to see.*
Managing dysphagia	G: *What's difficult* (about caregiving)*?* P5: *Because you have to be careful, you have to care, you have to be there I can say like 24/7 to look after some of them they don't eat, they can choke, some of them are bedridden you have to do all those things, turn them and all those things.* G: *Have you learnt anything stroke and if so who have you learnt it from?*

P5: *I've learnt a lot the first one I was at an agency so at school you know we did learn but you know with the agency the matron or the sisters do come, I did have one that was choking, but now I know what to do how to feed with the choking.*

The findings from the study also reveal that physiotherapists also seem to play an important role in the training and involvement of caregivers with patients who suffered from a stroke. As caregivers do complete most of the physically demanding jobs associated with the patient, physiotherapists can assist in teaching caregivers how to transfer safely not only for the patient's safety but for the caregivers' safety and wellbeing too. Participant 1 shared:

P1: *...It was very difficult, it was. Especially when you have to put her in the car because that was very difficult very difficult, even now my back is still sore, I think it was from putting her in the car. Because I was the only one who could do it properly, that's what the family used to say. So every Sunday we have to take her out so I'm the one to put her in the car, out the car so it was very difficult.*

G: *What have you learnt about stroke and who have you learnt it from?*

P1: *... this physio.*

G*: Did she teach you about stroke?*

P1: *Yes, she teach because she* (the patient) *couldn't walk but we managed to make her walk with the three of us, we always make sure that we are walking with her like the way she showed us how to. Like also, she the one who teach, we also didn't know anything about commode so she's the one who told us about the commode, that we can bath her, we can put her in the shower in a commode so we can put her in the shower so she can have a proper wash. She's also the one who teach us lots of things...*

Participant 1 further shared that she suffered from back pain after completing physically demanding tasks with her patient until a physiotherapist trained her in transferring safely:

P1: *Originally* (the) *patient had minor stroke and wasn't difficult to manage. Then she had another severe stroke and* (the) *job become difficult and needed training how to transfer her safely, commode, car and mobilizations…There are so many challenges because first of all you want to please the family. You want to do your best even though like you don't want to show that you tired … like if you want to pick up the patient, you don't even know how to do it, but if you are in a group or you with the*

people who have the experience with the group, they will tell the easiest thing to do so that you not hurting your back, so that you don't hurt yourself on the wheelchair, 'the easiest way to do this is do this, do this..' Unfortunately my patient died when we were in the process of physiotherapist was going to teach us how to move her from one place to another using support, but we didn't get there...

Despite most of the participants benefitting from training provided by therapists, one participant shared a varying opinion on the caregiver-therapist relationship. Participant 9 shared that she would like to learn more from therapists so that she can continue providing therapy for the patient even when they are at home, especially when there is financial pressure, and therapy is discontinued. However, she shared that she feels that therapists do not teach caregivers how to continue therapy in the home setting as they are threatened that if they do the therapist will no longer be required and will lose their job. She shared an occasion where a therapist completing home visits would intentionally exclude the caregiver and intentionally did not teach her, as she did not want the caregiver to replace her role.

Despite this, most of the participants felt that they would benefit and would like to have more training opportunities with physiotherapists, occupational therapists, and speech-language therapists. The participants felt that they learnt a lot of valuable information from the therapists and therapy centres and would like to receive additional training from them.

5.9. SUPPORT GROUPS

One of the sub-aims of this study was to explore whether or not support and or training groups are available for employed stroke caregivers in South Africa, and if not, if the need for these services is required. As caregiving in the South African context brings with it numerous challenges, the participants in this study feel that support and/or training groups are required, however, are not easily available to them and would like for the development of them to occur.

The need for support groups organized internally among one another seemed of great importance to the participants. Not only is meeting with other caregivers helpful in receiving advice, but meeting as a group and discussing areas of difficulty, was found to be beneficial to the caregivers who had been provided with this opportunity previously, as seen in table 16:

Table 16: Extracts depicting the need for support and training groups for caregivers

Examples	Quotes
Importance of support	P13: *Oh yes, yes. It's like the petrol in the engines the support group, we really need it. Especially if your present employee is like mine, you need the support group.*
One participant had attended a support group	G: *Have you ever gone to any support groups for caregivers?* P9: *Yes.* G: *And what happens at the support group?* P9: *She (caregiver agent – trained nurse) was teaching us about the stroke, she just explain*(ed) *to us about each patient…* G: *And how often does she do the support groups?* P9: *Once after 4 months…* G: *And is there ever anyone else there like a therapist or social worker to help you with anything?* P9: *No…* G: *Do you need to pay for it?* P9: *Yes we pay.* G: *Is it helpful that support group?* P9: *Yes.* G: *What's the best thing about it?* P9: *It's because they highlight us what to do if you get that kind of patient.*

G: *And do you ever talk about your feelings or difficulties you might be having?*

P9: *Most of the time we talk about the difficulties.*

G: *Have you ever received any counselling about being a caregiver…*

P9: *No.*

Besides the counselling, support, and training that could be provided at support groups, it seems that the participants would benefit from tips and information on how to care for themselves as caregivers. Only participant 12 had searched for information on how to care for herself as a caregiver:

G: Have you ever searched for information about stroke?

P12: *Yes I have like in the phone I once did this 'googling' thing that you as a caregiver must also take care of yourself, you need to rest, you need to check your health, all those things* (be)*cause it can also affect you.*

Support groups are commonly offered to family caregivers where various elements of support are provided, including skills and training, education, and emotional support provided by therapy (Oddy, 2010). Groups of this kind should be made available to both formal and informal caregivers as the need is increasingly growing within South Africa, to not only allow for improved care of patients to occur, but also to allow for caregivers to be cared for.

Despite the availability of smart phones in the present day, some people present with increased limitations when compared to others with regards to access to resources available on the internet as resources on the internet are not a viable option for everyone to access. As described by Kim, Chang, Rose, and Kim (2012), vulnerable caregivers, who do not have access to support resources, have been found to be at greater risk for burden than caregivers who can rely on support services to support and assist them. As mentioned in previous chapters, the caregivers within this study may be considered a vulnerable population due to their limited resources, finances, education, and opportunities within South Africa.

All of the participants in the current study expressed that should a caregiver training or support group become available to them, they would attend them regularly, even if it required for them to travel to the destination. It seems that caregivers would benefit from support groups where the caregivers themselves are providing and receiving support from one another, in order to gain advice from more

experienced caregivers who have developed skills working within the same caregiving environments. Support from professional services also seems to be required within specific situations where a difficult or traumatic event may have occurred. Emotional burnout occurs when a worker's involvement within the work is too high and over-investment of the self occurs (Stacey, 2005). The availability of services that could assist caregivers in dealing with the emotional load that comes with caregiving would be highly beneficial (Stacey, 2005).

With regards to training services, it seems that caregivers appreciate and would benefit from training provided by therapists, either in an individual or group setting, where caregiving strategies and practical assistance in caring for patients who have suffered from a stroke can be provided. Further, it seems that gaining information on how to care for themselves as caregivers, within difficult caregiving situations, would be beneficial to this caregiving population.

5.10. SUPPORT FROM EMPLOYERS

Another area of support that the participants frequently referred to was the support they received from the patients and patients' families that employed them. As a result of the support received from employers to some participants when patients passed away, those participants did not feel that external support needed to be provided to them. Further, despite the patient's impairments, the participants who had a good relationship with their employers described their job as easy and enjoyable as compared to the participants who did not.

Participant 14 shared that the best form of support for her patient was to smile, laugh, and be happy, by sharing in each other's stories and by making jokes with one another. She explained that this is her version of therapy. She feels that if you have a good relationship with the patient, then neither the patient nor the caregiver will require counselling as the laughing and connection shared will provide the best support possible:

P14: *No, to tell you the truth, to be a caregiver is counselling me- when I have problems, if I don't see my patient and see her and laugh, then I get all 'eeh!'* {shows frustration}*… that's my therapy, to be a caregiver if I don't see them and be happy and smile and we talk about everything and I tell them my stories even if others are jokes and we laugh and we make my stories. The thing that keeps me that makes me sane is we laugh and joke and I think it's the best therapy, to me, I don't know about others. I think it's the best therapy to have.*

Further extracts depicting the benefits of support caregivers receive from patients/patient's families can be found in table 17:

Table 17: The impact support from the patient and patient's family can have on caregiver functioning

Examples	Quotes
Care extended to caregiver from employer	G*: Tell me about the feelings you have when you working for the patients who suffered from a stroke.* P8*: I'm feeling happy, if you looking* (after) *someone and the person treat you nicely.*
Support encourages caregiving work	P13: *They always ask me if I'm alright, 'are you okay, are we doing okay? Are you short of anything, do you want this for your children', like this.*
Limited/no support from employers is hurtful	P13: *It's hard because they will leave you with the patient, they go to work, when they come from work, some will come with stress, from wherever he or she is working, and then the stress will be on top of your head. They can't say 'hi how are you… how was your patient, how was your day?'* All: *{agree} ja, ja.* P11*: It's rough because they don't recognize carers as human beings.* G: *Have any of the families told you or tried to help you find a counselling centre to help you get counselling? Maybe help you find your attachment areas* (clinic or hospital they attend within their living region)*?* *(One participant laughs at the thought)* All: *No.* P15: *They tell you to go 'Google'! That's the way you go away, they don't care about you.* P13*: You know the other thing that is better, that*

you have the closure, if they invite you to go to the funeral, you feel better after that.

As a result of increasing working hours, greater responsibility and increasing demands, caregivers across all caregiving settings, are experiencing poor quality of work life (Williams & Crooks, 2008). It seems that support provided by employers can assist the quality of employed caregivers' work life within the South African context.

5.11. SUPPORT THROUGH UNIONS AND LEGISLATION

The findings from this study reveal that employed caregivers feel that support is required not only through support from professionals, employers, and support groups, but also through governmental or societal structures such as legislation and unions. The findings reveal that the seemingly poor support-base available to employed caregivers is contributing to their lack of voice within South African society. Participant 2 shared that she feels undervalued due to the lack of support provided to her during times of need:

P2: *In South Africa maybe you* (are) *working too much. You have too much hours and we struggling and we focus on helping and you land up getting nothing* (be)*cause you not registered, some others can work on a private facilities, like me, and you find out no one is standing* (standing-up) *for you. Maybe you have a problem with your employer, you don't have a problem to report him or her sometimes it's getting problem when it comes on that and you find out maybe you doing 12 hours and maybe the offer is not certain.*

In South Africa, a high quantity of unionization occurs within the work force (Budlender, 2009). It is evident that unions are available to categories of care workers, however a union seems required to the population of employed caregivers within this study that will be available to support them. The participants in this study feel that they are not cared for or supported by a union and therefore they rely on the support of the above-mentioned systems. This links to the above section discussing the lack of voice that this population experience as they feel that without legislation and unions representing them, their voice within the country is unheard. As participant 11 said:

P11: *You don't have unions like other people like nurses, nurses have unions but caregivers you have nowhere to go, mostly you work for so long and you not even registered, you see, so anything happens to you, nothing! There's no benefits, that's it.*

If support services were made available to employed caregivers, their levels of burnout associated with the job may be decreased as a governing body may be able to assist with difficulties that occur

within the home. Having a recognized organization or legislation to defend and protect employed caregivers, may assist in ensuring their voice within the home, and within society is heard. An organization that allows for caregivers to turn to, in times of support or guidance, is considered to be required for this unheard caregiving population.

CONCLUSION

In conclusion, three main themes emerged from the participants within this study, with regard to their experiences and needs as employed caregivers working in South African homes. A leading factor contributing to their happiness within the job was the relationships that form with the patient, patient's family, as well as other employees within the home. Due to poor rights and benefits, many caregivers feel that working in South African homes deprives them of a recognized voice both within the home and within South African society. The support provided or not provided to employed caregivers further contributes to their caregiving experiences and results in their need for support being provided.

The results from this chapter will be discussed in chapter six in relation to caregiving literature and theories in order to gain increased understanding of the participants' experiences and needs working within South African homes.

Chapter 6

DISCUSSION

OVERVIEW

This chapter attempts to provide a deeper look and understanding of the influences that affect employed caregivers' experiences working in private South African homes. The significant themes most relevant to the study will be discussed in relation to current caregiving literature and theories, which will assist in the development of the employed caregiver model for a South African context. This model will reflect the influential factors affecting the experiences of employed caregivers working in private South African homes.

6.1. CAREGIVERS - THE HIDDEN PATIENTS

The findings of this study seem to reveal a situation that is occurring within private South African homes. Caregivers, who provide care to others daily, do not always seem to receive reciprocal care from their employers or from society. Despite many of the participants perceiving their relationships with patients as close and family-like, the lack of voice, exploitation and caregiving burden that they experience suggests otherwise. While the caregiver is employed to care for a patient who is ill, it seems that during the process of caregiving, the caregiver is also in need of care and does not always obtain it.

Literature has revealed that informal caregivers have been forgotten to the extent that they are referred to as a "hidden patient" (Thompson, Bundek & Sololew-Shubin, 1990). As stroke impacts the patient and family on emotional, psychological, and physical levels (Pierce et al., 2007), the primary caregiver is required to manage and care for numerous aspects, often placing them at risk of being a patient themselves. Previous caregiving research has shown that caregivers experience high levels of anxiety and depression, and caregiving has been associated with being a risk factor towards physical health (Pioli, 2010). It seems that the "invisible" care work, described by Razavi and Staab (2010), is occurring within the South African context, as it seems employed caregivers are being undervalued within their care work.

As the demographic information from this study reveals, the employed caregiver in this context is typically a black African female of low socio-economic status. These caregivers are often exposed to limited benefits, safety, and support. It can be seen that the caregivers who have limited resources and opportunities give of themselves to the patients through their time, energy, love and support. The caregiver often relates to the patient as a close friend or family member and often provides to the patient beyond their duties and requirements; i.e. choosing to spend time with the patient off-duty without overtime payment. As the relationship between caregiver and patient is more frequently

reciprocal compared to the relationship between caregiver and the patient's family, the relationship with the family has the potential to result in hurt and disappointment for the caregivers when the care they provide is no longer required within the home.

The employer and employee do not always perceive the relationships which form within the home in the same way. A mismatched expectation of the relationship seems to take place, as while the caregiver is employed to care for the patient, the relationship that forms within the home can be misleading to the caregiver. The caregivers described their relationships with the patients as if they had become like family or close friends, however, the perception of the relationship from the view of the patient or patient's family often seems to remain on a professional level, with boundaries present.

This may occur as past stereotypes and behaviours, relating to gender and cultural differences, start to arise within the private home setting, as the patients that require care are typically of a different socio-economic status, race, or class when compared to the employed caregiver. Power relations may occur within the home when and if they are required. Possibly, when the care being provided is to the family's standards and the patient is happy, the employer-employee relationship may shift into a friendship domain. However, should a negative event occur, the employee may revert and take the stand of an employee, rather than one of a companion, ultimately resulting in a perception by the caregiver as a lack of care. The employers may not be aware of this and the potential harm it brings to the caregivers, resulting in the caregivers becoming "hidden patients" themselves.

Swartz (2012) depicts the reality that power relations are still present within private homes in South Africa, not only for domestic workers, but for caregivers too:

> In this context, then, it is not surprising in some ways that our being 'kind', although initially clearly attractive to the carers, seemed to come to some of them to feel worse than our not being kind. We behaved as though we were their equals and friends when in reality we were not offering friendship. Indeed, when one of them upset us, we made sure we never had to see her again (Swartz, 2012, p. 35).

While Swartz (2012) was kind to the caregivers caring for his ill mother, he acknowledges that he still had the power to end the employment if he wished. This confirms the findings discovered in the current study, as despite the caregivers feeling as if they had become friends with the employers, when the caregiver was no longer required in the home, the caregivers were let go and the seemingly strong relationship faded abruptly. While Swartz (2012) believed he was acting kindly to the caregivers during their employment in his home, caregivers, as seen within this study, seem to

perceive the situation differently, and may expect care to be continuous even after employment has ceased.

The findings of this study confirm that caregiving relationships are no longer one-sided (Evans & Becker, 2009). Recent research has recognized that caregiving relationships are reciprocal and therefore not only is the ill or disabled receiving benefit from their caregiver, but each provides to one another whether emotionally or practically (Evans & Becker, 2009). When the relationship remains one-sided, it seems to result in caregivers experiencing sadness and disappointment as discovered in this study.

While some employers or family members do seem to form strong friendships with the patient's caregiver, it may be formed as a result of wanting the caregivers to provide the best care towards their loved one. If the caregiver feels cared for reciprocally, she may provide improved care towards the patient. However, this conditional "care" provided to the caregivers, seems to result in the caregivers' ultimate disappointment:

> As we were not home for large parts of the day, and not with my mother during the night, furthermore, there was self-interest in the way we treated the carers. We believed that if we treated them well, they would be kind to my mother… (Swartz, 2012, p. 35).

The potential lack of reciprocity of care seems to be interpreted by the caregivers as not receiving respect, dignity, or rights within the homes in which they work. Bradfield (2012) discusses the context in which domestic workers are employed to work in private homes and provides insight into the country's growth since Apartheid as well as highlights areas in which there is still room for development. The relationship, companionship, and communication that develops between different races and socio-economic classes, go against Apartheid stereotypes (Bradfield, 2012). The participants in this study shared that not only did they care for the patients but they also shared secrets, laughed together, and spent religious holidays with one another. The findings from the current study seem to contribute to Bradfield's (2012) findings as despite strong relationships being formed among caregiver and employer, a stereotype and disconnect may still exist among many of the homes where they were employed to work.

As the findings reveal, employed caregivers often feel unrecognized, unheard, and unsupported within South African society, despite them performing an important role in the lives of patients and patients' families. Despite the caregivers often being on a lower socio-economic status than the employers, having poor living circumstances, education, health benefits, and opportunities, they seem to act as the "glue" that holds the patient and the patient's family together. This allows for the family members to continue contributing to the productive labour force (Parrenas, 2000), and to continue with their

daily routine, as the employed caregiver takes the role of the primary, and often only, caregiver for the patient.

The loss experienced by the caregivers when a patient passes away or when the patient no longer requires care seems intense for the caregiver while the caregivers' perception of the employers is that they do not experience the same feelings of loss when they say goodbye to the caregivers. It seems that when a caregiver is no longer required in the home to care for a patient, the caregiver leaves the job and returns to the same status, rights, and benefits as they previously held, without guaranteed support or assistance being provided to them by the employer or by society.

It seems that a reciprocal relationship between caregiver and employer alone are not sufficient in contributing towards caregivers' levels of happiness. The relationships employed caregivers establish with the employers of different socio-economic status, race and class, seems to mirror a larger relationship found among populations with different backgrounds within South African society (Fish, 2006). If employed caregivers are not treated with respect by obtaining basic rights and safety within the framework of the private home, a reflection of a greater influence may be the cause.

6.2. INFLUENCE OF THE SOUTH AFRICAN CONTEXT ON CAREGIVING IN PRIVATE HOMES

One of the sub-aims of this study was to explore the unique aspects that caregiving in the private home setting in South Africa may have on employed caregivers. This sub-aim explored whether or not the different backgrounds, cultures, traditions, socio-economic situations, and gender stereotypes that exist within South Africa affect the employed caregiver's experiences and needs. The findings of the study seem to imply that the context of South Africa does contribute to the experiences and needs of employed caregivers, and will be expanded on with existing literature within the section below:

6.2.1. The impact of gender on caregiving in South Africa

Despite being 20 years post-Apartheid, South Africa still seems to present with harsh realities such as power, racial, and gender inequalities. Statistics in South Africa (Stats SA) reveal that inequality and poverty continue to affect the family structure within homes due to high rates of unemployment (Makiwane & Berry, 2013). The lack of income within a family results in poverty, and despite numerous attempts, many South Africans remain unemployed, leading to a direct impact on the family structure (Makiwane & Berry, 2013). The 2000 Time Use Survey suggested that South African men spend increased time on social, cultural, and learning activities while South African women complete the household and care related tasks (Budlender, Chobokoane, & Mpetsheni, 2001).

Women are categorized into the caregiving role with fewer opportunities for socio-economic growth and employment (Makiwane & Berry, 2013). As many females of low socio-economic status still

have limited opportunities and choices available to them, they seem to turn to their cultural and gender-influenced skills to secure working opportunities in order to earn an income. Many of the participants in this study grew up with family members being cared for within their home, or they themselves had cared for a loved one who had fallen ill. This depicts the collectivism and familism described by Pinquart and Sö rensen (2005) which are present in African and Western cultures to varying degrees.

The literature reveals that it is the role of women to care and nurture for others due to cultural, historical, or geographic influences (Evans & Thomas, 2009). While it is acknowledged that all of the participants in the current study were female, it seems that this fact further confirms the notion that caregiving is typically occupied by females, and within South African society, this seems influential by societal and cultural norms. As Lund (2010) found, the majority of nurses in South Africa are made up of black African females, as were the demographics of the participants within the current study. Tronto (1993) explains that care in today's time is still considered the role of the woman due to the emotions involved on an individual and societal level. It has become acceptable for women to take the lead in a caregiving role as women have lead in this role for numerous years across private and public sectors.

Gender roles influence work and income opportunities, ultimately affecting levels of poverty among females within the country. A strong link is found between gender and socio-economic status as among all races, women earn 71% of men's income potential. However, gender is not the only influential factor as African women earn 85% of African men's income and only 71% of white women's income (Makiwane & Berry, 2013). This may provide an explanation as to why the caregivers within this study expressed fear of losing their employment to other caregivers and why domestic workers were fearful towards the caregivers. It also may provide an explanation as to why caregivers chose to remain silent to employers when and if they became injured at work, or when they were asked to complete a task that they had no or limited experience in.

While "caring labour" (Razavi & Staab, 2010) and care work may be classified as vocational work, the income burden which falls within the burden of poverty and poor opportunities seems to negatively affect female employed caregivers in South Africa. The jealousy and competitiveness that occurs between other workers, as described by the participants, suggests that the low income that they receive is valuable and therefore the threat of losing it may cause additional stress and burden. It can be agreed with Razavi and Staab (2010) that respect, rights, and equal wage distribution for care workers is a concurrent problem that needs to be addressed in order for both care workers and care recipients to gain the benefits of the care work being provided.

As caregivers can only provide quality care to one individual at a time, wages are limited, as unlike other work, where numerous tasks can be completed in a day, quality care work requires complete

dedication from the caregiver. Another possible reason why this population receive limited wages is that care workers are completing care-labour and as they are receiving satisfaction from their work, minimal pay is sufficient as they are receiving "more" from satisfaction within the job. "Caring labour" is therefore considered a reward within itself (Razavi & Staab, 2010).

Many South African women with poor circumstances and opportunities, working in private homes, still seem deprived of democratic and gender rights (Fish, 2006). While public roles and opportunities have changed for women in higher-end positions, i.e. parliamentary seats, women working within private homes with limited education and employment opportunities, such as caregiving and domestic workers, prove that racial and gendered behaviour still exists, contradicting the commitment towards greater gender rights in South Africa (Fish, 2006). As this study shows, the role of caregiving within South African homes remains an important role, and therefore, possibly a culture of improved rights, income and training opportunities needs to occur for this population of care workers. Gender stereotypes within private South African homes was discovered through this study as many of the caregivers had been asked to complete tasks outside of their role, but completed stereotypically by females of similar backgrounds, culture, and socio-economic status:

6.2.1.1. *Risk of being task-shifted in the private home setting*

Besides caregiving, women generally hold more household duties and responsibilities, further contributing to their state of poverty (Makiwane & Berry, 2013), and as this study reveals, places them at higher risk of being task-shifted across various household tasks, i.e. domestic work. As the demographic and background information between domestic workers and caregivers may be similar, the boundaries separating these roles seems to become transparent in the eyes of employers, resulting in female caregivers being task-shifted between roles. Being task-shifted into domestic or nursing tasks, within private homes, soon became a leading theme among the information provided by the caregivers within this study. As Tronto (2002) explained, just as domestic workers are commonly task-shifted between roles, are highly vulnerable to abuse, receive low pay, and have poor working conditions, it seems that employed caregivers experience similar caregiving challenges.

Despite not receiving support from unions or organizations as domestic workers do, the findings from this study reveal that employed caregivers would not want the job of a domestic worker and that they were proud of being a caregiver and, despite being accused of it, were not out to claim work from domestic workers. Some of the participants seemed to look down on working as a domestic worker despite domestic workers seeming to have received a louder and more recognized voice within South African homes, represented by the literature and legislation available to them.

Caregivers feel that they have completed a caregiving course which separates them from domestic workers and of which they are proud. This may suggest why the caregivers feel disrespected when

asked to complete domestic tasks, as they are grouped into a general category of female workers in the country, when they have achieved a certificate and accomplished a role that should differentiate them from being a domestic worker. Caregivers also may feel that they are on a higher hierarchical level compared to domestic workers and therefore feel disrespected when they are not recognized for their role within the home.

It seems that black African females of a low socio-economic status in South Africa are still struggling to break the mould, that despite their background, they do not and should not be task-shifted between various household or care related tasks. Further, employed caregivers are often not guaranteed to work on a contract with stipulated hours, salaries, overtime compensation, or uniform and travel allowances. This seems to be an issue related to expectation and job description not being clearly discussed or negotiated between caregivers and employers. Due to their possible disempowered state, it seems that it may be difficult to discuss this topic with their employers.

As Tronto (2002) explained, despite receiving a poor income, caregivers, like domestic workers, feel that the lack of dignity and respect they receive within the home is more degrading, despite the caregiver becoming a quasi-family member. This study confirms the description provided by Tronto (2002) that a sense of powerlessness is experienced by caregivers when working in someone else's home as their own worth and value seem to become lost and unrecognized.

The findings from this study raise the following questions: where do employed caregivers fit within a South African society where other female workers, often with the same background and demographic information, already exist? Without a recognizable place or voice, they are unlikely to be recognized by society, preventing them from maintaining rights which would result in improved dignity and respect. While literature has explored domestic workers, HBCs, and nurses' rights in accordance with legislation and unions in South Africa, minimal literature exists related to employed caregivers. Consequently, this suggests that employed caregivers require their own place, rights and voice among other care workers within South African society.

6.2.2. The need to define employed care work in South Africa

While definitions exist for formal versus informal caregivers, it seems unclear where employed caregivers in South Africa should be categorized. While employed caregivers dedicate their time to caring for another and are paid for their work, some of the formal caregivers within this study have not received formal training as defined by Williams and Crooks (2008), nor does it seem that their income is influenced by the country's regulations and policies (Razavi & Staab, 2010). While informal caregivers are seen and acknowledged within various fields of caregiving literature (Evans & Thomas, 2009; Kim et al., 2012; Williams & Crooks, 2008), South Africa's population of formal caregivers, working in the private home setting, have previously not received the same attention. In

addition, despite these caregivers being employed to work in private homes, it is unknown whether or not these caregivers were registered employees. This was not investigated, as the focus of the study was to collect information on the caregivers' experiences while employed to work in private homes. Therefore, whether or not the caregivers within the study were aware of their rights and protection through legislative frameworks such as the Labour Relations Act or Basic Conditions of Employment, is unknown. As many of the caregivers did not speak of any legislative frameworks, which would have assisted them with employment benefits, it is assumed that many of the caregivers were not registered employees and were unaware of such acts and legislations.

Razavi and Staab (2010) adopted a different care work definition in order to include domestic workers, as they felt that these women contribute and form the majority of female workers within disadvantaged countries where race negatively influenced their opportunities. I would like to suggest that just as domestic workers received an adapted care definition, so too should employed caregivers working within South African homes. While employed caregivers seem more formal by definition, they do not seem to receive the formal policies that they should therefore attain.

It can be agreed with Razavi and Staab (2010) that as South Africa presents with various female workers working in jobs due to racially limited opportunities, that employed caregivers working within private homes should receive increased attention and research in order to develop policies and regulations suitable for them, and possibly require a refined caregiver definition or description. It seems that care workers caring for patients with other neurological disorders such as dementia or Alzheimer's disease have numerous literature and research studies (Zeller et al., 2012). However, caregivers caring for patients who have suffered from a stroke, who are employed and therefore formal in nature, have not been investigated sufficiently within South Africa.

As the findings reveal, employed caregivers seem to be viewed on a higher hierarchical level when compared to domestic workers. Despite this, it seems that domestic workers have received more attention and literature within the South African context as reflected by the availability of unions and legislation. When compared to nurses, caregivers seem to be looked down upon for their limited knowledge and training, and appear to be on a lower hierarchical level. Furthermore, despite caregivers possibly being on a higher hierarchical level within the home when compared to domestic workers, it seems that employed caregivers working for patients who have suffered from a stroke within the home setting, are on a lower hierarchical level when compared to other care workers within South Africa (i.e. HBCs, caregivers for HIV/AIDS and Alzheimer's disease), as represented by the amount of attention, support and recognition other care workers seem to have previously received.

The consequence of this study may provide an argument for increased awareness of the employed caregiving population as not only do they seem to be a "hidden" patient, but they also seem to be the "hidden" caregiver among the caring populations. Furthermore, while informal caregivers seem to be acknowledged through literature and support resources and groups, employed caregivers in South Africa feel unheard and unsupported due to the perceived inadequate availability of resources and support services. Rather than possibly being neglected or grouped among other caregiving or home workers (domestic workers, HBCs, family caregivers), it is suggested that employed caregivers working within private South African homes, receive an established identity and recognition through future research studies, legislation, and the formation of unions and support groups.

6.2.3. The burden experienced by employed caregivers in South African homes

Caregiver burden has been associated with informal caregivers assuming the caregiver role (Rigby, et al., 2009). While the caregivers within the current study confirmed objective and subjective burden, it seems that the burden experienced by employed caregivers differs from the caregiver burden experienced by informal caregivers found in previous studies. To agree with Campbell et al. (2008), the ability to manage levels of stress is dependent on external factors such as poverty, stigma, and poor social support.

The caregivers within this study described how they were often left to care for the patient alone even when assistance was available from family members within the home. The burden and pressure of resuming the responsibility of primary caregiver for another's loved one seems to impact the emotional burden of employed caregivers. Caregivers resume responsibility for the patient's daily functioning, needs, and participation (Hilton, 2001) and within this context, where the primary caregiver resumes all caregiver responsibilities, difficulties may be experienced physically and emotionally, especially if support is unavailable. Live-in workers, as many employed caregivers are, may be further exposed to abuse or harassment within the home, and may have limited resources to turn to for assistance (Tronto, 2002). The caregivers within this study did not have the resources available to them to assist in emotional or physical difficulties, due to poverty and unavailability of support systems, which seems to add greater burden to their caregiving work, as was described by Pinquart and Sö rensen (2005).

The findings of this study confirm the findings from de la Cuesta-Benjumea et al. (2012) who completed a study on employed immigrant care workers in Spain. The study revealed that the amount of burden experienced was similar to that of family members, and the level of burden was dependent on contextual factors including working conditions and on the amount of support received from social systems. Where the findings of the current study do not agree, is that caregiver burden is influenced by the level of dependency that the patient acquires. What can be agreed upon is that immigrant caregivers are more vulnerable than family caregivers, as the recognition for support and the need to

rest is lacking (de la Cuesta-Benjumea et al., 2012). Despite employed caregivers within South Africa not being immigrant workers, their vulnerability due to poor opportunities and lack of voice, places them at risk for enduring caregiver burden as their recognition for rest and support seems limited by the employer and by society.

The quality of life and challenges of family members taking the role of caregiver present with numerous difficulties including physical and emotional strain. This is understandable as a new role and a change in relationship occurs (Thomas & Greenop, 2008). Employed caregivers within South Africa do not seem to experience difficulties due to the same circumstances as informal caregivers, rather, cultural factors seem to negatively affect the caregiver's well-being. While numerous studies have been conducted on family caregivers, employed caregivers specifically working in private homes in South Africa have received minimal attention, resulting in their caregiver burden not being highlighted or addressed. Furthermore, the findings within this study seem to reveal that the caregivers' gender (White et al., 2003), socio-economic status, and race may further contribute to their caregiving burden. Power dynamics and inequalities between caregiver and employer may exist as well as tension between caregivers and domestic workers, leading to challenging relationships and situations occurring.

Therefore, in answering the sub-aim of this study, investigating what barriers and facilitators, stressors and resources are involved in being employed as a caregiver in South Africa - it seems that working within private South African homes, including the lack of reciprocal care received, and strained relationships that form, can contribute to employed caregivers' burden.

6.3. AWARENESS OF AND SUPPORT FOR EMPLOYED CAREGIVERS

As evident by the various areas of support reported in the results chapter, employed caregivers feel that they require support to assist them in their caregiving challenges. Various support systems seem beneficial and individual to caregivers, depending on their personal caregiving experiences, however, it can be suggested that increased awareness and support systems for this population of care workers is a requirement that is currently not sufficiently available in South Africa.

In the US, formal support is provided less frequently to ethnic minorities as explained by their motivation to care for others (Pinquart & Sö rensen, 2005). It may be suggested that despite employed caregivers in South Africa not forming an ethnic minority, the need for support when caring in others' homes is not recognized or prioritized. As Tronto (1993) recognized, the ideal state of caring for another and for oneself is difficult to attain when there are limited resources. While it has been acknowledged by numerous researchers that care for caregivers is important, the population of employed caregivers in South Africa do not seem to be benefitting from such recognition. Family caregivers have benefitted from education and information interventions with regard to caring for the

patients and for themselves. As described by Kalra et al. (2004), training programmes for family caregivers of patients who have suffered from a stroke, present with reduced caregiver burden, anxiety, and depression, and therefore it seems that such services are required and should be implemented within South Africa for employed caregivers.

Gender differences further seem to impact the availability of support services for caregivers. Female informal caregivers receive less informal support when compared to male caregivers (White et al., 2003) which results in female caregivers presenting with greater levels of caregiver burden. Caregivers who are female, older in age, and live with the care recipient experience higher levels of burden associated with caregiving when compared to male caregivers who live away from the care recipient (Kim et al., 2012). This description matches many of the participants within the current study.

While literature on training and support for informal family members and HBCs in South Africa exists, minimal training and support opportunities for employed caregivers working in private homes are present. The findings from this study reveals that employed caregivers have little faith in the government social work sector that is available at governmental clinics and hospitals, to assist in counselling or support when they require it.

It seems that caring for one another may be the most beneficial form of support at hand, as the caregivers understand the experiences that each other have gone through. However, while they already provide so much for others within their caregiving role, it seems that external training services are lacking and are required for this population of caregivers. To agree with the statement by Patel (2009), despite not being given the opportunities and acknowledgment within their work, the potential to allow employed caregivers to receive increased growth and development needs to be addressed within the country.

Furthermore, as domestic workers, community caregivers, and HBCs seem to be receiving support and assistance from various unions, these unions do not seem to be reaching out and assisting employed caregivers working in higher socio-economic homes, whom in conclusion of this study, also seem to require improved support and training opportunities. Possibly this population of caregivers are unrecognized as the conditions in which they work seem manageable and do not seem to present with difficulties on the surface. As they work within private homes and not within a community, their voice seems scattered and their burdens are unknown, as caregiver burden can be influenced by the availability of social resources (White et al., 2003).

Many of the participants in the current study did not know and were not aware of any union that they could join as caregivers. Should unions like NEHAWU be available to this population of caregivers, many caregivers are unaware, and increased awareness of these unions needs to occur. Despite the

presence of this union and its cause, the history present within South Africa still seems to differentiate the class between domestic workers and employers (Bradfield, 2012). It seems that domestic workers are still struggling to step out of the shadow of power asymmetries within the country. Therefore, employed caregivers working within similar home environments, who are fewer in number and less recognizable than domestic workers, with similar demographic status and background, also seem to be struggling to bring about awareness and change for their experiences and needs.

Furthermore, the current structures in place for domestic workers in South Africa seem to lack accountability on the part of employers to maintain and enforce legislation (Fish, 2006) and on conclusion of this study, accountability does not seem present for the population of employed caregivers, affecting the lack of power and unheard voice they experience. It is suggested that caregiving agencies identify the strengths and weaknesses of their programmes within South African society. When the caregivers in this study described feeling alone and unsupported, this included the participants who belonged to a caregiver agency. Despite not ensuring that the caregivers worked in a safe area or providing them with benefits, the participants further felt that they were not cared for with basic respect or dignity.

The findings reveal that both attaining rights and a voice within society, as well as establishing meaningful relationships within the home of the employers, is of value to this population of care workers. While the relationships seem important for short-term happiness within the workplace, the long-standing opportunities, rights, and benefits employed caregivers require within society, may be able to provide caregivers with long-term happiness and security. The development of a support group, therapy centre, union or legislation, representing and supporting caregivers outside of the home, may contribute to caregivers feeling that they belong to something greater with long-term benefits and security. Support provided by people outside of the home setting including therapists and support groups (as observed throughout this study through interactions by the caregivers with myself and with other caregivers), seem to be able to provide long-term support that employed caregivers are currently lacking.

6.4. THE EMPLOYED CAREGIVER MODEL FOR A SOUTH AFRICAN CONTEXT

While there is a large body of literature exploring various theoretical frameworks and the experiences of informal and formal caregivers, they were not found to be fully applicable to the experiences of employed caregivers working for patients within private homes, of varying race and socio-economic status, in South Africa. However, the multidimensional model (Raina et al., 2004), as described in chapter two, served as a useful model in understanding and analysing certain aspects within the research study with regards to the influence of the context and caregiver stress on the caregivers' experiences.

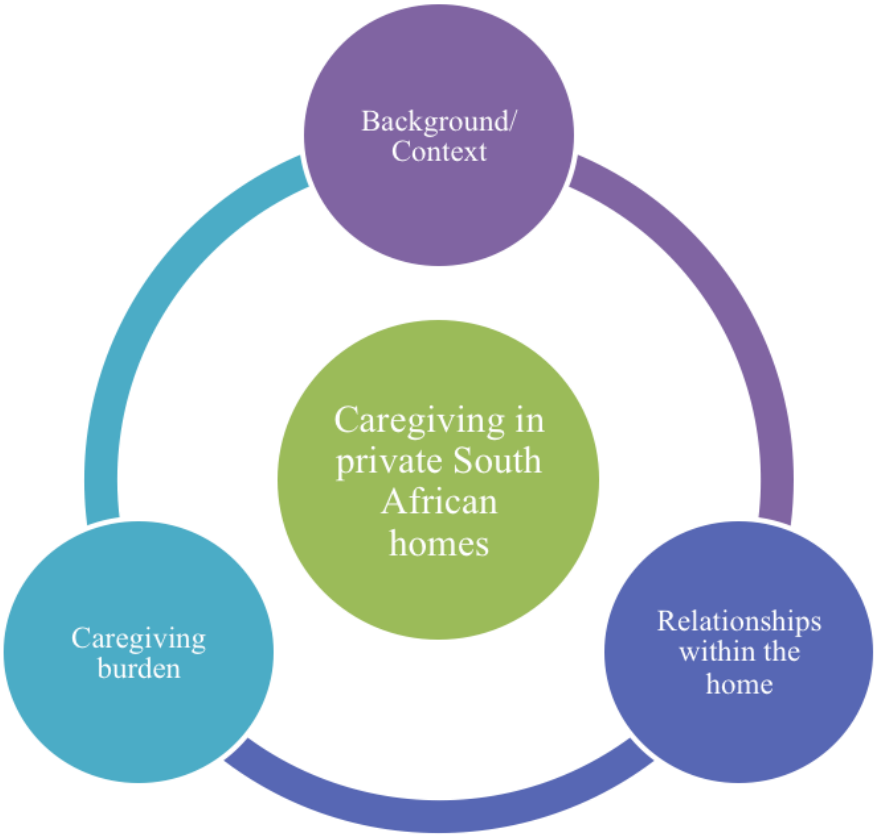
The leading factors that seemed to influence the employed caregiver's experiences working in private South Africa homes, were not related to the patient's impairments, as Raina et al. (2004) suggest, and rather the most influencial factors influencing employed caregivers' experiences were contextual factors. South Africa presents with a unique context and background that seems to be highly influencial towards the experiences and needs of this population of employed caregivers. It can be agreed with the multidimensional model that negative life events can lead to negative consequences experienced by caregivers including their background, context, and socio-economic status (Raina et al., 2004). However, the caregiver's stress and strain in the current study was not experienced due to a differentiation between occupational and caregiving roles as present in the multidimensional model (Raina et al., 2004), as the caregivers within the current study were caregivers by occupation.

The development of the proposed employed caregiver model was influenced by the multidimensional model (Raina et al., 2004), and provides an understanding of the influential factors that seem to contribute to employed caregivers' experiences working in South African homes. Three leading influential factors are found within the model and interrelate with each other. Both negative and positive experiences can occur from each influential factor within various situations.

The employed caregiver model for a South African context may allow for extended research to be conducted with other caregiving populations. Each influencing factor may require further analysis and insight which can occur within research studies exploring various caregiving groups, to assess whether these influential factors are specific to the caregiving population caring for patients who have suffered from a stroke, or if it can be applied across various employed caregiving groups working in private homes in South Africa.

The employed caregiver model for a South African context adds to current caregiving literature both internationally and nationally. While targeted towards the South African setting, the model may be applicable to other populations where a power dynamic may be present between the employer and caregiver. The model further fits into the South African literature on caregivers as it provides seemingly novel information regarding the stroke caregiver population working within private homes.

Figure 5: The employed caregiver model for a South African context



6.4.1.Background/Context

The experiences of employed caregivers may be influenced by their status as a vulnerable population, as women, children, older people, and people with disabilities are considered vulnerable groups (HPCSA, Booklet 6, 2008). The UNAIDS defines the following as contributors to becoming a vulnerable population: poor health and economic status, poor protection of human rights, being placed in a minor position in a hierarchical group, as well as having limited literacy skills (HPCSA, Booklet 6, 2008).

The demographic details of employed caregivers, namely their gender and economic status, seem to impact on their caregiving experiences working in private South African homes. As South Africa presents with a rich history in racial diversity (Makiwane & Berry, 2013), it seems to have had an effect on employed caregivers' experiences, as the homes in which they work are often racially and culturally diverse to their own. The race and gender of the caregivers seem to affect the opportunities and perceptions they attain within their role.

As described by Pinquart and Sö rensen (2005), caregivers who have external stressors within their personal lives seem to experience higher levels of caregiver stress and burden. External stressors for this population, such as poor socio-economic status and poor access to formal support services, seem to affect their caregiving experiences working in South African homes. The experiences of employed caregivers may be influenced by the negative life events that have occurred within the context and may place them at a disadvantage to receive the rights and support they may require. This seems to result in them experiencing an unheard and unrecognized voice within society.

The context where employed caregivers live and work may influence the social services that are available to them. When such social services are reported to be available, the support seems limited. The limited legislation, policies and unions that seem unavailable to this population, may be influenced by the contextual factors present within South African society. Social support and coping strategies may benefit and positively support the process of change, positively influencing caregivers' outcomes (Pearlin, Mullan, et al., 1990). As support at this level may be limited, as many may be living within a different culture and community to their own, caregiver burden may be increased as limited coping strategies and support are available.

6.4.2. Relationships within the home

The findings of this study suggest that the positive and negative relationships formed among the caregivers with various people within the home setting, contributed greatly to their caregiving experiences. As some caregivers move away from their families and homes and become live-in caregivers, their support systems are limited and if a positive relationship is established with the employers, the family often become the caregiver's new support base, as seen by their stories of friendship and support. While the psychological, cognitive, and physical impairments of patients contribute to caregiver burden and depression (Pinquart & Sö rensen, 2005), employed caregivers in South Africa seem to experience increased levels of burden when a close relationship between themselves and the patient or patient's family is not established. To confirm the findings of Pinquart and Sö rensen (2005), caregivers who feel a sense of closeness to the patient may experience greater levels of mental health.

As cited in Evans and Thomas (2009), Tronto's four-stage model of an ethics of care (Tronto, 1993) provided a useful framework for caring relationships involving power relations. Evans and Thomas (2009) applied this model within the context of HIV/AIDS in families where power relationships and structural inequalities were present. While not applied to family structures with HIV/AIDS, the caregivers in the current study are involved in power relations due to the differing socio-economic status, race, and employment opportunities found between themselves and the employer.

Despite the power relationship that may exist within the home, when a positive connection is established among caregiver and patient or the patient's family, the caregivers experience a sense of belonging and happiness. Furthermore, when respect is mutually provided and the caregivers feel a sense of dignity and safety, positive caregiving experiences occur as the caregivers feel that the care they are receiving is reciprocal care. The social relationship between two different cultures is not only additive, rather the experiences of one individual affects the experiences of the other (Stiell & England, 1997). As the study suggests, the patient/patient's family do not always view their relationship with the caregiver as more than a working relationship, and therefore, despite the caregiver providing care often above their duties, care is not always reciprocated, resulting in disappointment and hurt, ultimately influencing the overall caregiving experience.

The South African context further influences the relationships that develop between domestic workers and caregivers within the home. As many South African homes employ domestic workers, interactions between caregivers and domestic workers take place. The findings from this study reveal that these interactions are most commonly negative as vulnerability, fear of losing their job, jealousy, and competitiveness leads to unkindness within the domestic worker and caregiver relationship. Poor relationships between caregivers with other caregivers also have the potential of negatively influencing their caregiving experiences, adding to their emotional burden.

However, positive relationships among caregivers were described within the study and were found to positively influence the caregivers' experiences working in private homes. Interactions that occur among caregivers in minibus-taxis and therapy centres, within agencies or patient's homes, seem to provide support and encouragement, which has a positive effect on their caregiving work. The support and encouragement that occurs among caregivers in these situations seems to provide caregivers with a voice, making them feel less hidden as they feel heard and acknowledged among one another.

6.4.3. Caregiving burden

Physical and emotional caregiving burden seems to be experienced by employed caregivers working in South African homes. The burden seems to be influenced by the above factors, namely the South African context, including the poor income, lack of support and lack of perceived rights available to employed caregivers, as well as the direct/indirect relationships that form/do not form within the home.

As seen in Raina et al. (2004), the demands from the job as well as the caregivers' perceptions of their role influences the burden they experience. As the findings revealed, many caregivers are left to care for the patient alone without assistance from the family members or other caregivers. The physical demands of the job further seem to impact the burden experienced by employed caregivers. Emotionally, the loss of a patient or strained relationships within the home can contribute to

emotional burden within their role. Feelings of vulnerability and fear of losing their job seem to contribute to emotional burden as job and income security is not often guaranteed.

Due to background and contextual factors, employed caregivers in the South African context may experience prior burdens within society. Contextual factors impact the burden of caregivers as stress and concern surrounds the issues of safety, rights, and benefits within the job. This can influence the caregiver's levels of stress within their role. As caregivers may be task-shifted into various roles within the home, increased demands and workload may contribute to their physical caregiver burden while the fear of losing their job if they do not comply and complete domestic, nursing or therapy tasks, may influence their emotional caregiving burden.

The limited support and training opportunities available to this caregiving population further seem to affect the amount of caregiver burden they experience in their primary caregiver role. The opportunities to receive support from one another seem to relieve caregiving burden as an opportunity to counsel and train one another assists in their caregiving difficulties. Caregivers who do not receive support from one another or from society seem to experience greater emotional burden, while caregivers who receive limited training opportunities seem to experience greater physical caregiving burdens.

CONCLUSION

In conclusion, the findings from this study reveal that employed caregivers working in South African homes may be considered a hidden patient. These caregivers experience various forms of burden within their work and are often left without the support they require from employers and society. The employed caregiver model for a South African context, based on the influences from the multidimensional model (Raina et al., 2004), displays the influential factors that seem to contribute to employed caregivers' experiences working in South African homes.

Chapter 7

CONCLUSION

OVERVIEW

The following chapter will conclude the findings of this research study. It will include the implications resulting from the study as well as the limitations it faced. My personal reflections and experiences throughout the research process will conclude the chapter.

7.1. IMPLICATIONS OF THE STUDY

7.1.1. Support services

The results of this study indicate various areas of practice associated with employed caregivers. Limited support and resources seem available to this population of caregivers. Support is necessary for these caregivers in order to assist with the caregiving burdens that they experience working in private South African homes. Support for this population seems to occur inconsistently from the patient and/or patient's family, treating therapists, and from fellow caregivers, however, the potential and desire for increased support, from one another, seems required on a consistent basis. The development of collaborative relationships, in the form of support groups, seems to be the leading implication discovered through this study.

All of the participants within this study stated that they would attend support groups regularly if the opportunity to do so became available. It is felt that social interactions among employed caregivers are important and beneficial for their social health and well-being. As many caregivers move away from their immediate support systems, i.e. their family and community, additional feelings of loneliness may be experienced. The development of support groups, run by caregivers or by a professional, dependent on the needs of the caregivers, may be able to provide the support currently absent for these caregivers. Coping mechanisms for subjective and objective burden, strategies for how to care for oneself as a caregiver, and the ability to share and to listen to one another's stories, seems to be a valuable and necessary service for employed caregivers.

7.1.2. Training opportunities

As a result of limited training and poor availability of resources, training and education on neurological conditions and related impairments seems required for employed caregivers. This study discovered that many employed caregivers have a strong desire to learn more about stroke, and other diseases, and are aware that they are lacking skills and knowledge that could benefit not only the patient, but could also contribute to their personal safety and well-being.

Training could occur individually (i.e. by the treating therapist during therapy sessions) or in a group setting with many caregivers present. These training opportunities seem desired to be coordinated by a selected professional, i.e. a therapist, and could be organized by therapy/rehabilitation centres or through caregiver agencies.

Throughout the study, communication impairments were described as being one of the most challenging stroke-related impairments. As communication plays an important role in allowing successful caregiving to take place, speech-language therapists play a valuable role in assisting optimal communication to take place between patients and caregivers. If speech-language therapists can assist in developing communication between caregivers and patients, it will allow for both the patients' and caregivers' needs to be understood and established, allowing for optimal care and respect to occur.

Other therapists, including physiotherapists and occupational therapists, can also provide valuable information, skills, and support towards employed caregivers. When a caregiver is present with a patient in therapy sessions, therapists seem to have the opportunity to teach caregivers, directly and indirectly, about stroke, its impairments, and the best treatment measures to continue for the patient within the home setting. These therapists have the skills to train caregivers on how to care for the patient without bringing harm or frustration onto him or herself in caregiving situations.

Therefore, this study seems to indicate that therapists have the potential of providing training and support to caregivers, and that their role within South Africa may not be limited to providing therapy and support to the patient and patient's family. As therapists seem to be influential in the training of and support to employed caregivers, a suggested implication is the development of a caregiver-training manual, providing stroke and neurological information, as well as techniques and strategies on caring for patients. The training manual could be standardized or specific according to the patient's needs, and made available through rehabilitation centres or treating therapists. As there are limited resources available to these caregivers (written hand-outs, access to the internet, educational courses), it seems that therapists may be the most practical and beneficial source of knowledge, skills and training for employed caregivers.

Improving information accessibility may further allow for improved training opportunities to take place for employed caregivers. Information made available in their first language as well as opportunities to improve understanding of medical terminology and caregiving procedures, may improve and assist caregivers in feeling more confident in their role, and allow for ongoing development within caregiving to occur.

Caregiver agencies that would like to receive information on this study will be provided with the opportunity. A workshop or document, dependent on their request, will be made available to them in

order to inform them and increase their awareness of the issues that emerged from this study. Awareness of the areas specifically suggested by the participants in this study (mobility and communication difficulties) as well as other areas requiring additional input, will be made available to caregiver agencies should they want to implement training services for caregivers.

7.2. POLICY DEVELOPMENT

This study raises the question of whether enough policies are available for employed stroke caregivers or if the development of new policies and procedures for this caregiving population needs to occur. If current unions are unsuitable for employed caregivers, it is suggested that this study leads to the investigation of unionization occurring for populations of care workers without already established unions, by current unions servicing other care worker populations. Further investigation into this need is suggested to take place by current unions such as NEHAWU. If already established unions are available to such populations, increased awareness of their existence needs to occur.

The findings from this study reveal that unions and organizations serve to provide caregivers with a voice in society, which in their perception, is currently lacking. An established legislation or contract seems to be required in order to provide both employer and caregiver with an outline of the caregiver's role clarification, job description, agreed upon duties, and work-related benefits. This may assist both caregiver and employer to abide by previously established expectations, and regulations within the job, prevent task shifting, and prevent disappointment of expected benefits that may not be delivered. This may be increasingly beneficial in a home where a domestic worker is already employed.

7.3. THEORY DEVELOPMENT

The findings of this study provide new insights and perspectives on the experience of caregiving within private South African homes. The way in which caregiving has previously been conceptualized in South Africa may be challenged, as employed caregivers have had the opportunity to share their experiences and perceptions working in a home environment where a cultural or racial barrier is commonly present. This study adds to our knowledge of caregiving experiences but unlike previous studies completed on informal caregivers, i.e. family members, this study provides information to the current caregiving literature on the types of difficulties and burdens employed caregivers in South Africa may experience. Further, the perceptions of employed caregivers working in private homes has now been established from the source, rather than from predictions based on other caregivers' experiences working in a different context.

The findings of this study allows for greater insight that while caregivers are employed to care for a patient, the caregiver so too requires reciprocal care from the patient, patient's family, treating

therapists and society, as their role has the potential of being physically, emotionally, and psychologically challenging. This study may contribute to current literature in this field and highlights the need for further research to take place in the concept of "caring for caregivers" specifically for employed caregivers within South African homes. The findings of this study contribute to future research investigating the type and volume of care required for caregivers within local and global settings.

The employed caregiver model for a South African context, as described in the discussion chapter, may be beneficial in analysing other power dynamics between employers and employees, specifically within the South African context. Further development of this model may occur with other populations of care workers or with different disorders that may require the employment of a caregiver in the home setting. The influences described to have an effect on employed caregivers' experiences and needs working in private South African homes may be applicable to other contexts and caregiving situations.

7.3.1. Future research

The social constructivist perspective that influenced the methodology of the study was found to be beneficial. The collected results allowed for numerous subjective meanings of experiences to be obtained, further allowing the collected information to be categorized into various themes. It was found that the social and historical events that occurred within the participants' lives influenced their present social construct, as is described by Creswell (2003).

This study suggests that qualitative research designs are implemented in future research studies where an exploratory research design is used. The use of semi-structured interviews and focus groups allowed for detailed and descriptive information to be collected with regards to each participant's experiences within their caregiver role. The nature of the semi-structured interviews and focus groups allowed unanticipated information to be explored.

On completion of this study, it is suggested that further research be conducted on this and other caregiving populations that may have an unrecognized voice. As this study was completed on the population of caregivers working for patients who have suffered from a stroke, it would be beneficial to investigate whether or not caregivers caring in South African homes for patients with other disorders would share similar caregiving experiences and needs. If a commonality is found among caregivers working in private South African homes, support and training opportunities through agencies and other means may become more readily available. As limited information with regards to employed caregivers is present in South Africa, there remain many unknown aspects regarding their physical and emotional well-being that could be further investigated.

Possible research suggestions for future studies within this field include investigating: unequal power relationships within a private home setting, the views domestic workers may have on employed caregivers, possible situations where exploitation working in a home environment may occur, as well as hierarchies among care workers in South Africa. Furthermore, gaining perspective and an understanding of how employers view the caregiver-employer relationship, would contribute further to caregiving literature.

7.4. LIMITATIONS OF THE STUDY

The demographic information of the participants in the study could indicate a limitation, as all participants were female and no male caregivers participated in the study. Should male caregivers have been present, differing information, experiences, and needs of employed caregivers within the home setting may have been offered. Despite this, data saturation was achieved through the information provided by the participants and seems to adequately reflect the experiences and needs of this population of caregivers.

A possible limitation to the study was the language and cultural barriers between me (the researcher) and the participants. As an interpreter was not present throughout the data collection process, language barriers may have affected the information shared by the participants and details from the participants may have been omitted or misunderstood. Further, the cultural barriers that existed between the participants and myself may have influenced the type and amount of information that they decided to share or omit. As the interviews had the potential of being an emotional experience for the participants, an identified limitation of the study was to elicit information from the participants without causing any harm or emotional disturbances to them.

7.5. RESEARCHER'S REFLECTIONS ON THE STUDY

The journey I have taken over the past two years in completing this study has been simultaneously rewarding and challenging. The leading challenge and responsibility I experienced throughout this journey was sharing the feelings and experiences of these caregivers, through my voice, in the hope that it unequivocally represented their voice, in order to bring about a potential positive change to their lives. I felt a sense of responsibility as the participants had opened their hearts and minds to share their experiences with me, in the hope that their voice will become louder and stronger within South Africa. The study has provided caregivers with the opportunity to express their caregiving experiences and needs within a safe environment in the hope that a positive awareness or change will occur. As Budlender (2009) researched the voice of South African care workers including nurses, domestic workers and social workers, this study hopes to bring a voice to the employed caregiver.

My predictions of the results reached beyond my expectations, and rather than only identifying the experiences and needs of employed caregivers, I discovered numerous aspects that affect their daily work and life experiences. The decision to make use of a qualitative research design in discovering the caregivers' experiences and needs, seems to have been the correct method selected, as this allowed for descriptive stories and in-depth experiences to be captured. The fifteen interviews and two focus groups served as adequate sources of data collection, allowing enough information to be captured for data saturation to occur.

Discovering how empowering the focus groups were for the participants was inspiring. The focus groups provided a "mini-support group" to take place and allowed the participants to realize that they are in fact not alone in their caregiving experiences. The focus groups seemed to initiate a sense of unity and empowerment, and provided hope to the participants that support is available from one another through their caregiving difficulties.

My perception of caregivers was influenced after the first interview of the study. My relationship, view and manner towards interacting with caregivers, has been positively affected as a result of the study. When meeting a new caregiver, I ensure that increased effort is taken to remember their name, and to learn about *who* they are and not only *what* they do. I take greater concern in their education and take every opportunity to provide them with relevant information and any additional training or support that they may desire. I take more time in asking whether they have questions or concerns regarding the patient and ensure that they have understood what I may have taught them. I now inquire if they are taking care of themselves and not only caring for their patients. I have a deeper appreciation and sensitivity towards all caregivers and value their role, responsibility, impact and kindness that they continuously provide towards others.

I believe that I have developed as a clinician and have become a caregiver ambassador. I feel passionate in assisting employed caregivers' voices being heard and recognized in South Africa as well as assisting in any way in their training and support.

"Too often we underestimate the power of a touch, a smile, a kind word, a listening ear, an honest compliment, or the smallest act of caring, all of which have the potential to turn a life around"

- Leo Buscaglia

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APPENDICES

APPENDIX A

ETHICAL CLEARANCE CERTIFICATE

Research Office

HUMAN RESEARCH ETHICS COMMITTEE (NON-MEDICAL)
R14/49 Posner

CLEARANCE CERTIFICATE	**PROTOCOL NUMBER H13/06/36**
PROJECT TITLE	The experiences and needs of employed carers of strokepatients, working in home settings in the RSA
INVESTIGATOR(S)	Ms G Posner
SCHOOL/DEPARTMENT	Human & Community Development/Speech Pathology & Audiology
DATE CONSIDERED	21/06/2013
DECISION OF THE COMMITTEE	Approved Unconditionally
EXPIRY DATE	23/07/2015

DATE 24/07/2013 **CHAIRPERSON** (Professor T Milani)

cc: Supervisor : Dr J Watermeyer

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10005, 10th Floor, Senate House, University.

I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to completion of a yearly progress report.**

_____ _____/_____/_____
Signature **Date**

PLEASE QUOTE THE PROTOCOL NUMBER ON ALL ENQUIRIES

School of Human & Community Development

APPENDIX B

PARTICIPANT INFORMATION SHEET AND CONSENT FORM

INTRODUCTION

Hello, my name is Gina Posner. I am a Masters student at the University of the Witwatersrand. My Master's degree requires me to complete a research study for my dissertation. I would like to invite you to participate in my research study entitled: "The experiences and needs of employed carers of stroke patients, within a home setting, in South Africa."

WHY IS THIS STUDY BEING DONE?

Within South Africa, many homes employ carers to care for their loved one who has had a stroke. Employed carers of stroke patients in South African homes often spend a lot of time within the home caring for these patients. I would like to find out about your experiences as a carer.

WHAT DO I HAVE TO DO?

If you agree to participate, you will participate in one focus group (group discussion) with a group of other carers and then have an interview with me. The focus group will last about one hour to one and a half hours and the interview will last approximately one hour. I will ask about your experiences as a carer as well as what information or support would help you as a carer of people with stroke. You will be interviewed in a location away from your place of employment outside of work hours at a time that is suitable to you. The focus group will take place at a community centre in Johannesburg.

The interview and the focus group will be voice recorded. These recordings will be stored securely in a password-protected computer for a minimum of 2 years after publication and for 6 years should a publication not be completed. Only myself and my supervisors will have access to the recordings.

WHAT HAPPENS AT THE END OF THE STUDY?

At the end of the study, I will write up all the results in a dissertation. You will be given the results of the study if you would like to know them. Should any support groups or systems be started after this study, you will be told about them.

ARE THERE BENEFITS IF I PARTICIPATE IN THE STUDY?

There are no direct benefits to participating in the study. An indirect benefit of participating in the study will be the opportunity to attend future carer support groups and training groups that will take place following the research study.

WHAT RISKS ARE INVOLVED?

There are no risks involved in the study.

WHAT WILL THE STUDY COST ME?

The study will not cost you anything. You will not be paid for participating in this study. Transportation fees will be covered / reimbursed to you if you need to travel to the interview site.

RIGHTS

Your participation in this study is completely voluntary. If you wish to stop participating in the study at any time you are free to do so without any consequences. You do not have to answer any questions that you do not want to answer.

CONFIDENTIALITY

Your name will not appear in the study. It will be replaced with a number or fake name. Any information about you will be kept private. During the focus groups, you will meet other caregivers. You will be asked to keep the other caregivers' names and information that they share confidential. Your responses will not be shared with your employer or with the patient you care for.

DEBRIEFING

If you feel that you need to speak to a social worker after the study, one will be available to you without charge. If you would prefer to visit a social worker at your hospital attachment area, the researcher will contact them for you.

If you have any questions please contact me or my supervisors:

Ms. Gina Posner	Dr. Jennifer Watermeyer	Dr. Joanne Neille
Researcher	Research supervisor	Research co-supervisor
072-109-6389	011-717-4578	011-717-4574

Additional contact details

Mrs. Lynnette Chernick- Social Worker

082-782-5577

CONSENT FORM

I, _____, agree to participate in this study about experiences of caring for stroke patients. In giving consent I understand the following:

- I will need to participate in a **focus group** (group discussion) with other participants and in an **interview** with the researcher to discuss being an employed carer of stroke patients in South Africa.
- The **focus group** will last about **one hour to one and a half hours** and the **interview** will last **approximately one hour.**
- I can choose to leave the research whenever I want and have **no obligation** to participate.
- I have received and understand the potential risks and benefits involved in the research study.
- My **identity** will be kept **anonymous** and will be replaced with a number or pseudonym (fake name) throughout the whole research process.
- I will allow for the researcher to make use of direct quotes in the final dissertation that will be kept anonymous.
- The interview and focus group that I participate in will be **audio-recorded** for transcriptions and report writing. Access to the audio-recordings will be restricted to only the researcher, research supervisors, and potential transcribers. All audio-recordings will be **kept safe** by the researcher in a secure location during and after the research is complete for a minimum of 2 years post publication and for 6 years should a publication not be completed.
- I will be given the **opportunity** to **participate** in **stroke carer support and / or trainings groups** after the study has completed.

I have read or spoken about and **understood** this document and the information sheet. I recognise that Gina Posner is the researcher for this project and agree to participate in her study.

Participant name (Print) Participant signature

_____ _____

Date and place

_____ _____

Researcher's name (Print) Researcher signature

_____ _____

Date and place

_____ _____

School of Human & Community Development

APPENDIX C

CONSENT FORM FOR AUDIO-RECORDING OF THE SEMI-STRUCTURED INTERVIEW AND FOCUS GROUP

I_____, hereby consent to audio-recording of the interview and focus group. I understand that my confidentiality will be maintained at all times.

According to the HPCSA guidelines (1998), the audio-recordings recordings will be stored for a minimum of 2 years post publication and for 6 years should a publication not be completed.

Name: _____

Date: _____

Signature: _____

APPENDIX D

QUESTION SCHEDULE FOR SEMI-STRUCTURED INTERVIEW

The semi-structured interview will be conducted in the following way:

A. INTRODUCTION

The researcher will introduce herself and provide information about herself, her job and her interest in this area of research.

B. PERMISSION TO RECORD

The researcher will request permission from the participant to audio record their interview for later transcription and analysis.

C. PURPOSE OF THE STUDY

The researcher will describe why they have been asked to participate in the study and will provide the participant with the aims and objectives of the research study and how their information will benefit the findings of the study.

1. BACKGROUND INFORMATION OF THE CARERS

- **BACKGROUND**

1.1. Can you tell me about yourself?

1.2. Where do you currently live?

1.3. Where were you born and raised?

1.4. Who did you grow up with?

1.5. When you were growing up was anyone cared for in your home? If so who was it and who were cared for them?

- **TRAINING**

1.6. Tell me about your education and qualifications:

2. PREVIOUS CAREGIVING EXPERIENCES

- **EMPLOYMENT**

2.1. How long have you been working as a carer in South Africa?

2.2. Are you self-employed or do you receive jobs through an agency?

2.3. How many different employers have you had working as a carer?

2.4. What type of patients have you had the most experience with?

- **STROKE**

2.5. How many stroke patients have you cared for?

2.6. Tell me about what it's like to care for a person who has had a stroke.

2.7. Let's discuss what you've learnt about stroke and from where or whom you've learnt about it?

2.8. Let's talk about the most challenging problem/s that the patients you've cared for have had that you've needed to deal with?

2.9. What strategies do you find are the most helpful when dealing with these challenges (mentioned in 2.8)? Let's discuss what you do to overcome these problems.

- **EXPERIENCES**

2.10. Tell me about the feelings you have when working as a carer for stroke patients.

2.11. Do you feel that being a carer for stroke patients is an easy or difficult job? Let's discuss why.

2.12. Have you had any challenges working as a carer for stroke patients? Tell me about them.

2.13. If you have had challenges, what do you think helps you to get past these challenges?

2.14. What are some of your best experiences of being a carer for stroke patients?

2.15. What do you think would be different in the home that you work in if you were not there / they did not have a carer?

- **SUPPORT**

2.16. Have you attended any stroke carer support groups, meetings, information talks? If so, tell me about them.

2.17. Have you ever received any caregiving counselling or help after or while working with stroke patients? If so tell me about it.

2.18. Do you ever meet up with other carers to discuss difficulties in caring? If so, tell me about them.

2.19. Have you ever cared for a patient that passed away? How was that experience? (Did you speak to anyone about it?)

2.20. Have you ever searched for information about caring for stroke patients? Tell me about where you searched.

- **RELATIONSHIPS**

2.21. Tell me about the relationship you have with the family of the person you care for.

2.22. What have you learnt from any or all of your patients and families that you worked for?

3. <u>NEEDS OF THE CARERS</u>

- **SUPPORT GROUPS**

3.1 Would you attend a support group for carers that are working within South African homes?

3.2 Where would be the best location for these to take place? (Government clinics / hospitals; community centres; churches; homes?)

3.3 How often would you like such support groups to take place?

INFORMATION / EDUCATION

3.4 Would you like to learn more about stroke and its difficulties patients may experience? What would you like to learn about, let's discuss it.

- **OTHER SERVICES**

3.5 Are there any areas, besides caregiving, that you would like to learn about possibly if you attended such support groups?

3.6 If the following services were available to you, what would you like to lean about:

Service	Yes	No
Stroke information • Physical challenges. • Communication challenges. • Thinking / Memory challenges. • Other: _____		
How to help your patient • Tips on how to communicate. • Tips on how to move and transfer them safely. • Tips on how to feed them safely.		
Provide therapy / activities within the home • Tips on continuing therapy within the home (speech, occupational and physiotherapy). • Tips on functional activities you could provide.		
Support and Debriefing • Providing platform to discuss your feelings, difficulties, thoughts, and emotions while caring for stroke patients within a home environment. • Providing social workers to listen and help with any difficulties you may have. (Possibly situations within the home you are unsure how to deal with). • Debriefing sessions to discuss feeling and emotions after a patient has passed away.		
Financial Support • Advice on how to save and manage your finances.		
Nursing / Caregiving Courses • Update on caregiving or nursing courses that are teaching or revising skills that may be helpful to you. • Updates on new methods of care.		

APPENDIX E

QUESTION SCHEDULES FOR FOCUS GROUP

Introductions

Let's find out how long everyone has been a carer for.

Possible key areas

Think back to your caregiving experiences- lets discuss them.

Think back to how many stroke patients you have cared for.

Let's talk about being a carer for stroke patients within homes in South Africa.

Think back- have you had any challenges working as a carer for stroke patients?

Let's discuss what you find the most challenging stroke-related impairments to be? Possibly their speech, walking, get dressed? What tips and strategies can you share that help you in dealing with the impairments?

Think back – have you had any good experiences working as a carer for stroke patients?

Do you think being a carer for stroke patients in South Africa is different to other places in the world?

Think back, have you ever wanted any help working as a carer for stroke patients? For example, advice, information about stroke, support from other carers? Let's discuss this.