

**SOCIAL WORK SERVICES TO FAMILIES CARING FOR A FAMILY
MEMBER WHO SUFFERED FROM A STROKE**

**BY
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DECLARATION

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March 2021

Dedicated to my father, **Cedric Cairncross**, who survived a severe stroke and who was my motivation to pursue further studies in social work services to families caring for a family member who suffered a stroke.

To my mother, **Regina Cairncross** who challenged me in completing this degree, I hope I am making you and Daddy both proud.

Strength does not come from winning. Your struggles develop your strengths. When you go through hardships and decide not to surrender, that is strength.

Arnold Schwarzenegger

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ABSTRACT

Stroke has been shown to be among the top ten leading causes of disability worldwide. In Africa, inadequate information; traditional beliefs; restricted healthcare services; inadequate medical employees; early deaths and the inclination to use home-based remedies have resulted in underreporting of stroke-related illnesses. Stroke is amongst the most common chronic lifestyle diseases as well as one of the highest causes of disability in South Africa, which places a high burden on patients, their families and the communities in which they live. Discharging patients with stroke to unprepared caregivers at home is connected with a burden or stress that negatively impacts the quality of life, not of the caregiver only, but the stroke patient as well.

The ecological perspective was used as the theoretical point of departure for this study. The research question for the study was: What is the nature of social work services rendered to families caring for a family member who suffered a stroke? The goal for the study, which was to gain an understanding of social work services rendered to families caring for a family member who has suffered a stroke, was achieved. This made it possible to formulate appropriate recommendations in line with current policy and legislating documents related to social work services for family caregivers of stroke patients.

A qualitative research methodology was used to involve social workers who render services to family caregivers of stroke patients within tertiary hospitals, Non-Government Organisations and within the private sector in the Western Cape Metropole area. The study was based on both the explorative and the descriptive research design. For the aim of this study, the researcher used purposeful non-probability sampling. Eighteen social workers who met the inclusion criteria of the research study were chosen according to their willingness to participate. A semi-structured interview schedule was used for data collection during the empirical investigation and a pilot study was conducted with one participant to put to test the measuring instrument.

A literature study aimed at describing the policy and legislation guiding the care of stroke patients within the context of both international and South African legislation, as well as the challenges and needs of family caregivers and social work services from an ecological perspective was completed. An empirical investigation followed this, and results were then purposefully processed and analysed. Because challenges hampering the delivery of social work

services to families caring for a family member who suffered a stroke were recognised in this study, the researcher recommends the employment of more social workers and ongoing support, training and education to be available within organisations, as well as within communities. Social workers need to be empowered to utilise and receive training regarding the policies and legislation relating to the provision of social work services to family caregivers of stroke patients and to create more stroke awareness and education among the public. These resources are necessary for the improvement of social work services to family caregivers of stroke patients.

OPSOMMING

Bewyse toon dat beroerte wêreldwyd een van die tien voorste oorsake van gestremdhede is. In Afrika het onvoldoende inligting; tradisionele oortuigings, beperkte gesondheidsorgdienste; ontoereikende mediese werkers; vroeë sterftes en geneigdheid tot die gebruik van tuismiddels tot onderverslaglewering van beroerte-verwante siektes gelei. Beroerte is een van die mees algemene kroniese lewenstysiektes, sowel as een van die grootste oorsake van gestremdheid in Suid-Afrika wat 'n groot las plaas op familieledede as versorgers en op hul gesinne en die gemeenskappe waarin hulle woon. Hospitaalontslag van beroerte pasiënte na onvoorbereide familieversorgers hou verband met las en spanning, wat 'n negatiewe invloed op die lewensgehalte van beide die familie versorger en die patient self het.

Die ekologiese perspektief het die teoretiese raamwerk wat vir hierdie studie voorsien. Die navorsingsvraag vir die studie was: Watter maatskaplike dienste word gelewer aan gesinne wat vir 'n familielid wat 'n beroerte gehad het sorg? Die doel vir hierdie studie was dus om 'n bydrae te lewer tot die begrip van die maatskaplike dienste aan gesinne wat vir 'n familielid omgee wat 'n beroerte gehad het en afhanklik van familieledede geword het. Toepaslike aanbevelings word dus gemaak aan die hand van huidige beleids- en wetgewingsdokumente wat verband hou met maatskaplike werkdienste aan familieversorgers van beroertepasiënte.

'n Kwalitatiewe navorsingsmetodologie is toegepas op maatskaplike werkers wat by tersiêre hospitale, regsorganisasies, nie-regeringsorganisasies en die privaatsektor in die Wes-Kaap Metropool werksaam is. Die studie was op beide 'n ondersoekende en beskrywende navorsingsontwerp gebaseer. Vir die doel van hierdie studie het die navorser doelgerigte monsterneming van 'n nie-waarskynlikheidssteekproefneming gebruik. Agtien maatskaplike werkers wat aan die insluitingskriteria van die navorsingstudie voldoen het, is volgens hul bereidwilligheid om deel te neem gekies. 'n Semi-gestruktureerde onderhoudskedule is tydens die empiriese ondersoek vir data-insameling gebruik en 'n loodsstudie met een deelnemer is onderneem om die meetinstrument te toets.

'n Literatuurstudie wat daarop gemik was om beleid en wetgewing te beskryf wat die versorging van beroertepasiënte in die konteks van internasionale sowel as Suid-Afrikaanse wetgewing, maatskaplikewerkdienste aan gesinsversorgers vanuit 'n ekologiese perspektief, die behoeftes en

uitdagings van gesinsversorgers beskryf, is onderneem. Daarna is 'n empiriese ondersoek gedoen en die resultate is doelbewus verwerk en ontleed. Deur die resultate te verwerk en te ontleed, kon die navorser sekere gevolgtrekkings en aanbevelings maak rakende maatskaplike dienste aan gesinne wat 'n familielid wat 'n beroerte gehad het, versorg.

Sekere uitdagings in hierdie studie word erken as belemmering vir die lewering van maatskaplike dienste aan gesinne wat 'n familielid na 'n beroerte versorg. Gevolglik beveel die studie aan dat indiensneming van meer maatskaplike werkers en deurlopende ondersteuning, opleiding en opvoeding in organisasies beskikbaar moet wees. Maatskaplike werkers moet bemaagtig word om opleiding met betrekking tot beleid en wetgewing wat die versorging van beroertepasiënte lei, te ontvang en beroertebewustheid en opvoeding aan die publiek bekend te maak. Hierdie hulpbronne is nodig vir die verbetering van maatskaplike dienste aan familieversorgers van familieledede met beroerte.

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LIST OF ABBREVIATIONS

ACPF:	African Child Policy Forum
CASASP:	Centre for Analysis of South African Social Policy
CBR:	Community-Based Rehabilitation
CHW:	Community Health Workers
CDG:	Care Dependency Grant
DG:	Disability Grant
DoH:	Department of Health
DSD:	Department of Social Development
DWCPD:	Department of Women, Children and People with Disabilities
GIA:	Grant-In-Aid
IFRC:	International Federation of Red Cross and Red Crescent
INDS:	Integrated National Disability Strategy
NGO:	Non-Government Organisations
NRP:	National Rehabilitation Policy
NSF:	National Stroke Foundation
OSDP:	Office on the Status of Disabled Persons
PGWC:	Provincial Government Western Cape
PHC:	Primary Health Care
RSA:	Republic of South Africa
SASSA:	South African Social Security Agency
UN:	United Nations
UNCRC:	United Nations Conventions on the Rights of People with Disabilities
UNICEF:	United Nations International Children's Emergency Fund

WHO: World Health Organization

WSO: World Stroke Organization

CHAPTER 1

INTRODUCTION

1.1 PRELIMINARY STUDY AND RATIONALE

Stroke is a neurological condition which affects millions of people across the globe. Globally, approximately 5.5 million die annually, with 44 million disability-adjusted life-years lost (Mukherjee & Patil, 2011). Stroke is the second leading cause of death in the world (Katan & Luft, 2018) and the third leading cause of disability (WHO, 2012).

Strokes also are the third leading cause of death in the United States (The American Heart Association Statistics Committee and Stroke Statistics Subcommittee Writing Group, 2009), however in many African countries, inadequate information, traditional beliefs, restricted healthcare services, inadequate medical personnel, early death and preference for home-based remedies, have resulted in under-reporting of stroke-related illnesses (Connor, Modi & Warlow, 2009; Walker et al., 2000). Kaduka, Muniu, Mbui, Owuor, Gakunga & Kwasia (2019) report that registration of stroke in countries such as Kenya is incomplete due to existing burdens on the ailing health care system.

Puoane, Tsolekile, Sanders and Parker (2008) found that stroke is one of the highest causes of disability and amid the most common chronic lifestyle diseases. Moreover, it is reported to be the third leading cause of death in SA (Bertram, Jaswal, Van Wyk, Levitt & Hofman, 2013). This illness places a heavy burden on patients, their families and the communities in which they live. The discharge to their home of patients with stroke to unprepared caregivers is related to burden or stress, which negatively impacts the quality of life, not of the caregiver only, but of the stroke patient as well (Mudzi, 2010). Moreover, it places a burden on the policy framework and strategy on disability and rehabilitation services in South Africa 2015–2020 and the South African Government (DoH, 2013).

Mudzi (2010) further states that hospital costs entail some of the major socioeconomic concerns following stroke. Many stroke patients require extended hospitalization, nursing home consideration and rehabilitation affecting the financial circumstances of people, their families, networks and healthcare services (Bryer et al., 2010). These health care costs are often

exacerbated due to comorbidities experienced by patients and resulting in lengthier hospitalisation. These comorbidities include aphasia, haemorrhagic infarct, infection, history of smoking and atrial fibrillation necessitating a longer stay in hospital resulting in substantially higher costs (Göz, Kahraman, Genç, Kaya, Öztürk, Kutluk, 2017; Van Exel et al., 2003).

Langhorne and Legg (2003) state that stroke rehabilitation aims to reduce the disability and promote activity and participation of individuals affected by stroke. Rehabilitation can be carried out in two ways, namely in-patient and out-patient community-based settings (Rhoda, Mpofu & De Weerd, 2009; Haig, 2007; Ottenbacher & Graham, 2007). Prior to hospital discharge, professionals such as doctors, physiotherapists, speech therapists, psychologists and social workers should provide specific training for stroke patients and their caregivers. This preparation should include, by necessity, personal care techniques, communication strategies, physical handling techniques and pro-active secondary stroke anticipation (National Stroke Foundation, 2010). It was stated by Hale and Wallner (1996) that stroke patients are frequently discharged irrespective of findings that indicate that community-based rehabilitation (CBR) services are inadequate for the management of acute and sub-acute patients within South Africa.

It is articulated within the World Health Organization [WHO] (2004) and the Department of Health [DoH] (Western Cape Province, 2007) that the significance of CBR services concerns providing the community with a holistic service. These services aim to attend to people with disabilities within the communities in which they reside. The dynamic participation of persons with disabilities, their families, the community and all applicable sectors in the recovery process is being advanced by CBR.

CBR services improve and supplement facility-based services by providing services in a community setting and, moreover, by implementing instruments through which communities can become mindful of their health needs. It is a method for engaging the community in terms of information and the requirements of persons with disabilities. It is a process that generates the equalisation of opportunities and the social incorporation of all persons with disabilities into the community, work environment or school. Additionally, Strydom (2010) states that a variety of

organisations and professions in South Africa render services to persons with disabilities; these include Non-Government Organisations (NGOs) delivering social work services.

Social work services are part of the primary support services available to 31% of those with disabilities in South Africa (Graham, Selipsky, Moodley, Maina & Rowland, 2010). It has also become evident that younger people with disabilities seem to be more aware of social work services, as opposed to services rendered by CBR workers, home-based carers and therapists (Lorenzo & Cramm, 2012). This is indicative of the importance of social work services and supports the view held by Strydom (2010), who argues that social workers are crucial role players in service provision for people with disabilities.

Due to a lack of stroke support services, which include social work services, patients suffer emotional distress which is often exacerbated by financial constraints and the burden the condition places on family members (Andre, Kilkenny, Naylor, Purvis & Cadilhac, 2015). The emotional distress may result in anger, agitation, feelings of loss, rejection and suicidal thoughts, which are prominent in patients who remain in denial of their actual condition, particularly when full recovery is not achieved and patients are rendered disabled. The occurrence of mood disorders amongst stroke patients may be the result of the emotional distress they experience (Ch'Ng, French & Mclean, 2008).

The burden of care often becomes the responsibility of the family members (Andre et al., 2015). This is exemplified by the experiences of the researcher's mother, who experiences stress as the primary caregiver of the researcher's father who suffered a severe stroke four years ago and has been left disabled as a result. He cannot be left unattended at home, as he requires 24-hour care. Disability as a consequence of a stroke thus is significantly life changing and places strain on the family.

The extended consequence of being left disabled after the stroke is the financial burden placed on the family. Additional expenses, which have become the responsibility of the family, include paying for a nurse on a weekly basis to support this researcher's mother with duties such as washing and grooming her father, purchasing of nappies, acquiring a special hospital bed, obtaining a wheelchair, and buying a urine bottle.

Consequently, the motivation for the study was this personal experience. The available healthcare services were experienced as being extremely limited. Limited intervention took place when the researcher's father was discharged from the rehabilitation centre after three months. An example of the limitation of intervention experienced by the family included a lack of preparation and support for the family when the discharge from the rehabilitation centre took place. The consequences of the sudden stroke have caused the family severe trauma.

As a social worker, the researcher had a strong interest in the outcome of this study conducted through a social work lens in terms of social work services available for families caring for a relative who suffered a stroke and became disabled and dependent on family members. Taking into consideration the outcome and consequences of a stroke for the family, it is important to recognise the significance of social work services to family members caring for a relative in such a situation. Engstrom (2012) posits that social work services have the power to buffer stress in life transition and strengthen the health of the patient or family.

Redfern (2013) indicates that, in South Africa particularly, there is an absence of research and no recent studies with respect to disabilities in urban and peri-urban settings. This relates to the researcher's study of instances of patients who are permanently disabled as result of a stroke. The Nexus research database (Nexus, 2016) does not present any study with a similar focus on social work services to assist families caring for a family member who suffered a stroke, for the past 10 years. However, 30 studies on the Nexus research database did focus on social work services to persons with a disability in the past 10 years, in South Africa. These studies focused predominantly on the necessity of social work intervention with disabled persons.

Such studies focusing on the necessity of social work intervention with disabled persons differ from the current study. While, components around dealing with the stroke patient were included, the researcher explored social work services available to families caring for a relative who suffered a stroke and consequently is disabled. Available studies, for example, dealt with community-based services offering support towards avoiding a secondary stroke and accessing stroke-specific services.

Various studies found on the Nexus research database (Nexus, 2016) of the past 10 years, emphasize the services and aid of a social worker because social workers are trained to treat and evaluate individuals within the broader family context. The lack of significant past studies reveals that there is a gap in the research field. A study of this nature was therefore seen as valuable to the social work profession to gain a better understanding of the scope of potential social work services to families caring for a family member who suffered a stroke.

1.2 PROBLEM STATEMENT

The prevalence of stroke patients needing assistance with activities of daily living in South Africa is almost the same as in high-income countries (Connor et al., 2004). The burden of stroke is especially high in rural South Africa with 33 500 strokes reported in a population of 13 000 in 2011 (Maredza, Bertram & Tollman, 2015). It has also become evident that stroke patients are more often younger than expected. A study by Wolf, Baum and Connor (2009) found that 45% of stroke patients were younger than 65 years and a further 27% were younger than 55 years. This has resulted in a mean age of stroke patients reported as 51 years (Duff, Ntsiea & Mudzi, 2014), in South Africa. This means that a stroke cannot be perceived as an illness experienced only by the elderly, and therefore it has a direct negative impact on the economic status of many families: Statistics indicate that it is those who are economically active and responsible for supporting families who are affected (Maredza et al., 2015; Wolf et al., 2009).

According to Connor and Bryer (2005), little is known about the socio-economic effect of strokes in South Africa. Edmans (2010) furthermore postulates that two-thirds of those who experience a stroke will require some type of support offered by family and not merely by health workers. This supports the argument for new research to concentrate on the true burden, causes and outcome thereof. Studies such as these may aid health care practitioners to develop suitable social work intervention policies.

Ross and Deverell (2010) indicate that persons who are diagnosed with immobilising conditions experience strong emotional responses. Sorrow, nervousness, failure, anger, blame,

defencelessness and confusion are some of the feelings that stroke patients, and their families, experience.

According to Bernhardt, Hayward, Kwakkel, Ward, Wolf, Borschmann, Krakauer, Boyd, Carmichael, Corbett and Cramer (2017) indicate that there should be more focus placed on research related to the recovery and rehabilitation process of stroke patients. This recovery and rehabilitation process should be inclusive of all therapy-based interventions and services post-stroke and should include family caregivers (Bernhardt, et al., 2017).

In summary, the main concern is when the stroke patient returns home and the subsequent challenges the family members face. This research consequently explored social work services to families caring for a family member who suffered a severe stroke – from the acute rehabilitation unit until their discharge. In other words, social work services from the in-patient rehabilitation unit where the stroke patient benefits from an intensive, multidisciplinary rehabilitation programme, until the patient is discharged into their home setting. Recommendations for social workers practising in the field of rehabilitation in respect of stroke patients were made.

1.3 RESEARCH QUESTION

What is the nature of social work services rendered to families caring for a family member who suffered a stroke?

1.4 GOAL AND OBJECTIVES

The goal of the study was to gain understanding of the social work services rendered to families caring for a family member who suffered a stroke and has become disabled and dependent on family members. The objectives of the study were:

- To describe policy and legislation with regard to stroke patients and the challenges families experience in caring for them.
- To identify the social work services that should be rendered to families who care for a family member affected by a stroke from an ecological perspective.

- To explore the social work services rendered by social workers to families affected by a stroke.
- To present conclusions and recommendations on social work services for organisations and rehabilitation centres that offer intervention to the family members who deal with stroke patients' post-acute rehabilitation.

1.5 THEORETICAL POINTS OF DEPARTURE

The ecological perspective was utilised as the theoretical framework in the context of this research. Gitterman and Germain (2008) posit that the principles of the ecosystem deepen our perception of all phenomena being mutually dependent and interconnected. Jack (2012) further posits that this framework provides a holistic perspective on all aspects of an individual's life and their inter-connectedness. Ross and Deverell (2010) assert that the holistic experiences of family caregivers and stroke relatives are likely to be a combination of several levels of influence, with small changes in one having the ability to produce a substantial impact on other systems. To gain a holistic understanding of the consequences of a stroke, the crucial strategy is to investigate the entire range of experiences of stroke patients and their caregivers on several levels. These interconnected levels are recognised as the micro, meso and macro systems (Jack, 2012).

1.5.1 Micro system

The micro system deals with the individual. Here intervention focuses on the stroke patient. Moreover, it embraces the psychosocial aspects of recovery from a multidisciplinary viewpoint and not embracing the physical consequences only (Muller, 1999, as cited in Ross & Deverell, 2010:165). Gardner and Werner-Lin (2012) propose that psychosocial support at a micro level should include:

- The comprehensive assessment of the individual and the family's emotional, social and behavioural functioning, for example, also what emotions the patient and family experience.
- Teaching of strategies to manage medical regimes and to reduce symptoms, for example, support by the social worker to guide the patient and the family through the healthcare

process and to equip them with tools to manage the stroke patient at home and to function within the social context at the meso level.

1.5.2 Meso level

The meso system takes into consideration the person's family and social context, thus a needs assessment is required for the stroke patient in terms of social support available for both the patient and the family (Engstrom, 2012). According to Fouché (2005), individuals with strong social connections are more likely to change their behaviour and attitude than those with poor social connections; therefore the attitudes of family and friends have a powerful effect on the behaviour of stroke patients.

It is thus important for a comprehensive assessment in which social workers should explore the patient's social support, considering factors such as the composition and size of the patient's social network, availability of social support as well as the strengths and obstacles to engagement and sharing with others (Hepworth, Rooney, Rooney & Strom-Gottfried, 2013). Here, social workers could utilise the eco-map as a tool to identify and organise relevant environmental factors outside the individual or family context. The eco-map could guide the social worker to recognise support and stresses in the patient's environment and informative patterns, such as unresponsive social systems, thus allowing social workers to assess the support networks of family members caring for a stroke patient and utilise macro-level systems in order to tap into relevant resources such as policy and legislation for effective intervention.

1.5.3 Macro level

According to Engstrom (2012), the macro system places the person's social and environmental considerations at the forefront of assessments. According to Bronfenbrenner (1979), the macro system, also referred to as the public policy level, provides general social-cultural context. This macro system consists of cultures, subcultures and broader social contexts (Bronfenbrenner, 1979). Every culture has a belief system that assists the particular cultures' individuals to diagnose, predict, treat and prevent numerous health conditions (Fouché, 2005). This view is shared by Engstrom (2012) who explicates that an individual's cultural background informs their frame of reference and impacts how they will recognise and label problems. In some cultures, for example, strokes are allegedly triggered by malicious spirits and not remediable by physical

means (Ross & Deverell, 2010). People therefore turn to traditional healers or herbalists for treatment (Fouché, 2005).

Cultural practices and negative lifestyles, which include the use of tobacco and unhealthy diets, as well as health factors such as hypertension, ethnicity and limited healthcare facilities, are contributing factors to the high rate of stroke in South Africa (Lemogoum, Degaute, & Bovet, 2005). These authors further propose that, in order to reduce stroke rates globally, public health programmes and health policy to enable the adoption of a healthy lifestyle are necessary. These programmes should include increased awareness of stroke and education on modifiable risk factors, particularly to those at high risk.

The Draft White Paper on Mainstreaming Rights of Persons with Disability (2015) begins to address the need for public health programmes in terms of disabilities by advocating for a multi-sectoral, coordinated, interdisciplinary approach in planning programmes that impact on those with disability, including disability caused by stroke. This effort may, however, not be sufficient, as cultural background impacts on how social work services are rendered (Engstrom, 2012), thus complicating intervention on a macro level.

1.6 CONCEPTS AND DEFINITIONS

1.6.1 Social work services

The National Association of Social Workers (1971) states that social work is the professional activity of aiding individuals, groups and communities, with the intent to advance or restore their ability for social functioning and forming societal circumstances, which is favourable to this aim. The levels of practice which enclose micro, meso and macro levels, at which social workers implement interventions are highlighted by this definition.

1.6.2 Family member

The term family member signifies any person related to one by marriage, adoption or blood (Definitions and Acronyms, 2008). Moreover, it could also encompass a group of individuals connected by heredities, for instance siblings, children and parents. The term, however, can also be broadened to encompass people living together in a household, who are emotionally attached,

or persons that interact regularly (Mosby's Medical Dictionary, 2009). For the purpose of this study, a family will be the family members of the stroke patient by marriage, adoption, heredity or by living within the same household, being emotionally attached and interacting on a regular basis.

1.6.3 Stroke

According to the WHO, a stroke is a clinical condition characterised by rapidly developing clinical signs of central (or universal) interruption of cerebral function, with symptoms lasting 24 hours or longer or leading to death, with no perceptible reason other than of vascular cause (World Health Organization, 1989).

1.7 RESEARCH METHODOLOGY

The discussion in covers the research approach, research design, research method, population, sampling, data collection and data analysis, to be followed with the ethical considerations adhered to.

1.7.1 Research Approach

A qualitative approach was followed. Green and Thorogood (2009) state that the aim of qualitative research is to understand the perspectives of participants, explore the meaning they give to phenomena or observe a process in depth. Fouché and Delport (2005) additionally state that qualitative research is applicable when understanding of the importance people ascribe to their daily lives is sought. Mohajan (2018) states that the qualitative researcher depends on the participants to provide an in-depth response to the research questions about how they have understood their experience.

The views of social workers rendering services to families caring for a relative who suffered a severe stroke were explored. The focus was on the meaning of the phenomenon and the role of the social worker in rendering services to families caring for such a relative was discussed and understood through the participants' views.

1.7.2 Research Design

An exploratory and descriptive research design was used. De Vos, Strydom, Fouché and Delpont (2011) indicate that exploratory studies assist the researcher to develop methods that are used cautiously in later studies. Terre Blanche and Durrheim (2002) state that exploratory designs allow the researcher to investigate people's experiences from an open, supple, inductive and orderly approach as they look for new insights into the phenomenon. Descriptive research can be explained as a more intensive analysis of phenomena to gain a more comprehensive description (Rubin & Babbie, 2005). As the researcher aimed to understand the social work services rendered to families caring for a family member who suffered a stroke, an exploratory and descriptive research design was appropriate.

1.7.3 Sample

Polit, Beck and Hungler (2001:234) define a sample as "a proportion of a population". In this study, the sample was selected by means of the non-probability, purposive sampling method. Strydom and Delpont (2005) articulate that this sampling method comprises the choice of participants with features that will be advantageous to the study. Silverman (in Strydom & Delpont, 2005:328) states that purposive sampling is generally preferred as it "illustrates some feature or process that is of interest for a particular study".

Initially, the researcher proposed two rehabilitation centres in the Western Cape Metropolitan area to be included in the study and that the proposal would be sent to the Director or Central Executive Officer of the Social Work Department at both of the rehabilitation centres which would form part of the study. Moreover, it was stated that once approval was received from the rehabilitation centres, the researcher would schedule a date with the Directors of both centres, in order to present and explain the study to the social workers.

The one rehabilitation centre only employed six social workers and this did not provide enough participants for conducting the study. The social work manager of the other proposed rehabilitation centre denied access due to potential participants in private practice wanting to be remunerated since they were working for remuneration per hour and the study stated that no compensation would be provided to participants. As a result, the researcher had to seek alternative participants and sent her proposal to the provincial Department of Health, which

granted approval for her research at seven government institutions. Additionally, NGOs and private rehabilitation centres were also approached to obtain an adequate number of participants for the study.

Tertiary hospitals, NGOs and both private and government rehabilitation centres in the Western Cape Metropolitan area therefore were included in the study. Telephonic and email contact was made with the directors who serve as the gatekeepers of both government facilities, NGOs and private rehabilitation centres in the Western Cape in order to obtain consent and gain entry into the facilities to conduct the study. The researcher explained the purpose of the research telephonically and via email. In addition, she sent her proposal and letters to conduct the research to the managers at the identified government facilities, NGOs and the private rehabilitation centres in order to request permission to conduct the research.

The aim was to include social workers rendering services to families caring for a family member who suffered a stroke in the Western Cape Metropolitan area. The social workers were fluent in Afrikaans or English, irrespective of their race, gender, culture, religion or age and formed part of the research sample. In addition, the number of years of experience of the social workers was not important in this study as the researcher focused on the social work scope of services the selected rehabilitation centres and hospitals render to families caring for a family member who suffered a stroke. Eighteen participants were included in the study. Data saturation was reached by interview number five, but the researcher completed another 13 interviews to obtain enough data to effectively describe the phenomenon of this study and address the research questions. In addition, larger samples also support the reliability of the study and help in obtaining quality (Farber & Foncesca, 2014).

1.7.4 Instrument for data collection

In-depth interviews are known as the most common method of qualitative data collection as it discovers subjects in greater detail (Skinner, 2007). To collect data, the researcher made use of a semi-structured interview schedule (see Annexure 2) to conduct interviews. A voice recorder to audiotape the interviews was used, after consent from the participants obtained. A semi-structured interview schedule as data collection instrument, according to De Vos et al. (2011), is generally used to gain the viewpoints of the participants regarding the research topic. The

researcher conducted the interviews in Afrikaans and English, depending on the preferred language of the participant.

1.7.5 Data Analysis

The method of data analysis summarised by Creswell (2007), which consists of five steps, was utilised by the researcher. The five steps are as follows:

Step 1: The researcher organised and prepared the data for investigation. This involved typing up the interviews conducted; scanning materials optically; typing up field notes; classifying any visual material; and arranging and organising the information into various kinds, relying upon the sources of information.

Step 2: The researcher read all the information that was typed. The initial step provided a generic sense of the information and an opportunity to reflect on its general significance. Within this step, the researcher identified the consistencies and differences across the participants' responses as well as the tone of the ideas. The researcher focused on the overall credibility, the overall depth and the usefulness of the information.

Step 3: This step involved the coding of all the information. This means that the researcher assigned a code word, for example, one, two or three words to describe what are being said by the participants. When possible, the researcher made use of the participant's actual words. Creswell (2007) refers to using a participant's actual words as *in vivo code*. Here the researcher reduced repetition by taking out codes that duplicated ideas and reducing the codes to a manageable list. To bring meaning to the text, the researcher identified patterns, collapsed the codes into themes and organised them into coherent categories that emerged from the information.

Step 4: The researcher used the coding process to generate a description of the participants as well as themes for analysis. To show which categories appear more important, the researcher counted the number of times a particular theme arose. These counts provided a very rough estimation of individual importance. They were not suited to statistical analysis, but they could reveal general patterns in the information.

Step 5: The researcher represented the themes in a qualitative narrative. This is a detailed discussion of several themes and sub-themes to convey the findings of the analysis.

Step 6: The researcher interpreted the findings. The researcher reflected on the personal meaning of the information. Information was compared and contrasted with the existing literature that the researcher had accumulated. Subsequently, limitations concerning the study were addressed. This provided the researcher with suggestions for further research.

1.7.6 Data verification methods

1.7.6.1 Validity and reliability

Bryman (2012) declares that validity and reliability are two of the key components in evaluating social research. He further elaborates that reliability is centred on how consistent measures are, and that the term “dependability” is frequently utilised as an alternative statement in qualitative research. It is recommended that researchers follow an auditing process in their research to ensure they keep all the information for all phases of the research.

Bryman (2012) states that validity refers to the honesty of the conclusions that are presented from a research endeavour. Validity is concerned with whether an indicator that is configured to measure a concept, measures a concept with quality. In order to make sure that the semi-structured interview schedule measured accurately, the researcher conducted a pilot interview with Participant 1, who formed part of this study. It could be determined in the first interview of the study whether the data recorded was measured as per the intention for which it was recorded. The first interview revealed that the interview schedule correctly captured the ideas and that the interview schedule did not require changes.

To further ensure validity and reliability, the researcher had one participant from the study who read through the empirical chapter, (Chapter 4), to state their view on whether she agree with the findings that the researcher outlined in the study. The participant informed the researcher that they agree with the findings of this study. The researcher also made use of an independent coder that is currently busy with a post graduate degree in Social Work and that is also registered with the South African Council for Social Service Professions (SACSSP). This independent coder

read through the researcher's transcriptions and empirical chapter to confirm the themes, sub-themes and narratives (Appendix 8).

1.7.6.2 Credibility

De Vos (2011) views credibility as the strength of a qualitative study and that it can be considered an alternative for validity within the study. Credibility of the data was addressed by means of triangulation of information from different sources and through reaching consensus on themes (Mabuza, Govender, Ogunbanjo & Mash, 2014). De Vos et al. (2011) state that the objective of credibility is to show that the subject of the study is honestly identified and portrayed. According to Shenton (2004), tactics to help ensure honest sharing of information by participants further add to the credibility of the study. For the goal of this study, all participants were given the chance to withdraw or decline to participate and were also given the opportunity to refuse to answer any questions that they did not wish to answer, with assurance of their anonymity (Annexure 1). If anyone wished to determine whether findings could be transferred to other settings, an audit trail and record-keeping system was available (Mabuza et al., 2014). Additionally, three of the transcripts were sent via email to the participants, to verify whether an honest reflection of the interviews was recorded. These participants verified the information via email and declared that the interview transcripts were honest reflections of the interview.

1.7.6.3 Transferability

Transferability is considered a choice for a study's external validation. This applies to the capacity in other cultures, communities, and settings to use the results. The researcher sets the theoretical limits of the study by rethinking theoretical frameworks to illustrate how principles and models can guide data collection and analysis. In this research, the theoretical framework influenced the manner in which knowledge was collected and analysed (De Vos, 2011). For social workers rendering services to family caregivers of stroke patients and for the Department of Health and Social Development, the results and recommendations of this research may be useful to explain the problems faced by social workers and how they could be strengthened.

1.7.6.4 Dependability

The alternative word for reliability is dependability, whereby the researcher seeks to account for any changes that arise in the phenomenon selected for the study. De Vos (2011) maintains that explorations cannot be readily duplicated to a new collection of circumstances because the social climate is ever evolving. The investigator did not have to make any adjustments that could have affected the study's reliability.

1.7.6.5 Conformability

The alternative term for objectivity is conformability. A conformable study suggests that someone other than the researcher may determine the results of the study (De Vos, 2011). All the narratives in Chapter 4 of this study report the participants' direct contributions, with the researcher making no modifications. All themes, sub-themes and categories in Chapter 4 have also been checked using established published research by means of literature control.

1.8 ETHICAL CLEARANCE

The term “ethics” alludes to preferences that affect human relationships and transactions, such as upholding a code of principles, behavioral laws, the researcher's duty, and a population group's behavioural expectations (De Vos et al., 2011). The researcher acted in compliance with the principles set out in the Social Workers Ethical Code and performed the study in an ethical manner. The researcher is also registered with the South African Council for Social Care Professions and behaves as required at all times in a professional manner. The study was conducted under supervision and management of the Department of Social Work at the University of Stellenbosch. The proposal was submitted to the Departmental Ethics Screening Committee (DESC) of the University of Stellenbosch for approval as a low-risk study. Ethics entail preferences that affect human behaviour within human relationships; being compliant with a code of principle; the accountability of the researcher; and the values of conduct of a given profession and the rules of conduct (Babbie, 2007 in Strydom 2011).

The following ethical issues were taken into account for the study:

1.8.1 Voluntary participation

De Vos et al. (2011) describe that participation within research must always be voluntary and no one should feel obligated to participate in an investigation. The participants were informed that they could withdraw from the study at any stage in order to ensure that participation was voluntary. The informed consent form also included this information; participants had to read this and sign before the interview began.

1.8.2 The avoidance of harm

As per Strydom (2002), harm to participants within the social sciences field is predominantly emotional in nature. The participants were informed that they had the right to withdraw from the study at any stage. To protect the participants from possible harm with regard to their setting, they were assured that their identity, opinions and views would be treated as confidential. In this study, there was no expected potential distress or risk to be suffered from participation other than the participants' time within their working hours.

1.8.3 Informed consent

According to De Vos et al. (2011), informed consent means that participants must at all times be allowed the opportunity to choose what must happen to them. Before the interview started, the informed consent form (Annexure 1) was discussed. A clear outline of this study and its goals and objectives were provided to the participants in order for them to make informed decisions about their participation in the research. Besides being informed that they could withdraw from the study at any point, participants were also informed that the interviews would be audio recorded (refer to Annexure 1). Following these explanations, the participants completed the consent forms.

1.8.4 Confidentiality

Confidentiality can be defined as keeping something private (Oxford Dictionary, 2017), thus handling the information gathered from participants during interviews in a private manner. The confidentiality of participants was maintained during the study as only the researcher and her supervisors have access to information and no names were used during the capturing of the information. The researcher assigned pseudonyms to the participants, for instance, Participant A, and audio recordings, field notes and transcripts were managed exclusively by the researcher.

The record of information, such as the audio recordings, are kept password protected on the researcher's cell phone. Field notes and transcripts are kept in a lockable drawer in the researcher's office, which is accessible to the researcher only. The information that was gathered was used for research purposes only.

1.9 COMPENSATION

No rewards in any form were given to the participants.

1.10 LIMITATIONS OF THE STUDY

There is a scarcity of literature on this subject in the field of social work. Literature from other disciplines was consulted and adapted.

Due to a lack of recent research on this topic, some resources are outdated. The researcher attempted to create balance with more recent online sources and journal articles.

The study involved 18 participants; therefore, findings cannot be generalised to reflect the considerations of all social workers in this setting. However, it can be applied to comparable settings and under comparable conditions. Irrespective of the above limitations, the current study has revealed several service challenges from which stakeholders can learn to improve the quality of services to families caring for a family member who suffered a stroke.

Some potential participants declined to participate in the study due to being private social workers working on a costs per hour basis.

1.11 PRESENTATION

The research consists of five chapters, namely:

Chapter 1, the introduction and rationale for the study, includes the theoretical framework, problem statement, goal and objectives, an overview of the research methodology, ethical obligations and the limitations of the study.

Chapter 2 provides an in-depth discussion of policy and legislation with regard to stroke patients and the challenges and needs of family caregivers caring for such patients, which is the first objective of the study.

Chapter 3 presents the second objective of the study, which is the description of social work services rendered to families caring for a relative affected by a stroke from an ecological perspective

Chapter 4 presents the empirical findings of this study and the literature control.

Chapter 5 is the final chapter of this study. It presents conclusions and recommendations regarding social work services for organisations and rehabilitation centres that offer intervention to the family members of stroke patients.

CHAPTER 2

POLICY AND LEGISLATION GUIDING THE CARE OF STROKE PATIENTS AND THE CHALLENGES OF FAMILY MEMBERS CARING FOR A STROKE PATIENT

2.1 INTRODUCTION

The intent of this chapter is to elaborate on the first objective of this study, which is to describe pertinent policy and legislation in connection with disability, as people who suffer from strokes are often rendered disabled. There are various international and national legislative policies which guide service provision to those who are disabled, as stroke patients are. The international policies inter alia consider the United Nations Rules on the Equalisation of Opportunities for Persons with Disabilities (UN, 1993), the United Nations Convention on the Rights of People with Disabilities (UNCRPD) (UN, 2006), the World Health Organization (2010) and the Global Stroke Bill of Rights (2014).

In South Africa, national legislation and policy that guide services to stroke patients include the Constitution of Republic of SA (Act No: 108 of 1996), the National Rehabilitation Policy of South Africa (NRP) (RSA, 2000), White Paper on Integrated National Disability Strategy (RSA, 2000) and the Policy on disability (DSD, 2013). The above-mentioned policies and legislation outline objectives for accountable and effective rehabilitation services with regard to full participation of persons with disabilities in the planning, assessment and monitoring of services.

2.2 INTERNATIONAL POLICY FRAMEWORKS GUIDING SERVICE PROVISION FOR PEOPLE WITH DISABILITIES

Policies and legislative documents play a fundamental role in the provision of services to persons with disabilities and their families. There are different policies that provide assistance, both globally and nationally. The international policy frameworks guiding the provision of service to people with disabilities are discussed in this section, with the focal point on stroke patients.

2.2.1 The United Nations Rules on the Equalisation of Opportunities for Persons with Disabilities (UN, 1993)

The United Nations Rules on the Equalisation of Opportunities for Persons with Disabilities (UN, 1993) were developed on the foundation of the experience gained during the United Nations (UN) Decade of Disabled Persons (1983-1992). The General Assembly, which is the principal deliberative, representative and policy-making organ of the UN, has declared the period 1983-1992 the UN Decade of Disabled Persons. This declaration highlights the determination of the international community to sustain the impetus given by the International Year of Disabled Persons in 1981 towards the prevention of disability and the equalisation of opportunities for persons with disabilities, as well as their reintegration back into society.

The Standard Rules on the Equalisation of Opportunities for Persons with Disabilities encourages governments to engage in actions that will accomplish the equalisation of opportunities for all persons with disabilities. Even though these rules are not legally binding, they can be used as a basis for policy making for the improvement of life for people living with disabilities (Howell, Chalken & Alberts, 2006). Additionally, this policy document stipulates that it is the duty of governments to take correct action to eradicate impediments which prevent people with disabilities from obtaining the same services as those without disabilities. Furthermore, the UN (2006) urges that organisations which render services to persons with disabilities should assume a functioning role as partners in the development of equal opportunities for such persons. The Standard Rules on Equalisation of Opportunities applicable and relevant to this study are discussed below.

Rule 4 notes that states must guarantee the improvement and provision of support services. This includes assistive devices for persons with disabilities, in order to assist them to reach their maximum independence level within their daily activities and to exercise their rights. Many people with physical disabilities are being excluded from active participation within society because of doorways that are too narrow for wheelchairs; steps giving access to buildings; buses, trains and aircraft that are inaccessible; toilet facilities that cannot be used; and light switches and telephones that are unreachable. Moreover, Bayat (2014) noticed during his fieldwork in West Africa, that people with disabilities were neglected in institutions; were denied stimulation;

and that the conditions of these institutions were suboptimal. Bayat (2014) additionally argued that staff did not treat people with disabilities with any perceptible degree of respect.

Rule 5 outlines that the overall significance of accessibility in the activity of equalisation of opportunities in all spheres of society must be realised by governments. For persons with disabilities of any kind, states need to (a) take on measures to supply access to communication and information; and (b) establish programmes of action to make the physical environment accessible. However, there nonetheless are barriers preventing persons with disabilities from exercising their freedom. This results in challenges to participating in social activities, in all societies of the world (UN, 1993).

Zhou (2015) indicated in her research that there is a need for support groups and counselling programmes in Southern Africa to help families cope, since families could live in cultures that express a negative view of disability. The negative views can impact families and result in a low self-esteem; hence the need for counselling programmes. Mackenzie et al. (2007) found that family caregivers were in need of stroke information, inclusion in decision making and planning, as well as professional assistance. Pindus et al. (2018) expressed feelings of frustration and dissatisfaction with a lack of follow-up either from the hospital or connected healthcare professionals. Such lack of follow-up may leave families and patients frustrated and this, in turn, may interfere with the family functioning.

Rule 8 speaks about income maintenance and social security concerning persons with disabilities. It mentions that states are responsible for the provision of social security and income maintenance for persons with disabilities. Such support should point out the special needs of the person, for example, and other expenses related to the disability. Moreover, as much as possible, the support offered should additionally provide cover for family caregivers. Family caregivers are often in need of financial support due to their caregiving role (UN, 1993). In South Africa, social security takes the form of a Disability Grant (DG) for the person with a disability.

The Centre for Analysis of South African Social Policy (CASASP) (2005) and Mitra (2005) found that no state grants are provided to persons with a disability in South Africa if the person is employed, despite extra disability-related expenses. Therefore, the South African DG is seen as

an income substitution benefit for people with a disability who are not capable of engaging in paid work, as opposed to compensatory benefits that are covering the extra costs of disability (CASASP, 2005; Mitra, 2005).

Rule 9 stipulates that full participation in family life of persons with disabilities should be encouraged by states. States must encourage the right to personal integrity and guarantee that discrimination by laws against persons with disabilities concerning parenthood, marriage and sexual relationships are prohibited. Zhou (2015) found that disabled persons are amongst the world's most vulnerable population due to discrimination and stigma, with constricted access to livelihood opportunities, healthcare and education. While people with disabilities are eligible for the same rights as those without disabilities, their lives too frequently are handicapped by physical and social impediments within society, which restrain their full participation (WHO, 2011).

In December 2001, the UN General Assembly embraced a declaration during a comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities. It noted that the Standard Rules assume a crucial role in effecting positive advancements at national and international levels. Yet, it also acknowledged that, irrespective of the fact that various attempts to expand collaboration, incorporation, expanding disability awareness and sensitiveness to disability challenges (both by national and international bodies), these attempts have not been adequate to advance full and successful investment and open doors for people with disabilities in financial, social and political life.

Moreover, the UN Rules, as outlined above, are to ensure that persons with disabilities have equal rights and opportunities. Consequently, the UNCRPD was established to protect, improve and guarantee the full and equivalent delectation of all human rights and basic opportunities by all people with disabilities, and to advance honour for their dignity (UN,1996). As aforementioned, Zhou (2015) found that persons with disabilities are amongst the world's most vulnerable population due to stigma and discrimination, and the WHO (2011) argues that, too frequently, the lives of persons with disabilities are handicapped by social impediments within

society, which puts restraints on full participation. From this, it is clear that impediments which prevent persons with disabilities from exercising their rights and freedoms in society remain.

Thus, the significance of international alliance and its promotion of national implementation efforts are recognised by the UNCRPD. This includes the acknowledgement of actions that the international community could take to encourage worldwide cooperation, for instance, to ensure that international improvement programmes are inclusive of and aid persons with disabilities, facilitate capacity-building, cooperate in research and acquire admission to technological and scientific knowledge. The UNCRPD, which incorporates a social development approach to promote and protect the equal opportunities and rights for people with disabilities, is discussed in the following section.

2.2.2 The United Nations Conventions on the Rights of People with Disabilities (UNCRPD) (UN, 2006)

The UNCRPD is an international human rights charter of the UN. This charter is supposed to advance and protect the rights and dignity of persons with disabilities. It embodies a “paradigm shift” from one which perceives persons with disabilities from a medical perspective to one that is strongly grounded in human rights, which, as aforementioned, is referred to as the social development approach to advance and protect the equal opportunities and rights of people with disabilities. The UNCRPD includes persons with disabilities who have long-term physical, mental, intellectual or sensory impediments that may impede their full and efficient participation in society on an equal basis with others (UN, 2006). The inclusion of all people with disabilities is indicative of a social development approach that concentrates on the continuous advancement of the welfare of the family, community, society as well as the individual (Green & Nieman, 2003), as indicated in various South African policy and legislative documents (RSA, 2000; DSD, 2013).

The South African Government ratified this convention in 2008. Thus, the country must ensure that the human rights and fundamental freedoms of persons with disabilities are protected and advanced (Lorenz, 2011). The ratification of the UNCRPD implies that South Africa must submit a report to the Committee on the Rights of Persons with Disabilities every four years (Rule, 2011 In T. Lorenzo (ed.)). South Africa submitted its first report towards the end of 2012. The country’s commitment to realising the rights of persons with disabilities is expressed in this

report. In response to signing the UNCRPD, the South African government has created a Ministry for Women, Children and Persons with Disabilities; however, accomplishing the objective of equalisation of opportunities for persons with disabilities as yet is to be achieved (Kathard & Ka Toni, 2011). Opportunities for work accessible to persons with disabilities are scarce. According to the National Development Plan, disability and poverty works in a vicious cycle. Disability leads to hardship and disadvantage (Research Brief on Disability and Equality SA, 2017).

Articles 9, 19, 20, 25 and 26 of the UNCRPD specifically refer to service delivery, rehabilitation and health care services for disabled people, which are of particular relevance to this study, which focuses on support services rendered to the family caregiver of the stroke patient. Moreover, it encourages the full participation of persons with disabilities in all spheres of life. These articles are discussed in the following section.

Article 9: Accessibility and full participation

Article 9 concerns the requirement that member countries must ensure that physical barriers to entering buildings, transport, roads, workplaces and housing are eliminated, for people with physical disabilities to have the same access as those without such disabilities. Physical impediments within the environment, such as uneven roads, steps and transport, hinder equal access to public infrastructure and other amenities for disabled people (Swann, 2008; Chimatiro & Rhoda, 2018).

In South Africa and other parts of Africa there are copious examples of hindrances resulting from inadequate infrastructure, including stairs and inaccessible pathways to grant equal access to amenities for people with disabilities (Coulson, Napier & Matsebe, 2006; Algurén, Lundgren-Nilsson & Sunnerhagen, 2009; Urimubeshi & Rhoda, 2011).

Article 19: Independent living and inclusion in the community

Article 19 deals with the capacity of persons with disabilities to live independently and be included in the community. It states that people with disabilities should have the opportunity to choose their residence and with whom and where they live on an equal basis with others. Furthermore, it states that people with disabilities should have access to a range of community

resources which support them and should not be obligated to live in a specific living arrangement. Coulson et al. (2006) found that people with disabilities are still prevented from accessing many societal benefits due to barriers to health care, housing, transport, education, social security grants and welfare services. Zhou (2015) conducted a study with participants who were physically disabled in Namibia, and all participants specified that they experience institutional barriers. These institutional barriers included a lack of accessibility to transport, buildings and employment opportunities. Consequently, it is clear that people with disabilities are being excluded from the community.

Article 20: Personal mobility

Personal mobility is covered in Article 20, which endeavours to ensure personal mobility to empower the best possible independence for people with disabilities. This would include the assistance for access to quality mobility devices, forms of live aids, intermediaries and assistive equipment, including making these available at an affordable price. Assistive technology is described as equipment aimed at advancing the functional abilities of the disabled. The WHO (2011) identifies one of the most common types of assistive technologies as mobility devices.

Wapling & Downie (2012) recognised the need for material support in the form of assistive devices to increase the active participation of people with disabilities and their well-being. Marsella (2009) conducted a study on the experiences of family caregivers with stroke patients on weekend home passes from in-patient rehabilitation. This study found that assistive devices appeared to increase the positive experiences of family caregivers when the stroke patient was home for a weekend. Caregivers who did not receive assistive devices reported feelings of frustration. As a result, many family caregivers reported that assistive devices should be arranged prior to weekend passes.

There has been an attempt to address the apparent lack of assistive devices, such as hearing aids, vision devices, wheelchairs, walking frames and prostheses, as well as screen-reading software, computers and custom-made electronic equipment in South Africa (WHO, 2015). These assistive devices are provided to those receiving a state pension or disability grant who require it (WHO, 2010), when available. Unfortunately, access to assistive devices is sometimes hampered due to a lack of funds (Chappell & Lorenzo, 2012).

Article 25: High standard of health

Article 25 stipulates that persons with disabilities deserve the privilege of a supreme achievable standard of health without discrimination. To provide the highest achievable standard of health to people with disabilities, early recognition and provision of services intended to lessen and counteract further disabilities should be taken into consideration (UN, 2006).

De Wet (2014) states that free healthcare services for disabled people who are dependent on public healthcare provision were instituted by the South African National Department of Health in July 2013. He affirms that this movement acknowledged that people with disabilities may require progressive medical treatment. However, provinces differed with regard to the application of the policy. In the Western Cape it was decided to provide free healthcare to all persons in receipt of a disability grant, including old age pensioners. At the time, the province did not have sufficient rehabilitation professionals to evaluate each person prior to determining whether they were disabled and therefore eligible for free healthcare services. Consequently, patients in the Western Cape do not have to wait for an evaluation to be done in order to determine whether they qualify for free health care services. These patients automatically have access to clinic and hospital services (Chappell & Lorenzo, 2012).

Article 26: Rehabilitation and Habilitation

Article 26 addresses the need for Rehabilitation and Habilitation and articulates that suitable and affective measures should be taken to empower persons with disabilities to achieve and maintain maximum independence, full mental, physical, vocational and social capability, and full involvement and participation in all parts of life. The WHO (2011) describes rehabilitation as the time-limited and goal-orientated process intended to enable a person with a disability to reach an optimal level of functioning by equipping the person with the needed tools to change his or her own life. Habilitation refers to a process aimed at helping people to attain new skills or abilities in order to achieve an optimal level of functioning (UN, 2006). Rehabilitation training programmes and the promotion of the use of assistive aids to develop optimal functioning are therefore needed (The African Child Policy Forum [ACPF], 2019).

Habilitation or deficiency thereof is an issue faced by numerous South Africans, not just those with a disability. The deficiency of habilitation may result from various challenges such as a lack

of financial resources and personnel, lack of personnel training and inaccessible facilities (ACPF, 2011). According to Howell et al. (2006), much has been done since 1994 to guarantee that persons with disabilities are not discriminated against by way of exclusion and inequities. Nonetheless, Howell et al. (2006) argue that a great deal of change in attitude still needs to be realised amongst South Africans to guarantee that disabled people are not denied their right to dignity, equality and freedom (Bill of Rights, 1996).

Article 26 goes on to address the need for Rehabilitation and Habilitation and stipulates that applicable measures should be put in place to empower persons with disabilities to accomplish and maintain maximum independence, full mental, physical, vocational and social capability, and full involvement and participation in all parts of life. Rehabilitation and habilitation, however, is hampered and not successfully implemented (Dube, 2011 & Kwenda, 2010).

Rehabilitation can be seen as a fundamental support service for a stroke patient and their caregiver as it offers them the opportunity to engage fully in society (DoH, 2007; Cawood & Visagie, 2015; Bernardt et al., 2017). Adequate subsidies from government are needed to offer effective rehabilitation services (DoH, 2007). However, this need for rehabilitation services to ease the burden of family caregivers and to improve the lives of people with disabilities is often overlooked in South Africa (Mlenzana, Eide & Frantz, 2019). This may be because people with disabilities make up a minority proportion of the SA population (Coleridge, 2006).

2.2.3 World Health Organization (WHO, 2010)

The WHO was established in 1948 for the coordination of health affairs within the UN system. At first, its priorities for this coordination concerned illnesses such as tuberculosis, malaria, venereal disease and other transferable diseases, plus children and women's health, sanitation and nutrition. From its inception, it worked with member countries to determine and address public medical issues, assist medical investigation and issue guidelines. It additionally categorised diseases. Disability is acknowledged as a human rights issue, as well as a global public health issue by the WHO and the aim is for all people to achieve the topmost level of health.

The WHO action plan to meet its aim state three objectives: firstly, to eradicate obstacles and improve access to health programmes and services; secondly, to extend and strengthen

habilitation, rehabilitation, assistive technology, CBR and support services; and thirdly, to intensify the accumulation of applicable and internationally corresponding information on disability and to assist with research in respect of disability and affiliated services. This action plan supports the execution of measures aimed to meet the rights of persons with disabilities, as stipulated in the UNCRPD, specifically in Articles 9 (Accessibility), 19 (Living independently and being included in the community), 20 (Personal mobility), 25 (Health) and 26 (Habilitation and rehabilitation) (UN, 2006).

The first objective of the WHO, namely, to eradicate obstacles and improve access to health programmes and services, relates to Article 9 of the UNCRPD. This section stipulates that member countries must ensure that physical barriers to entering buildings, transport, roads, workplaces and housing are eliminated, for people with physical disabilities to have the same access as those without any physical disabilities. The WHO argues that to successfully eradicate barriers and advance access to health services, the input of people with disabilities will be needed due to them being most familiar with and influenced by such barriers.

The second objective of the WHO (to extend and strengthen habilitation, rehabilitation, assistive technology, CBR and support services) relates to Article 26 of the UNCRPD. This section summarises the need for States Parties to take on strategies that organise, strengthen and extend rehabilitation and habilitation services in the areas of employment, education, health and social services. Article 26 additionally specifies that States Parties shall advance the availability, knowledge and utilisation of assistive devices and technologies configured for persons with disabilities. Article 20 of the UNCRPD requires States Parties and the international community to commit to assisting access to quality assistive technology, for example, by making this accessible at a low cost. The WHO (2015) states that assistive technologies play a significant role in enabling people with disability to function and participate. In addition, it can lessen the physical burden on family caregivers and reduce the need for formal support services.

The third objective of the WHO, namely to intensify the accumulation of applicable and internationally corresponding information on disability, and to assist with research in respect of disability and affiliated services, is crucial, as it oversees national and international development of disability policies as well as the execution of the principles of the UNCRPD. The WHO states that research and good-quality information on disability are required for providing the basis for

policy and programmes and for cost-effective apportioning of resources. They are also crucial for intensifying apprehension of successful methods to eradicate obstacles, guaranteeing that people with disabilities can contribute to society and participate within society on an equivalent basis. The third objective, furthermore, relates to the Integrated National Disability Strategy (INDS) (1997), which is discussed below as a South African Policy guiding service provision for people with disabilities. The strategy calls for research to advance the rights and participation of people with disabilities in society.

On 27 October 2010, the WHO launched CBR guidelines in the capital of Nigeria, Abuja. Practical suggestions for programme managers on how to strengthen and develop community-based programmes that include people with disabilities and their families are provided by the CBR guidelines. These guidelines provide guidance on how to develop and strengthen CBR programmes by focusing on promoting CBR as a strategy for community-based development through involving disabled people. CBR is a plan of action for social integration for both adults and children with disabilities and to equalise opportunities. It is enforced through the cooperative efforts of persons with disabilities, their families, and representatives of the suitable health, vocational, educational and social sectors and communities. The CBR guidelines strengthen community-based development by incorporating people with disabilities (WHO, 2010).

CBR guidelines additionally support stakeholders to meet the basic needs, enhance the quality of life and encourage the empowerment of disabled people and their families, which links to the second objective of the WHO and Article 20 of the UNCRPD. Assistive technologies, rehabilitation and support services can be provided by CBR programmes in countries that have restricted resources. Moreover, CBR programmes can also serve to empower persons with disabilities and their families, thus easing the burden of care.

Furthermore, the World Stroke Organisation [WSO] engaged with stroke patients and the caregivers across the world and subsequently developed the Global Stroke Bill of Rights (WSO, 2014), which is discussed below.

2.2.4 The Global Stroke Bill of Rights (2014)

The Global Stroke Bill of Rights (2014) serves as a tool for organisations and individuals to confer with governments, in order to render effective health and support services to stroke patients and their caregivers.

The Bill illustrates the most essential aspects concerning rehabilitation for stroke patients and their caregivers and identifies three fundamental rights stroke patients are entitled to. These include the right to receive the best stroke care, the right to be informed and prepared regarding the stroke and the right to be supported in their recovery.

The first right states that stroke patients should receive the best care. This is aligned with Rule 4 of the United Nations Rules on the Equalisation of Opportunities for Persons with Disabilities (UN, 1993), which deals with people with disabilities receiving adequate support services, and Article 25 (UNCRPD, 2006), which emphasises access to high standard of health care for people with disabilities. It can thus be argued that people with disabilities should receive holistic health care treatment and support services for Multi-Disciplinary Teams (MDT). This treatment provided by the MDT should be applicable to the stroke patient and caregivers needs and should be received at all stages of the recovery process both inside and outside of hospital. Moreover, a rapid diagnosis should be executed, which allows the patient access to rapid treatment that should be offered irrespective of culture, gender or financial circumstances.

The absence of stroke diagnosis and the certification of sick leave might obligate the stroke patient to return to the workplace with stroke-associated psychosocial consequences (O'Brien & Wold, 2010; Alaszewski et al., 2007; Hartke, Trierweiler & Bode, 2011). This may have a negative impact on their recovery and could compromise the well-being of the patient causing further setbacks (Gustaffsson & Turpin, 2012).

The second right states that stroke patients should be informed and prepared regarding the impact of the stroke, this is aligned with Article 19 (UNCRPD, 2006), which addresses independent living and inclusion in the community. Stroke patients and their caregivers should be provided with information regarding the signs of stroke and on how the stroke has transpired and how to live with the consequences thereof for as long as the patient requires it (Global Stroke Bill of Rights, 2014). According to Pindus et al. (2018), stroke patients and family caregivers'

sometimes feel marginalised and neglected by health services and lack the skills and knowledge to re-engage with the needed services and/or healthcare providers.

Additionally, these families and stroke patients expressed feelings of frustration and dissatisfaction with a lack of follow-up either from the hospital or connected healthcare professionals. Moreover, they voiced that no information was provided about the stroke that was tailored to their specific needs. Furthermore, they also expressed little or no help from social services. Stroebele et al. (2011) similarly found that warning signs and knowledge amongst stroke patients and their family caregivers of the risk factors of stroke are low in the general population across a variety of countries, with specifically insufficient knowledge in developing countries. These authors further found that stroke patients with pre-existing conditions such as diabetes mellitus or heart disease seemed to be more knowledgeable than stroke patients without pre-existing conditions.

The third right mentioned in the Global Stroke Bill of Rights (2014) states that stroke patients believe that they should be supported in their recovery; this right aligns with Rule 4 (UN, 1993) which speaks to support services. The National Rehabilitation Policy (NRP) (DoH, 2002), which is a South African policy guiding service provision to disabled people states that the plan of action should comprise support programmes and services to ensure community follow-up after discharge.

The Global Stroke Bill of Rights (2014) is in precedence, as the components of care that are important for all caregivers as well as stroke patients from all over the world are acknowledged by these rights. It is a tool that can be utilised by organisations to converse with stroke care providers and governments about what people affected by a stroke perceive are the most important components of rehabilitation. Components within this document have been shown to lessen disability as well as post-stroke death.

In conclusion, the above policies outline international policy documents that guide service provision for people with disabilities, with the focus on stroke patients. The following section presents South African policy and legislation guiding service provision for people with disabilities, with the focus on stroke patients.

2.3 SOUTH AFRICAN POLICY AND LEGISLATION GUIDING SERVICE PROVISION FOR PEOPLE WITH DISABILITIES

The current guiding policies on stroke in South Africa are the Constitution of the Republic of South Africa (Act No. 108 of 1996); the Integrated National Disability Strategy (INDS,1997); the White Paper on Social Welfare (RSA, 1997); the National Rehabilitation Policy (NRP) of SA (DoH, 2000); and the Policy on Disability (DSD, 2013). These policies stipulate objectives for effective rehabilitation services, which include the full participation of people with disabilities in the preparation, supervising and assessment of services rendered. A discussion of these policies follows.

2.3.1 Constitution of Republic of South Africa (Act No. 108 of 1996)

The Constitution of the Republic of South Africa (Act No. 108 of 1996) encourages the full equalisation of opportunities for persons with disabilities; promotes and advances the rights and dignity of persons with disabilities; and promotes their integration into society within a human rights policy framework and a social development approach. Also included is the right to education, healthcare, housing, social assistance, water and a healthy environment. It is moreover acknowledged within The Constitution of the Republic of South Africa that there was discrimination against persons with disabilities. This discrimination was based on their disability and the realisation of justice for them implies reworking past injustice.

Section 9(3) of the Constitution prohibits unfair discrimination on various grounds, including disability. Section 9(4) contains an additional provision, which states that national legislation must be enacted to make unfair discrimination illegal. National legislation in South Africa prohibiting unfair discrimination based on disabilities concern the Promotion of Equality and Prevention of Unfair Discrimination (Act No. 4 of 2000). Section 9(3) and (4) of The Constitution of the Republic of South Africa connects with section 9 in The Promotion of Equality and prevention of Unfair Discrimination which lawfully prohibits unfair discrimination on grounds of disability.

Section 9 of the Promotion of the Equality and Prevention of Unfair Discrimination Act (Act No. 4 of 200) further states that no unfair discrimination may take place against persons with disabilities by means of removing or denying the disabled person any supporting facility contributing to their functioning in society. Moreover, no breach in respect of the code of

practice of the South African Bureau of Standards that regulates environmental accessibility may occur. Additionally, section 9 of the Promotion of Equality and Prevention of Unfair Discrimination Act states that failing to decimate obstacles that unreasonably prevent people with disabilities from enjoying equal opportunities or failing to implement measures to meet the demands of people with disabilities, is a violation of the rights of such people.

Furthermore, section 39(2) of the Constitution of the Republic of South Africa specifies that, in defining legislation, courts are compelled to support the spirit and objectives of the Bill of Rights. The Bill of Rights, as contained in South Africa's constitution, highlights equality and non-discrimination for people with disabilities. Nhlapo, Watermeyer and Schneider (2006) found that, despite the objective of the Bill of Rights, discrimination at ground level is still present. Nhlapo et al. (2006) urge South Africans to develop a strong human rights culture to assist in creating an accessible society that will enable full participation of all citizens, including citizens with a disability.

For an improved human rights culture to be established amongst South Africans, there needs to be a change in attitude to ensure that people with disabilities are not marginalised (Howell et al., 2006). Despite the progress required by the Constitution (RSA, 2006), people with disabilities continue to face several challenges, including stigmatisation and discrimination (Dube, 2011). This phenomenon is not unique to South Africa as similar challenges are faced elsewhere in Africa, and disabled people are thus classified amongst the most vulnerable in society (Khupe, 2010; Zhou, 2015).

The WHO (2011) explains that the lives of persons with disabilities are sometimes handicapped by social and physical barriers within society that have an influence on their right to equality. In South African these rights are said to be defended by the Human Rights Commission, which holds a mandate to secure the rights of all citizens who are disabled and vulnerable to abuse. These rights are protected by the White Paper on an Integrated National Disability Strategy (INDS, 1997) that indicates that the rights of people with disabilities as assimilated in the Constitution of the Republic of South Africa (Act No. 108 of 1996) should be upheld.

2.3.2 Integrated National Disability Strategy (INDS, 1997)

The INDS was released by the Office on the Status of Disabled Persons (OSDP) of South Africa in 1997. The South African government made a commitment to treat disability as a human rights issue in the INDS. The Strategy views a person with a disability as an individual whose potential of securing and retaining applicable employment is considerably decreased as a result of mental or physical impairment. The vision of the INDS thus is “a society for all”.

The rights of people with disabilities are extensively addressed and protected in the Constitution of the Republic of South Africa and are upheld through policies such as the INDS (1997). To uphold these rights, an objective constituted in the OSDP is to promote the development of a disability-friendly environment. The OSDP will work in cooperation with a variety of departments and state bodies in order to develop such an environment while maintaining close working connections with the NGO sector.

The goals of the INDS includes the advancement of a governing body that is integrated and responsible for the planning, monitoring, co-ordination and execution of a variety of line functions at all levels of government and to integrate disability challenges into government developmental strategies, programmes and planning. Setting up a programme of public education and raising awareness intending to alter underlying preconceptions in South Africa is also included, and lastly, to develop a plan of action aimed at capacity building that will improve the Government’s capability at all levels, in order to execute recommendations stipulated in the INDS. The INDS believes in a partnership with persons with a disability. Consequently, the INDS states that their goals can only be met through the engagement of people with disabilities themselves.

According to the INDS (1997), essential monitoring mechanisms should be included in all disability programmes and these should be carried out with proper facilitation and consultation. In South Africa, the Standard Rules on the Equalisation of Opportunities for People with Disabilities (UN, 1993), serve as a guideline for the implementation of national policies as well as the improvement of other significant strategies and programmes within the country like that of the INDS.

The INDS (1997) noted the call for research to advance the rights and participation of people with disabilities in society, as did Watermeyer, Swartz, Lorenzo, Schneider and Priestley (2006), stating a need for research on people with disabilities accessing transport systems, built environments, as well as research that will advance outcome measures to monitor progression on international instruments such as the Standard Rules for the Equalisation of Persons with Disabilities (UN, 1993).

The funding of the INDS as part of the development and restructuring of services for people with disabilities should form a connection with prospective sources of funding and affiliated policies, whether from the public or private sector. In South Africa, shifting to the developmental approach with the intent of reducing poverty and integrating economic as well as social development is patent in the White Paper on Social Welfare (1997). The incorporation of social development goals and economic advancement within a developmental approach to social welfare are sought by these documents. In addition, it informs the reshuffling of social welfare programmes and services both the private and public sector. The White Paper on Social Welfare will be discussed next.

2.3.3 White Paper on Social Welfare (1997)

This policy document outlines social welfare policies and programmes that are responsible for the provision of social relief, cash transfers and enabling developmental services to ensure that persons with a disability have enough social and economic security in the course of unemployment, ill-health, widowhood, maternity, child-rearing, old age and disability. Furthermore, it argues that social welfare services advance non-discrimination, mutual respect, diversity, tolerance and the inclusion of mentally as well as persons with a physical disability (RSA, Ministry for Social Welfare and Population Development, 1997).

In addition, this policy stipulates that social welfare services and programmes must be positioned on respect for human rights and basic freedoms as stipulated in the Constitution of the Republic of South Africa (Act No. 108 of 1996). The social developmental approach is pertinent as it guarantees socioeconomic development and embraces human rights morals. It is thus of vast significance for the social work profession to integrate this approach into its professional engagement.

The White Paper on Social Welfare (1997), inclusive of respective different authors like Green and Nieman (2003), explain that a social development approach targets the continuous advancement of the well-being of the individual, family, community and society. Additionally, the White Paper on Social Welfare (1997) notes that the eradication or reduction of inequality, conditions of underdevelopment and mass poverty are extensively acceptable pointers of social progression positioned on the social development approach.

The way for the betterment of a national social development approach to social welfare policy is paved by the White Paper on Social Welfare (1997), in accordance with the UNCRPD. These two policy documents specify that the approach and strategies enclosed in the White Paper on Social Welfare (1997) will instruct the reorientation of social welfare programmes and services within both the private and public sectors. Moreover, the White Paper on Social Welfare (1997) further outlines that the recognised guidelines and recommendations for developmental social welfare policies and programmes will be executed increasingly.

Irrespective of the fact that the White Paper on Social Welfare (RSA, 1997) distinctly defines the principles of a social development approach and additionally provides guidance for the restructuring of social welfare services. The impression is conveyed that social workers are still experiencing challenges in the execution of the social development approach (Dlangamandla, 2010). Lombard (2014) is of the opinion that these challenges are a result of the social work profession still traditionally connected with social grants and food security. Consequently, it continues to be a challenge to strengthen social development and alter community work to community economic improvement.

It is guaranteed by the Constitution of the Republic of South Africa (Act No.108 of 1996) that all citizens have the right to dignity. This right is perceived as one of its chief values and signifies the integral worth of humanity. The White Paper for Social Welfare (RSA, Ministry for Social Welfare and Population Development, 1997) specifies that social welfare services and programmes will be designed in honour of human rights and fundamental freedom as stipulated in the Constitution of the Republic of South Africa (Act No. 108 of 1996).

The researcher asserts that the South African Social Welfare services are established in the rights-based approach by emphasising minimal living standards, social justice, equal

opportunities and equal access to all social services. Specific focus on persons with disabilities is specified in Section 3 of the White Paper on Social Welfare (1997). It continues to be pertinent that a national coordinated disability strategy will equalise opportunities in all spheres of social life, advance social integration and attend to poverty among people with disabilities, regardless of the document being authored 20 years ago.

It is stated in the White Paper that the Department of Social Development (DSD), in collaboration with other government sectors, would revise the facilitation of access of disabled people to public facilities and national buildings. In addition, public awareness to assist the progress of integration concerning people with disabilities into all spheres of life would be raised by the DSD. A broad scope of opportunities to advance independent living and integration into the community life would be proposed by community-based support services and facilities. Community development as a crucial component of developmental social welfare could provide support to family caregivers of persons with disabilities. Therefore, the importance of community development is stressed by this policy (Department of Social Welfare, 1997).

A Ministerial Committee, whose duty was to critique the enforcement of the White Paper on Social Welfare (1997), was appointed by Bathabile Dlamini, the former Minister of Social Development, in September 2013. This committee was appointed following the 10-year appraisal of the White Paper on Social Welfare, which was in the year 2008. This review identified some challenges to developmental social services. These challenges were in line with government's priorities, in cooperation with its social partners, to orientate social security with socioeconomic programmes, in order to make a sustainable impact on inequality and poverty in South Africa (Lombard, 2008).

The White Paper on Social Welfare (RSA, 1997) noted that the incomplete nature of information led to the inability to evaluate the need for and impact of welfare expense. Additionally, restricted participation by "stakeholders" and citizens in decision-making processes connected to social welfare policies, priorities and programmes, which have resulted in a deficiency of legitimacy of the system, were noted. It was also discovered that the social service delivery system was organised along specialist lines and disconnected amongst various fields of service, which made a holistic approach challenging. Further, while some social workers had community

development skills, the approach was still largely rehabilitative and institutional instead of developmental.

An assessment of an orientation training programme for social workers and other social service workers conducted shortly after the White Paper on Social Welfare (1997) was launched, highlighted challenges that remain persistent. The programme was actuated by the cognisance that existing training prepared practitioners for restorative work and did not equip graduates to react suitably to the most crucial social development needs in South African communities. It was established during the assessment that, while the programme supplied participants with the theory of developmental social welfare, it did not provide them with the ability to implement developmental social welfare.

A reappraisal of budget apportions demonstrated that, within government, social development is considered a low priority at both provincial and national level. Moreover, there is no social development element in the formula for equal sharing, which reports on a major part of provincial budgets at provincial level. The lack of a social development element is an indicator marks this as not being an important area in need of substantive resources. According to the review of the White Paper, this is due to poor information and data about the need for services, in addition to the costs of service delivery. It was further noted that current legislation was not based upon evaluation and planning but rather reflected partial, ad hoc reactions to various needs at various times. Furthermore, it noted the deficiency of adequate policy guidelines concerning the principles and values that ought to underlie welfare services and the degree of government obligation.

The Ministerial Committee found that the White Paper on Social Welfare (RSA, 1997) did not provide clarity on the role of community development. Moreover, it was suggested in the White Paper on Social Welfare that the low level of skills and training amongst people with disabilities was an “important” ground for unemployment within this group. The White Paper further noted that not being able to access the community is a critical challenge facing people with disabilities, though. This pertained particularly to challenges related to buildings, public transport and sport and recreation.

Meetings were held with people with disabilities and Non-Profit Organisations. A range of challenges concerning service delivery were highlighted in these meetings. These included a lack of understanding of the various types of disabilities, each with different needs; challenges in the South African Social Security Agency's (SASSA) disability assessments; confusion around and changes in institutional arrangements and policy development processes; the need for provision and funding of assistive devices alongside personal services; a lack of acknowledgement of the skills required to deliver services to people with disabilities; and poor linkages between DSD and the Departments of Health and Education, which meant that people – particularly children – with disabilities were “falling through the cracks”.

This group made various proposals for amendments to the White Paper. One of the proposals included challenging the assumption that people with disabilities should not be economically active. Ultimately, the group suggested that the revised White Paper consider a separate subdivision on disability.

2.3.4 The National Rehabilitation Policy (NRP) (DoH, 2000)

The National Rehabilitation Policy (DoH, 2000) was created to guarantee the affordability and availability of rehabilitation services to persons with a disability. The NRP (DoH, 2000) states that the plan of action for the prevention of disabilities should entail the prioritisation of family participation, sufficient hospital stays to achieve rehabilitation goals, support and educational programmes and services to secure community follow-up post-discharge.

Nonetheless, a set of norms and standards was amassed in September 2001, which declared that rehabilitation services should provide all patients with a comprehensive assessment followed by a treatment programme tailored to the patient's needs in discussion with the family, as the latter may have to be the programme implementers (Birkhead & Graham, 2005). This is in accordance with the UNCRPD that urges families to be involved in the process of rehabilitation. However, adequate execution of this process relies on the involvement of the families who access the services (UN, 2006).

The primary objective of the NRP is to advance the availability of rehabilitation services in order to facilitate the acknowledgement of each citizen's constitutional right of access to healthcare (DoH, 2000). This objective is linked to the Constitution of Republic of South Africa (Act No:

108 of 1996), which advances and promotes the rights and dignity of people with disabilities and encourages their integration into society within a social development approach and human rights policy framework which also includes the right to healthcare. Additionally, this objective links to the Standard Rules of the Equalisation of Persons with Disabilities (UN, 1993), which encourages governments to engage in actions that will attain the equalisation of opportunities for persons with a disability. In addition, Section 26 of the UNCRPD urges that effective measures should be implemented in rehabilitation and habilitation services to empower persons with a disability to achieve maximum independence.

2.3.5 Policy on Disability (DSD, 2013)

The Policy on Disability (DSD, 2013) is intended to support the department's accomplishment of the improvement of integrated developmental services for persons with disabilities and parents of children with a disability. Additionally, it focuses on public awareness of the challenges and stereotypes and facilitates the removal of deceiving insights on disability. A social development approach to service delivery to persons with a disability is adopted by this policy. It was established through an enlightening multi-disciplinary procedure incorporating all stakeholders that render services in divisions within the constitution that particularly focus on disability.

The policy drew on and is in alignment with INDS (1997) and international and continent-broad instruments that focus on addressing disability from a social development approach, for instance, the UN Standard Rules on the Equalisation of Opportunities for People with Disabilities, the UNCRPD, and the principles and policy objectives of the White Paper on Social Welfare (RSA, 1997).

Moreover, an opportunity for the development of rehabilitation services at all levels of healthcare service is established by this policy. It conceptualises rehabilitation as both a community-based and a facility service. Rehabilitation aims to facilitate smooth reintegration of the patient into the home environment and for the patient to attain an optimum level of independence. As a result, the burden of care on the family caregivers would be lessened. According to this policy, a patient who had a stroke should begin with rehabilitation at the point of admission into the healthcare system. Afterwards, rehabilitation must continue along a continuum of care before the patient is

reintegrated back into the home and into the community environment (DoH, Western Cape Province, 2007).

This policy links to section 3 of The White Paper for Social Welfare (RSA, Ministry for Social Welfare and Population Development, 1997) where the focus is placed on people with disabilities. It is stipulated in this section that community-based support services will provide persons and their families with a variety of options to advance independent living as well as reintegration into the home. Significance is placed on community development, which is a significant component of developmental social welfare and may correspondingly provide assistance to family caregivers of persons with physical disabilities (Department of Social Welfare, 1997).

2.4 CHALLENGES IN SERVICE DELIVERY

There are pointers indicating that social workers are facing challenges in the execution of their role of referring vulnerable families to a range of services, which encompasses social security. Several opportunities to build connections amid social security and other services are therefore lost. Nevertheless, as stated earlier, the Social Assistance Act (Act 13 of 2004) does not address disability, although it necessitates that the disability is confirmed by a Medical Officer who stipulates it on a medical report. (Global Social Service Workforce Alliance, 2015).

The South African Revenue Service (SARS) is of assistance to people with disabilities as well as their families by permitting them to claim 33.3% of the qualifying out-of-pocket medicinal and disability-related costs paid throughout the applicable year of assessment. Any taxpayer who has a disability or whose child or spouse has a disability as set out in the criteria in the ITR-DD form, which is a form to confirm diagnosis of disability, qualifies for these claims (SARS, 2010a). With respect to the above-mentioned benefits, Smith, Lawrence, Kerr, Langhorne and Lees (2004) have reported that the services of a third party, normally a social worker or a Citizens Advice Bureau representative, are often required in Scotland to make sure that applicants receive the benefits to which they are entitled.

People with disabilities are also in need of assistive devices, as this reduces the burden on the families and makes adjustment to the community easier (WHO, 2015). Those assistive devices may include walking sticks, wheelchairs and hearing aids. It was, however, reported that the assistive aid that was used by persons over the age of five was mostly eyeglasses (Statistics South Africa, 2014). Eyeglasses were used by 214% of this population group in South Africa and by 2,8% in the Western Cape. Other assistive devices, for instance wheelchairs and walking sticks, were only used by 2% to 3% of the population group in South Africa, including the Western Cape (Muller-Kluits, 2018).

Although some progress has been made concerning the provision of assistive devices, less has been made with regard to such assistive services. One of the reasons for this is the recurrent, and greater, cost attached to assistive services (White Paper on Social Welfare (1997). Moreover, the inability of health professionals to interact with family caregivers during the in-patient hospital period following a stroke can also be attributed to a lack of funding of the healthcare sector. The funding cuts to healthcare are decreasing the time healthcare professionals have to interact with the families (Cameron & Gignac, 2008).

Access to services and social spaces such as restaurants are sometimes hindered physically, particularly for people who are wheelchair bound (Chiwandire & Vincent, 2017). This in spite of Article 9 on Accessibility of the 2006 UNCRPD imposing obligations on signatory countries to increase accessibility for wheelchair users. Correspondingly, Rule 4 on The Standard Rules on Equalisation of Opportunities (UN, 1993) stipulates that states should ensure the development and supply of support services, including assistive devices for persons with disabilities, to assist them to increase their level of independence in daily living and to exercise their rights.

Various authors found that wheelchair users at South African universities expressed concerns regarding the inaccessibility of some campus buildings, including facilities like toilets (Losinsky, Levi, Saffey & Jelsma, 2003; Matshediso, 2010; Chimwandire & Vincent, 2017). As a result, social workers have to play a role in carrying out research in order to document gaps, suggest answers and advocate for persons with disabilities from an informed viewpoint of the goal of empowerment and assisting persons with disabilities to fully participate in all aspects of society.

2.5 CHALLENGES FOR FAMILY CAREGIVERS OF A STROKE PATIENT

The experience of a stroke by a relative includes uncertainty about the future for families (Nordin, Sunnerhagen, & Axelsson, 2015). The family's belief system, including their fears and aspirations for the future, are exposed due to this occurrence. It is further indicated by Nordin et al (2015) that families reported that they experience continuous adjustment after their family member's stroke and they often fear what the future might hold. Hassan (2009) supports this view and mentions that caregivers experienced their daily duties as a great strain and as overwhelming.

Cameron, Naglie, Silver and Gignac (2013) and King and Semik (2006) explored the strain that family caregivers of stroke patients undergo. These authors found that the most strain is undergone during the acute hospital phase and during the early transitional period back home. In some instances, this strain was provoked by no or ineffective stroke information, no or poor training of family caregivers, a lack of follow-up services post-stroke, no home visits and poor healthcare services. Hassan (2009) further mentions that the period after discharge was perceived by family caregivers as the most challenging period when they needed the most support.

2.5.1 Strain experience during the transition period of the stroke patient once home

The prominence of transitioning from the acute hospital phase to being discharged home to the family as caregivers has traditionally been undervalued and as a result, under investigated to a serious extent (Coleman, Mahoney & Parry, 2005). Consequently, in spite of its importance, there is little known about the transitioning phase and what emerges after the patient has been discharged from hospital (Rittman & Van Puymbroeck, 2005). The family caregiver needs to determine how to adjust to the abrupt necessities of the stroke patient throughout this phase.

The unexpected and rapid adjustment of becoming a family caregiver for a stroke patient can be physically challenging, thus a very distressing experience (Cameron, Cheung, Streiner, Coyte & Stewart, 2006). Caregivers are often confused about the condition of the patient, the nature of the available support and their new role (Hassan, 2009). It would be expected that family caregivers would receive adequate preparation from healthcare professionals or discharge facilities in order to fulfil all these obligations. Moreover, should the patient have additional medical conditions, such as Aphasia, there may be additional needs which result in increased caregiving strain. Barnes (2016) describes Aphasia as a language disorder that influences a person's capability to

use language efficiently in all modalities. A discussion on the increased strain on family caregiving to stroke patients who have Aphasia follows below.

2.5.2 Increased strain on family caregiving with stroke patients who have Aphasia

A review of the accessible literature on the strain experienced by caregivers of stroke patients and the relationship between Aphasia and caregiver strain was conducted by Manning, MacFarlane, Hickey and Franklin (2019). Manning et al (2019) conducted a systematic appraisal, following Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines, and thematic analysis. Following an investigation of 7 electronic databases, 31 articles were enclosed and critically reviewed utilising predetermined criteria to determine all publicised peer-reviewed literature, which analysed the affiliation between the family caregiver's burden of strain and caring for stroke patients with or without Aphasia. The study concluded that the loss or limitation to communicate was disheartening to both the stroke patient and family caregiver and could consequently result in misery and negatively affect the social functioning of the patient. Due to inability to socially engage, additional strain is placed on the caregiver as patients become increasingly confined (Geiger, 2012; Mathye & Eksteen, 2015).

Draper and Brocklehurst (2007) further suggest that family caregivers may be required to perform a wide range of roles for stroke patients with Aphasia, since the stroke patient cannot communicate easily with others, which leads to an increase in the already high burden of care. Thompson and Ryan (2009) and Ch'Ng et al. (2008) found that language impairments create a lack of understanding, hinder a person's expression of feelings, increase emotional distance between patient and spouse and interfere with intimate activities. This therefore negatively impacts the quality of life of the stroke patient and increases risk of depression (Hilari et al., 2010; Hilari & Byng, 2009).

According to the literature, family caregivers are not prepared to deal with the sudden onset of Aphasia, which results in increased strain, anger, resentment and caregiving burnout, as well as interpersonal relationship changes, e.g. for marital quality of life (Avent et al., 2005; Howe et al., 2012). The emotional distress and burden caused by stroke patients with Aphasia not having the ability to take care of them and in this way completely dependent on the family caregiver, is also emphasised by Masuku, Mophoso and Tshabalala (2018).

2.5.3 The lack of preparation for caregiving duties

Family caregivers lack preparation for their caregiving duties and provide care to stroke patients with little or no support (Avent et al., 2005; Dawson, 2011; Howe et al., 2012). Dias et al. (2019) further indicate that patients return to homes where there is poor infrastructure and lack of equipment to meet the specific need of the patient. Cameron et al. (2013) and King and Semik (2006) are in agreement that family caregivers are overwhelmed by their caregiving duties. This lack of preparedness is sometimes aggravated by a loss of income, poor healthcare service delivery at the time of the stroke, no or inadequate explanation of stroke, poor or no training of caregivers, no home visits and a lack of follow-up services in the community (Hassan, 2009).

Hassan (2009) goes on to report that primary givers of patients admitted to the Western Cape Rehabilitation Centre perceived their caregiving duties to be overwhelming and strenuous. Family caregivers may also undergo different emotions once they are faced with significant changes, which stem from their relative having impairment; in addition to the lack of preparation for caregiving duties (Ross & Deverell, 2010). These family members are precipitously expected to take on a caregiving role in the recovery of their relative's condition, with little or no assistance (Coleman & Berenson, 2004; The National Academies Press, 2016). The sudden nature of the stroke does not allow for a steady transition period for caregivers to adapt to their new role as would be the case for a person with chronic conditions (Ross & Deverell, 2010).

2.5.4 Loss of income

Kochi et al. (2005) found that stroke patient's experiences challenge returning to work due to depression, and cognitive challenges related to thought processing. Family caregivers of stroke patients experience financial stress, specifically under circumstances where the stroke patient was the primary wage earner, or if they have to alter their work hours by reducing them or terminate employment, in order to take on the caregiving role (Anderson, Linto & Stewart-Wynne, 1995; White, Lauzon, Yaffe, Wood-Dauphinee; Trollope, 2013; Hartley et al., 2011). The loss of income will result in poverty, particularly if the person with the disability was the breadwinner as the caregiving role will not permit the caregiver to be employed (Cordier, 2014; Makiwane & Berry, 2013)

It is similarly reported by Hassan (2009) and Collins, Swartz, College and Jefferson (2011) that, some family caregivers are required to change their work schedules in order to accommodate

their relatives and meet their caregiving duties. This has led to financial difficulties such as a loss of benefits or reduction in savings. It has been found in a large-scale longitudinal study surveying 9,857 mid-aged women in 2001 and 2004 that those providing care for someone ill or disabled had decreased participation in paid employment (Berecki et al., 2008).

2.5.5 Impact on spouse relationship

Kon (2011) conducted a study on the marital relationship after a stroke and found that spouses of stroke patients underwent a dramatic change in their relationship after their partner's stroke. Kon (2011) reported that females explained that their husband's traditional role and reflexive nature of the relationship influenced the quality of their relationship as a whole. Wives of stroke patients stated that their partners showed loss of motivation to take part in their own recovery. They also felt less like a wife and more like a mother to their husband. The loss of equality, balance and a shared burden within the relationship was mourned. Forsberg-Wärleby, Möller and Blomstrand (2004); Simon, Kumar and Kendrick (2009); White, Lauzon, Yaffe and Wood-Dauphinee (2004); and Visser-Meily, Van Heugten, Pos, Schepers and Lindeman (2005) similarly indicated that caregivers of spouses with a stroke reported deterioration in the quality of the spousal relationship. White et al. (2004) moreover found that spouses of stroke patients experienced a loss of companionship and support from the stroke patient.

Changes within communication patterns, especially with stroke patients that have Aphasia, negatively impacted their marital life, because of communication difficulties, the loss of independence and the loss of self-efficacy and self-identity due to restructuring their lives around a spouse and fulfilling caregiving duties (Avent et al., 2005; Howe et al., 2012; Cao et al., 2010; Green and King, 2010; Green & King, 2009; Pierce, Thompson, Govoni & Steiner, 2012).

2.6 THE NEEDS OF THE FAMILY CAREGIVER OF A STROKE RELATIVE

The family member who is taking on the caregiving role is often challenged with various feelings, which include anger, anxiety, guilt and depression. These feelings may arise as a result of the post-stroke impairments (Thomas & Greenop, 2008). Due to the demanding nature of caregiving, caregivers have several needs. These needs come from how they experience their new role as caregivers. Caregiving needs were identified by the researcher and are discussed below.

2.6.1 Need for information on stroke care

The need for information on stroke care is amongst the greatest commonly recognised needs, having the uppermost precedence amid family caregivers, as reported by Huang, Min, Yao, Guo and Zheng (2008) and Mak, Mackenzie and Lui (2007). Clarke, Hanson and Ross (2003) argue that basic knowledge of stroke care should be offered to family caregivers and that family caregivers should have basic knowledge of practical skills in physical caregiving. Further, information regarding the prevention of stroke recurrence, the protection of stroke patients from physical injuries due to a possible fall and accessible support services must be made available to family caregivers, as this is considered to be essential information.

According to Khondonwe and Mpofu (2007), informal caregivers of stroke patients in receipt of out-patient physiotherapy expressed a lack of information, the requirement for skills training, home-based services and financial support. Caregivers moreover suggested that information of this nature improved support from their physician and community nursing and social services. Information related to these services may also be useful when seeking respite care.

It has also been reported that many stroke patients are discharged from the acute hospital to proceed with rehabilitation in their homes. Hence, family caregivers require information with regard to community-based care as opposed to an institution-based approach to treatment (Khondonwe & Mpofu, 2007). Pierce, Steiner, Khuder, Govoni, Horn (2009) found that poor communication and inadequate information sharing on stroke care in post-discharge settings and some hospitals have been recognised as major areas of dissatisfaction by family caregivers. In addition to poor communication, the availability of further community support and vagueness regarding timeframe of counselling regarding stroke caused further dissatisfaction among family caregivers. Consequently, repetitive questions are asked by stroke patients and family caregivers as a way of searching for the information they require (Manning et al., 2019).

2.6.2 Need for respite care

Cohen (1982:6) describes respite care as “temporary care given to a disabled individual for the purpose of providing an interval of relief to the individual’s primary caregivers”. According to the Respite Care Association of Wisconsin (2010), respite care is temporary relief for family caregivers who are caring for people with a disability or other terminal or chronic conditions.

Respite care could be for at least a month in order to relieve the family caregiver of caretaking responsibilities (Hassan, 2009).

Family caregivers in Pakistan and in Butterworth, Durban, expressed the need for respite care in the form of more leisure time and verbalised feelings of isolation due to 24-hour caregiving duties (Dingana, 2012; Qayyum, Lasi & Rafique, 2013). Nonetheless, Goodhead and McDonald (2007) found that family caregivers frequently were not aware of the availability of respite care, which resulted in family caregivers feeling unassisted.

Kim, Chang, Rose and Kim (2012) go on to argue that patients need to be re-examined during respite care for any additional rehabilitation needs and receive treatment accordingly in the event that additional rehabilitation should be received in the form of assistance with demands of daily living, such as feeding, grooming and monitoring medicine. Thrush and Hyder (2014) add that this additional rehabilitation will decrease the caregiving burden. However, respite services are sometimes already overburdened and lacking (Hassan, 2009).

2.6.3 Need for support from family and friends

Family support can be viewed as the relationship amongst individuals where contact is regular through individual communication, letters and phone calls (DeGenova & Rice, 2002). Taanila, Syrjälä, Kokkonen and Järvelin (2002) remark that support from friends and family is considered as crucial for family caregivers in order to manage their daily lives. Moreover, these authors found that during a six-month rehabilitation period, the role of family support is vital.

According to Sumathipala, Radcliffe, Sadler, Wolfe and McKeivitt (2012), stroke patients view support from family and friends as a vital enabler of functioning. The support provided by family members was favoured over formal service provision concerning regular activities. Wolff and Boyd (2015) reported that families desire the involvement of friends and family when it comes to decision making processes and to assist with the activities of daily living. Taanila et al. (2002) similarly discovered that practical, economic well-being and depression were affected by the extent of support provided by the family. These needs speak to the need for psychosocial support required by families and caregivers in order to adequately execute their new role.

2.6.4 Need for psychosocial support

The International Federation of Red Cross and Red Crescent (IFRC) Societies for Psychosocial Support (2009) describe psychosocial support as a process which promotes resiliency within individuals, families and communities. Moreover, the description adds that psychosocial support improves social cohesiveness through respecting the dignity, coping mechanisms and independence of individuals. The aim of psychosocial support is to assist individuals to retrieve their strength after a disruptive life event, and to improve their capability to return to a normal state of mind after undergoing stressful events (IFRC, 2009).

Danzl, Hunter and Campbell (2013) investigated stroke patients in rural Appalachian Kentucky. All participants in this study expressed a need for a local peer support group that offers psychosocial support. Both stroke patients and their caregivers in this study were unfamiliar with any existing local support groups but were equally interested in them. Collins et al. (2011) state that caregiving is linked to psychological burden for caregivers; hence the need for psychosocial support.

Hankey (2004) states that family caregivers intend to meet the needs of the stroke patient while at the same time adjusting socially, emotionally and vocationally to the sudden change in their own lifestyle. Family caregivers need to be psychologically sound, motivated, adequately informed, trained, and skilled for them to cope with the daily duties of caregiving. Shortfalls in receiving psychosocial support in any of these areas can result in caregiver strain or burnout.

It is stated by Morris and Morris (2012) that peer support groups for stroke patients and their caregivers post-stroke are unique and valuable since the shared experiences empower peers to understand others and permit the provision and receipt of related affirmative, emotional and informational support. Parker, Mills and Abbey (2008) support this statement by stating that support groups for family caregivers are proved to be valuable since those who are providing support relish it, feel a sense of personal development from offering it, and feel they are making a difference in someone else's life.

2.6.5 The need for financial assistance

Studies have stressed the impact of stroke on return to employment (Maleka, Stewart & Hale, 2012; Rhoda, Cunningham, Azaria, & Urimubenshi, 2015) and consequent financial difficulties.

This results in reduced access to resources, hence the need for financial assistance. Maleka et al. (2012) found that the majority of stroke patients wish to return to work, while others intend to apply for financial assistance by means of a government disability grant. Similarly, Dayapoglu and Tan (2010); Daniel, Wolfe, Busch and Mckevitt (2009); and Coombs (2007) found that stroke patients need financial assistance due to failure to return to work or former engagements through which they made a living. Daniel et al. (2009) support this argument by stating that post-stroke depression affects the stroke patient's ability to return to work, which results in increased need for financial assistance.

2.7 CONCLUSION

It can be concluded from the policies and legislation discussed above that there has been global advancement in legislation concerning the rights of people with disabilities. Nevertheless, the execution of these policies and legislation by relevant bodies tends to be doubtful. There are ample reviews and discussions which state that people with disabilities are still excluded from services in the community and are denied enjoyment of the same rights as those without disabilities by virtue of a variety of impediments. Thus, policy and legislation indeed ensure that equal opportunities should be enjoyed by all people with disabilities but remain questionable.

Additionally, access to community support services and stroke information has also been proven to be insufficient. A significant burden is generally placed on family caregivers who are required to assist the stroke patient through the recovery process. Aspects that compose effective interventions for family caregivers, particularly in relation to dealing with affective symptoms, however, continue to be evasive. Moreover, significant dissatisfaction with available support services is also experienced by family caregivers due to their needs, which are frequently disregarded.

It appears that little attention and few resources have been provided to shift rehabilitation services from policy to practice. It can be reasoned that not just advanced disability legislation is required but also for such policy and legislation to be implemented and enforced.

CHAPTER 3

SOCIAL WORK SERVICES TO FAMILIES CARING FOR A FAMILY MEMBER WHO SUFFERED A STROKE

3. INTRODUCTION

In the previous chapter policy and legislation with regard to stroke patients and the challenges and needs families experience in caring for the family member when they return home were discussed. In this chapter, the focus is on social work services rendered to families caring for a relative affected by a stroke from an ecological perspective. This relates to the second objective of this study. The ecological perspective, which views families as social environments, recognises three levels of a person's social environment, which are the micro, meso and macro levels of interaction (Visser, 2007). The social work services rendered to family caregivers are discussed under each of these levels.

The importance of social work services can be determined from the fact that they aim to improve human relationships. The social work services that are specifically aimed at catering for families who are caring for a family member suffering from stroke provides for the ways in which such families can be protected. Further, it is also crucial to provide such families with services that promote their mental and emotional well-being while managing the family members who suffer from stroke. The ecological perspective discussed this chapter highlights the impact that the environment and family caregivers have on one another. Along with this, this chapter also provides a discussion on some of the key concepts of the ecological perspective, which includes person-environment fit, habitat and niche, and the use of an eco-map.

3.1 THE ECOLOGICAL PERSPECTIVE

As discussed in Chapter 2, various legislative and policy documents describe a change in how people with disabilities are viewed and suggest that social work intervention should take on a social model and not only a medical model. This comes amid an increased call for people living with disabilities to be included in mainstream society and forms the basis for the ecological perspective being chosen as the theoretical framework for this study (Ross & Deverell, 2010).

The ecological perspective is based on Bronfenbrenner's (1979) ecological systems theory. It views the individual within a specific context and places emphasis on the impact that the individual and the environment have on one another. Moreover, it outlines a holistic framework within which to locate the various elements of people's lives and the connectedness between them (Jack, 2010). Within the ecological perspective, the holistic experiences of family caregivers as well as stroke patients are presumed to be a combination of multiple levels of influence, with small changes in one having the potential to bring forth significant influence on other systems (Ross & Deverell, 2010). These elements, which are interrelated with one another, are recognised as the micro, meso and macro levels of intervention (Jack, 2012).

Aquirre (2018) indicates that a key assumption of the ecological perspective is that the levels do not exist in isolation. Instead, elements across levels influence each other. For instance, the lack of public transport can influence access to social work counselling services. Jack (2012) argues that the desegregation of these different levels allows an in-depth understanding of family caregivers as well as stroke patients in the environmental context in which they live. Social workers should therefore be cognisant that challenges experienced by family caregivers of stroke patients are consequences of a combination of factors. It should thus aid social workers to understand the way the various elements of family life interact jointly to shape circumstances and behaviour.

Donoghue and Maidment (2005) state that the ecological perspective helps social workers to construct their intervention to the requirements of the person, the environment and the interaction between the two. In addition, Gitterman and Germain (2008) point out that the utilisation of the ecological perspective indicates that social workers should improve the level of fit between stroke patients and their environment by advancing their abilities and manipulating their environment for transaction to support development. Makhanye and Carmel (2018) argues that, by utilising the ecological perspective, the purpose of social work services would be to improve the level of fit between the stroke patient and the environment by advancing their abilities and influencing the environment so that group action will promote growth.

Elliot and Pezent (2008) argue that it is highly unlikely that an institution or service provider can sufficiently address the needs of family caregivers, as these needs are evolving, dynamic and fluid. The changes include psychological, physical, social and financial aspects. It is therefore

crucial that service delivery to family caregivers is rendered at the three levels of the ecological perspective, namely the micro, meso and macro level, in order to address needs effectively and holistically. Elliot and Prezent (2008) further highlight various elements of the ecological perspective relevant to service delivery to family members caring for a stroke patient. These elements include the person-environment fit, habitat and niche, structure and eco-map, which enable a foundation for the ecological perspective pertinent to understanding the mutual interaction between stroke patients and their environment (Hepworth et al., 2017). Each of the concepts mentioned above is discussed next in relation to family caregivers of stroke patients, on a macro, meso and micro level of intervention.

3.1.1 Concepts of the ecological perspective

The concepts of the ecological perspective deal with the interaction between the environment and the person. These concepts encourage social workers to look at the environment surrounding a person or group when attempting to provide support. The social worker's approach that underpins the ecological perspective respects the interaction and further aims to provide maximum benefit out of the interaction without causing any kind of negative impact (Elliot & Prezent, 2008). Three of the key elements of the above-mentioned ecological perspective, namely, person-environment fit, habitat and niche, and eco-map will be discussed in relation to the needs of the family caregivers of a stroke patient.

3.1.1.1 Person: Environment fit of the family caregiver of a stroke patient

Gitterman (1996), in Donoghue and Maidment (2005), and DuBois and Miley (2016) indicate that the level of environmental fit is concerned with the level of interchange and balance amongst the person's abilities, aspirations, needs and resources available in the environments. Pulla & Kay (2017) states that a great fit between what the client wants, what his or her strong qualities are and what assets are accessible within his or her environment, is imperative for successful goal achievement. Both the environment and the person undergo change, as one gives and the other one takes and vice versa. Mutual adaptation happens when people develop through change and the environment assists the change.

To develop a more holistic approach to address the needs of the environment fit of the family caregiver of a stroke patient and to provide an environment that best supports these needs, a range of political, public, and personal limitations must be overcome. For instance, assistive devices, toilet seats, lifts and tub seats are commonly more invasive than structural modifications to the home that might provide better performance and more space (The National Research Council, 2010).

3.1.1.2 Habitat and niche of the family caregiver of a stroke patient

Habitat and niche assist the social worker to understand the influence that the environment has on the caregiver of a stroke patient (Hepworth, Rooney, Rooney & Strom-Gottfried, 2013; Hepworth, et al., 2017). Habitat refers to the location where stroke patient and caregiver live and recognises the social and physical settings within specific cultural contexts. When habitats are affluent and within reach of the resources needed for development, people are inclined to thrive. However, when habitats are poor in important resources, emotional, social and physical advancement may be unfavourably affected. This indicates that stroke patients who have supportive networks of relatives, friends or organisations might experience lesser negative effects of stroke (Makganye, 2015). The caregivers also benefit from a poor habitat as they are able to gain insight into the situation with the stroke patient and social workers are able to provide the family caregivers with social work services after assessing the influence that the environment has on the family caregivers.

Niche refers to the role or status of the stroke patient and caregiver within the community (Hepworth et al., 2017). The authors further state that people need to find their niche in the society, in order to gain self-respect and a stable sense of identity. Donoghue and Maidment (2005) argue that niche can be enabling or entrapping. An enabling niche offers support and resources that enable social connectivity, social belonging and social mobility, whereas an entrapping niche is present where persons are marginalised without resources and little potential of belonging or social mobility. Both niche and habitat are crucial for ensuring the best medical treatment for the patient. A niche on one hand ensures the provision of the best status while habitat on the other hand aims to provide a positive environment. The habitat and niche of the patient has a direct impact on the family caregivers. The poor habitat of the patient prevents the

family caregivers providing proper care to the patient due to various issues like a communication gap and ethical barriers.

Niche and habitat links to the rules and articles of the UNCRPD discussed in Chapter 2, in stating that persons with disabilities should have personal mobility. This includes (1) providing stroke patients with assistive devices which aid in optimal independence; (2) support groups and counselling programmes in order to help families cope, since families live within cultures that express negative views regarding disability; (3) undertake measures to provide access to information and communication regarding caring for the stroke patient; (4) making caregivers aware of which social security benefits they are entitled to while providing care for the stroke patient; and (5) promoting full participation of the stroke patient within family life.

Additionally, the Policy on Disability (DSD, 2013) in this respect is an optimum step of the South African government in raising public awareness of challenges and stereotypes, and facilitating the removal of mendacious perceptions of disability, such as believing in witchcraft or that spells were cast for someone to have a disability. This policy serves as a foundation to ensure social mobility and belonging.

An important role of the social worker is to assess the personal networks of the stroke patient and the family. The eco-map is an instrument that can be utilised to assess these networks (Bennett & Grant, 2016). Social workers utilise an eco-map, which is a paper-and-pencil activity to depict the family caregivers' descriptions of their supportive and non-supportive relationships. This activity also includes the family's description of their family structure and social networks.

Authors stipulate that the eco-map is a visual means of facilitating discussions around the structure and strengths of networks (Ray & Street, 2005). It is an effective instrument which aids communication with people across a broad range of abilities and ages, assisting to visually recognise some of the strengths and weaknesses that exist within a person's network (Hepworth et al., 2013). The eco-map can be further used for adult education and human resources development to provide care to stroke patients.

Donoghue and Maidment (2005), Johnson and Yanca (2010) and Hepworth et al. (2017) further mention that the eco-map is a useful tool for a social worker to identify applicable factors outside the family's context. The eco-map will aid in clarifying the stresses and support in the family's

environment by indicating patterns such as unresponsive social networks or social isolation. This forms a crucial part of the meso level of intervention where it works on improving social work services to the patients to the maximum extent possible. The meso level services are discussed later.

For intervention purposes, awareness of the extent and nature of the social network of the family is helpful and will guide who must be included in social work services, for example, in family conferences. Mapping supportive networks can identify actual and potential sources of nurture (Ray & Street, 2005). The use of the eco-map during discharge planning will permit social workers to provide stroke patients with holistic, wrap-around services upon discharge. By using the eco-map, the social worker may better address the psychosocial needs of both the stroke patient and family caregiver upon discharge by working with the family caregiver and stroke patient, as well as community organisations (Miller, Fields, Adorno & Smith-Osborne, 2016).

3.2 SOCIAL WORK SERVICES TO FAMILY CAREGIVERS CARING FOR A RELATIVE WHO SUFFERED A STROKE ON THE MICRO, MESO AND MACRO LEVEL

Social workers provide various services to family caregivers so that they can provide proper care to the stroke patients. The services are provided at different levels, namely the micro, meso and macro level. The social workers enable family caregivers to access the needed resources through interventions such as advocacy, guidance and referrals that assist the family (Dorset, 2010). Various needs expressed by the family would be attended to when social workers provide information, as social workers would link families to support groups, refer families to available services, for instance respite services, and also provide guidance regarding the application process for financial aid such as a Care Dependent- or Disability Grant.

Blanes, Carmagnani and Ferreira (2007) state that family caregivers who received of support were more satisfied with their lives than those who did not receive assistance. Rosell-Murphy et al. (2014) and the International Conference on Intelligent and Advanced Systems (ICIAS) research group (2014) have indicated that strengthening the family caregiver's support advances quality of life and lessens the caregiving burden. Thus, it is pertinent to converse about social work services with family caregivers at various levels of the ecological perspective. The

ecological perspective will help the social service workers to ensure that there is positive interaction between the individuals and the environment where the main focus is on the aspect of accessing the needs of the patient and family caregivers.

3.2.1 Micro level

The micro level is concerned with the individual and includes attitudes, knowledge, values, self-esteem, self-concept, skills and behaviour (Miley & DuBois, 2010). On a micro level, the individuals are being dealt with as a client system. Bronfenbrenner (1979), Segal, Gerdes and Steiner (2010) and Hepworth et al. (2017) stipulate that the micro level includes relationships between the individual and the immediate environment that surrounds him, such as the workplace, school or home. These authors further elaborate that interventions on this level mainly focus on the family and caregivers, or on the stroke patients themselves. For family caregivers of stroke patients, the microsystem includes spouses, very close friends or extended family members. Wolf and Boyd (2015) say that the significance of support from friends and family is regarded as critical to family caregivers when it comes to the decision-making process and to manage their daily lives at micro level. Services rendered by social workers on a micro level are discussed below.

3.2.1.1 Counselling services

At micro level social workers render counselling services to family members to enable adjustment to the change and disability, inter alia by focusing on a variety of challenges of an interpersonal and personal nature. The aim of such services is to ensure that social workers provide the family with counselling, where required, while assisting in understanding of the nature of the disability, to assist the person with a disability and to improve the capability of family caregivers (Chitereka, 2014).

However, each party might have contrasting expectations about the services of social workers and trust can only evolve amongst the social worker and family if distinct objectives and obligations are agreed upon. Nevertheless, a lack of trust can lead to difficult relationships amongst family caregivers and professionals that give rise to distrust and conflict that result in depression, which many family caregivers of people with disabilities are suffering from (Russell, 2007).

Carlson (2014) states that social workers can provide individual and family counselling. According to Leshilo (2004), persons with physical disabilities in South Africa are being aided initially by professionals through counselling, with the use of peers with a similar disability. Peer counselling forms part of the meso level of social work intervention, which is discussed below. Furthermore, Strydom (2015) and Chitereka (2014) found that counselling provided by social workers to enable adjustment to the disability should involve the family in order to assist them to understand the nature of disability, to aid the disabled person and to advance the capability of caregivers.

According to Loupis (2013), social workers can assist family caregivers to adjust to the new role, by providing counselling and preparing them for the discharge of the stroke patient, in order to ensure a more supportive return to everyday life. Caregivers seemingly recognise their difficulties and uncertain future and the readjustment of their home lives (Grant, Elliott, Giger, & Bartolucci, 2001; Ski & O'Connell, 2007) and therefore need the counselling and support services of social workers (Loupis, 2013). This can also be supported with the provision of stroke related information and other written resources (Bråndal, Eriksson, Wester & LOundin-Olsson, 2016).

3.2.1.2 Practical support

According to Forster et al. (2001) and Bhogal, Teasell, Foley & Speechley (2003), family caregivers can be provided with supporting information from social workers about the management of daily problems such as post-stroke fatigue, prioritisation of activities, physical activity and administering medication. Additionally, telephonic guidance by social workers to family caregivers can be useful as it supports the well-being of family caregivers and provides guidance for their daily activities, thus reducing feelings of anxiety about a doubtful future for the stroke patient and their family (Carlson, 2014).

Multi-disciplinary teams, according to MacIsaac, Harrison, Buchanan, Hopman (2011) and Bråndal et al. (2016) which involve social workers are important support systems for family caregivers, particularly if the social worker assists with the development of the discharge plan. It is particularly important for the needs of the family caregivers to be adequately addressed (Breteon et al., 2002).

It is clear from the above discussion that services to families, on the micro level of the ecological perspective, should focus on a multidisciplinary approach where information is given, but that the role of the social worker should focus on determining the needs of the family and enable the family through individual and family counselling to adapt to their new circumstances.

3.2.2 Meso level

The meso level can be defined as a set of micro systems which are interlinked with one another. On a meso level, support systems such as family members, friends, school or work and social networks interact with one another (Miley & DuBois, 2010; Donald, 1997). Bronfenbrenner and Morris (2006) and Connor (2011) state that the meso level is connected to the functioning of the family. Fouché (2005) state that social work interventions on this level are intended to help families to discover improved connectedness amongst the family and its environment. Hepworth et al. (2013) state that social workers must explore the family's social support, considering attention to size and composition of the family's types of available support, social network, obstacles, and strengths to sharing and engaging with others. Hepworth et al. (2017) declared that social work services aim to address issues that negatively influence interaction and family relationships on a meso level. This includes addressing the mental wellbeing of family caregivers and the patients themselves (Engstrom, 2012). The types of services that should be available to families with a stroke relative are discussed below.

3.2.2.1 Peer counselling

According to Hlongwane (2005), peer counselling is seen as a crucial tool for facilitating change in the attitudes of persons with disabilities. Nozawaa, Ikegama, Michii, Suganoa, Ando, Kitamura and Ogami (2019) stipulate that peer counselling is a consultation-support approach where people in comparable statistic positions commonly listen to an individual's difficulties, show support, and provide solutions. Numerous professionals involved with rehabilitation make use of former patients who share their experiences with new patients with great success. This becomes a potential source of peer counselling and helps in the development of trust along with improving the morale of both patients and caregivers (O'Hagan, 2011).

3.2.2.2 Family conferences

Family conferences are considered a meso level intervention because it involves the family and friends in fulfilling the needs of the patients. Metze, Abma and Kwekkeboom (2016) highlight that family conferences focus on addressing the family caregivers' strengths and abilities instead of their obstacles and seek to include extended social networks. The family conference is family driven, meaning that the social worker merely follows the ideas of the family and the family's social networks. Decision-making power therefore is given to the family and their social networks. This is known to have an empowering impact on families and their social networks.

It is common practice for the social worker to provide a formal invitation to a family conference. This invitation provides information on the agreed family conference date, time and venue, in addition to the contact person in the rehabilitation team and their contact details (Loupis, 2014).

Loupis (2014) furthermore states that the invitation includes a brief account of the agenda, format and reasons for the family conference. Additionally, the invitation encourages the family to note particular questions they wish to ask during the meeting. The social worker keeps a record of the discussion during the meeting, includes further planning arrangements and provides a copy for the family. This enables the family to be fully engaged in the discussion and avoid being distracted by the need to take notes. Family members are then encouraged to spend extra time with the social worker after the meeting to explicate perception of the discussion. These family conferences are utilised mainly as a discharge planning tool.

3.2.2.3 Seminars and training

These are similar to family conferences and are focussed on the family's strengths and abilities instead of their obstacles, and seek to include extended social networks, and are known to have an empowering impact on family caregivers. Workshops and training help the family caregivers to understand the way in which the patient is to be managed and further dealt with (Li & Tang, 2001). Specific training concerning caring for the stroke patient and training in active coping skills and problem-solving methods were more likely to be connected with positive caregiver outcomes (Carole, White, Adelita, Cantu, Misty & Trevino, 2015). Normal training of family caregivers regarding delivering care decreases personal expenses as the family caregiver does not need to pay for help and it advances their quality of life (Rhaman & Salek, 2016).

3.2.2.4 Self-help groups

Self-help groups are groups in which individuals mutually assist each other by means of collective activities with the aim of advancing their own lives (Biscaye, True, Clark, Harris, Anderson, & Gugerty, 2014). A variety of collective activity groups including peer counselling groups can be considered as a self-help group. Posner (2015) articulates that self-help groups aim at and assist in improving the level of fit between the family caregivers and their environment. In South Africa, The National Academies Press (2016) found that the most beneficial and cost-effective way to support family caregivers may be via peer counselling groups and self-help groups as these groups provide emotional support and skills training to assist family caregivers in their caregiving duties.

Guerty et al. (2018) further add that self-help groups should aim to advance the group members' wellbeing, independence and member involvement in decision making; develop trust within the individual in relation to knowledge; and regular personal interaction between members. This should thus enable family caregivers to help one another within this group through sharing personal knowledge, skills and techniques with one another. This will contribute to improving their quality of life and with becoming self-reliant.

3.2.3 Macro level

According to Bronfenbrenner (1979), Swanson, Spencer, Harpalani, Depree & Noll (2003) and McWhirter, McWhirter, McWhirter and McWhirter (2013), the macro level entails society's beliefs, norms and values at international and national level for a specific culture or subculture. Hutchinson (2015) adds that the macro level is impacted by elements such as government policies, financial support and society's cultural beliefs. These macro level elements influence the livelihood of individuals.

Hepworth et al. (2017), Miley & DuBois (2010) and Poulin (2005) further state that the goal of macro-level social work intervention is the advancement of service delivery by developing policies, evaluating unmet needs, taking on an advocacy role and initiating programmes. Zastrow & Kirst-Ashman (2013) adds that as mobilisers for activity, social workers convene and recognise macro systems and resources to identify needs and impact changes that enable the client system globally. Social workers should thus increase their knowledge about the problem

or need, the population involved in that problem and the environment or community where changes are needed, in order to bring about macro-level change (Netting et al., 2005).

Macro-level social work intervention should therefore focus on impediments to equality and social justice including advocacy programmes to ensure individual rights and mainstreaming in society (Cohen, 1994). People with disabilities are confronted with structural impediments such as receiving housing and employment, for example. They comprise a big minority group that possibly undergo the highest level of discrimination in society (Dejong & Batavia, 1990). Miley & DuBois (2010) articulate that social workers also act as social planners, whereby their actions include advocating for social injustice change, a role that is reasserted in the National Association of Social Workers Code of Ethics (NASW, 2008). When it comes to delivering services to family caregivers, social workers can influence disability policies concerning services rendered to families caring for a stroke survivor. Dalrymple and Boylan (2013) declare that social workers partner with external agencies to help advance and incorporate empowerment and advocacy practices for people with disabilities.

3.2.3.1 Home-based care

Home-based care is viewed as care that is provided in the home by caregivers through both the formal and informal health sector (National DoH, 2001). The overarching objective of home-based care is to guarantee the independence of users the best quality of life by providing suitable care.

Home-based services cover an extensive range which could encompass basic nursing care, clinical care, social support, legal support, supplying medication, health education, and counselling and support with basic activities of daily living (Aantjes, Quinlan & Bunders, 2014; Moetlo, Pengpid & Peltzer, 2011; Tsolekile, Puoane, Schneider, Levitt & Steyn, 2014). Home-based care has developed quite substantially in the last two decades in South Africa as a result of shorter periods of patient hospitalisation in association with the increase of chronic conditions such as HIV-infection and/or AIDS (Aantjes et al., 2014; De Wet, 2012; Mataure & Thupayagale-Tshweneagae, 2013). While home-based care was started in response to the HIV pandemic, it has advanced and services currently are oftentimes extended to everyone in need of home care and not only to persons with HIV or AIDS (Aantjes et al., 2014). Mashau, et al (2015)

comparably states that the establishment of home-based services in developing countries, which includes South Africa, resulted in the prevention of deinstitutionalisation of stroke patients.

Home-based care in South Africa is often provided by Community Health Workers (CHW) with some training who work either as volunteers or for remuneration (De Wet, 2012; Mataure & Thupayagale-Tshweneagae, 2013; Morton, Mayekiso & Cunningham, 2013). Generally, the CHWs are from the same communities as the service users and often live in close proximity to the service users. Additionally, they might face the same health and socioeconomic challenges as their service users (De Wet 2012; Morton et al., 2013).

The advantages of home-based care is that it is designed to equip family caregivers to provide the necessary assistance to their relative by introducing them to a variety of elements such as education on the management of the patient's condition and assisting the patient with mobility (Singh, Chaudoir, Escobar & Kalichman, 2011). Several studies found that education specifically plays a crucial role in home-based care as families stated that they require specific education about the condition of their relative (Mwai et al., 2013; Mataure and Thupayagale-Tshweneagae, 2013; Crowe, O'Malley & Gordon, 2001). The Global Stroke Bill of Rights (WSO, 2014) recognises home-based care as one of the elements of care that are crucial for all stroke patients and caregivers.

Although home-based care is recognised as one of the elements that are crucial for all stroke patients and families and prevent deinstitutionalisation, research by Mataure and Thupayagale-Tshweneagae (2013) has shown that a lack of medication, transport and consumables is a hindrance to offering home-based care services in South Africa. Tsolekile et al. (2014) reported that home-based carers lacked knowledge regarding the provision of rehabilitation services in South Africa. Home-based carers moreover indicated that they experience burnout (physical and psychological) alongside stigma from the community that they live in (Moetlo et al., 2011). Furthermore, patients do not comply with home-based carers and the non-compliance creates challenges in delivering effective services by the home-based carers. Additionally, a lack of resources, for instance home-based care kits and money for transport, lack of welcome in houses of some patients and challenges with supervisors created further challenges.

3.2.3.2 Rehabilitation services

The aim of rehabilitation services is to provide for patients whose functioning is impaired, with services such as occupational therapy, speech and language therapy and cognitive therapy, which improve and maintain their social functioning. Additionally, rehabilitation services are an effective way of lessening the demands on family caregivers as well as publicly funded support systems, as it helps to shorten hospital length of stay, avoid costly hospitalisation and prevent deinstitutionalisation (DSD, 2006). Within rehabilitation, the social worker's role is to evaluate the family's support system and home needs; providing information about types of care; helping the family to access community resources such as financial entitlements, home care and transportation; and counselling about adjustment issues concerning the disability (Dorsett, 2010). Social workers also provide counselling to the patient, as well as the family, to enable adjustment to the disability by concentrating on a variety of personal and interpersonal problems. This allows the family caregivers also to understand the nature of the disability and advance the capabilities of caregivers (Chitereka, 2014).

Hassan (2009) found that rehabilitation services for stroke patients in the Western Cape are both facility-based and community-based. In South Africa, rehabilitation services are provided at out-patient settings, in-patient settings, and, to a slighter degree, in the patients' communities and homes (Kumurenzi, Goliath, Mij, Mlenzana, Joseph, Stathum & Rhoda, 2015). The Department of Health: Provincial Government Western Cape (PGWC) (2006) similarly mentions that these services are offered in a variety of forms such as step-down facilities, and outpatient or ambulatory services offered by community healthcare centres and adult day care centres. These centres are driven predominantly by nursing staff, with, in a few instances, a social worker on staff to provide out-patient rehabilitation services (Hassan, 2009).

3.2.3.3 Adult day care centres

Adult day care centres provide care to persons who are in need of care throughout the day while the family caregiver sees to daily duties. The family takes the patient to the facility or the facility can pick up the patient from home if the patient resides within a certain radius of the centre. It also depends whether transportation is available to collect the patient from home. Throughout the day, patients are cared for by a variety of trained caregivers and professionals. As a result, this helps the family in that the caregiver does not have to resign from employment (Hassan, 2009).

Tretteteig, Vatne and Rokstad (2016) state that adult day care centres offer respite services, which are discussed in the following section, for family caregivers and an activity programme for service users. Hassan (2009) similar notes that a planned programme for the day is organised by adult day care centres. The planned programme's target is to provide persons with physical and mental disabilities, including older persons, to maintain their maximum capacity for self-care. Being part of a group helps elderly people and adults with disabilities who are isolated by loss or illness to maintain a positive attitude to life as they can socialise. These services prevent de-institutionalisation and guarantee that the patient can live with the family for as long as possible. Moreover, the adult day care centre has nursing as well as medical staff, occupational therapists, physiotherapists, speech therapists, dieticians, social workers and could include psychiatric services if needed.

Choi (2013) states that social workers are trained to offer various services in adult day care centres. These services may include assessment and care planning; case management; programme design; outreach services; assistance within assessing community volunteer services; assessing transportation services; and family and individual counselling. McKenzie and McConkey (2016) conducted a study on family caregivers caring for adults with an intellectual disability in South Africa. Their study found that caregivers experienced feelings of frustration since there were no adult day care centres available within their communities. Hassan (2009) further found that adult day care services in the Western Cape are regrettably very limited, which means that relatives caring for a family member suffering from a stroke will not have access to this type of respite support.

3.2.3.4 Respite care services

Pilkington, et al (2019) state that respite care is the temporary provision of care to a dependent person, which allows the caregiver to have a short break. Pilkinton et al. (2019) add. that respite care focuses on assistance for family caregivers in preference to the individual who is receiving care. Respite care improves the psychological well-being of family caregivers, increases family caregiver resilience, reduces risk of caregiver breakdown and avoids expensive unplanned admissions to hospitals (Mitchell et al., 2016; Remedios, Willenberg, Zordan, Murphy, Hessel & Phillip, 2015; Carter, Edwards & Hunt, 2015).

The role of respite care services is to provide in-patient care to the patient for a specific period. This period allows family caregivers to release stress and take a break from the caregiving duties. As mentioned previously, it is acknowledged by family caregivers that they would prefer respite care as an option, with the majority stating that they would want additional assistance in their home (Kerr & Smith, 2001). Nonetheless, basic nursing care by informal and formal caregivers provided to patients within the comfort of their homes is provided by home-based services, as aforementioned.

Although the importance of respite care to family caregivers is highlighted in the literature, Makganye (2015) found that there is a lack of respite care services for stroke patients in South Africa. Correspondingly, Pretorius and Steadman (2017) found that respite service lack in rural communities of the Western Cape, which is a support-related hindrance for family caregivers.

3.2.3.5 Social security

Social security in cash and in kind is made available across the world by governments (Muller-Kluits, 2018). Muller-Kluits further argues that South Africa is no different. SASSA issues disability grants, care dependency grants and Grant-In-Aid, in order to ease the burden of those with disabilities and their caregivers. The Grant-In-Aid (GIA) provides support to an individual who is in need of full-time care due to physical or mental disability, the DG provides funding to adults with disabilities and the Care Dependency Grant (CDG) offers funding to families with a child who has a disability and who is below the age of 18. The GIA is unobtainable if the person in need of care is living in, or taken care of by an institution which is fully government funded – for example a psychiatric hospital or a prison or Old Age Home (as defined in Section 1 of the Prevention and Treatment of Drug Dependency Act of 1992).

Family caregivers in South Africa are often in need of financial support due to their caregiving role; social security takes form in means of a disability grant, which is facilitated by SASSA. This is in line with the provision made by the Standard Rules on Equalisation of Opportunities for persons with disabilities states within Rule 8 of the (UN, 1993) that states are responsible for the provision of social security and income maintenance for persons with disabilities.

Social workers complete DG applications while the patient is hospitalised, but this often does not happen due to patients being discharged from hospitals after short periods (DoH, 2007). Kelly

(2019) found that psychiatrists in a few hospitals in Cape Town make the final judgement concerning DG commendations. Nevertheless, DG assessments were initially discussed in a multi-disciplinary meeting, which included social workers, nurses and psychiatrists.

The GIA is an additional grant, which is provided to adults who are already in receipt of one of the other grants. Hence, the GIA is not available on its own. If the recipient dies, the GIA lapses and nobody can receive someone else's GIA. The GIA is available until the last day of the month in which the person dies. Yet, there could possibly be benefits that can still be claimed after the grant recipient has died. These benefits can be claimed either by the estate of the late recipient or by the person accountable for the funeral expenditure (Social Assistance: A reference guide for paralegals, 2010). The role of social workers cannot be ignored here, as the social worker becomes a mediator to provide the benefits of such GIA to the persons who are entitled to gain such benefit. The social work services in this respect ensure justice and equality.

The DG intends to provide financial assistance to persons with disabilities who are unable to assist themselves. It is granted to the recipient until he/she turns 60 years old. The DG can be received by adults who are in need of the grant as well as those with formal refugee status within South Africa. In the event that the health of a person receiving a permanent DG improves (for instance, as a result of an operation), SASSA has to be informed. Failure to inform SASSA could be considered dishonourable. In addition to voluntary declarations, nonetheless, SASSA requires that beneficiaries of grants that support those who have disabilities (like the DG and the CDG) have medical assessments performed from time to time for confirmation of eligibility for the specific grant they are receiving. The DG may also be terminated or suspended for a period following an annual review of the applicant's circumstances to evaluate whether they are still meeting the eligibility criteria for the grant (Social Assistance: A reference guide for paralegals, 2010).

The appraisal for the CDG is similar to that of the DG, according to the Social Assistance reference guide for paralegals (2010). However, as the grant depends on the disability of the child, Medical Officers are provided with extra help by means of a developmental milestones table that assists them to determine age appropriate capabilities. Referring to the table, a child qualifies for a CDG if he/she is not able to show three or more of the age appropriate

capabilities; the inability to show two skills and in need of assistance to a level that is to a large indefinite quantity higher than would usually be required; has behavioural problems which necessitate a lot of attention; needs special schooling or extra classroom assistance; has a caregiver who has to stay at home; or has treatment that incurs a high cost to the caregiver (Guidelines for the Medical Assessment of Disability for Social Assistance Purposes, n.d.). This is assessed by means of a functional assessment report and medical report, which confirms age appropriate capabilities. The CDG lapses when the child turns 18 years old. When the child turns 18, he/she meets the eligibility criteria for a DG and can apply for it themselves, should they pass the means test.

For the GIA, DG and CDG, individuals must have a medical referral letter from their own doctor (which is followed by a formal medical assessment with a state doctor that is required during the application process). The GIA is not available to those who look after children. People in receipt of a DG may additionally be in receipt of the GIA if relevant persons are unable to take care of themselves and are in need of daily care at home. On the other hand, people in receipt of a GIA may simply be in receipt of this grant if they are already in receipt of one of the other three grants for adults (Social Assistance: A reference guide for paralegals, 2010). Social workers should play a critical role in enabling persons with a disability to access services, including social security transfers.

3.3 CONCLUSION

In conclusion, as seen from various literature sources, it is highly unlikely that an organisation or one service provider can amply address the needs of family caregivers as these needs are subject to undergoing changes because of the financial, psychological, social and physical resources of the family caregiver and the resources and extent of disability of the care receiver. Consequently, it is essential to deliver services to family caregivers at all levels of the ecological perspective, namely the micro, meso and macro levels. At each level, services such as advocacy, guidance, support groups and referrals that assist the family should be rendered by social workers, to thereby enable family caregivers to access the resources they need by means of such interventions.

Social workers should provide resources to reduce the caregiving burden. The family caregivers could be furnished with advice on the provision of practical support for their stroke relative and with information on how to prevent a secondary stroke by means of social work resources. The information provided by social workers should additionally address a variety of needs declared by family caregivers, such as referring the family to support groups; information on the availability of services, for instance respite care; and helping the family with financial applications for social security grants. To ensure the needs of the family caregivers are addressed, it is important that there should be consultation with social workers regarding the development of an ongoing care plan.

Home-based care in South Africa is provided by CHWs with some training, who work either as volunteers or for remuneration. Based on the caregiving needs and challenges expressed by families, it is important that CHWs be trained specifically to address caregiving needs and challenges effectively. It is also important to have proper training in grant applications to avoid fraud and abuse of grants with regard to persons with disabilities.

CHAPTER 4

EMPIRICAL FINDINGS OF SOCIAL WORK SERVICES TO FAMILIES CARING FOR A FAMILY MEMBER WHO SUFFERED A STROKE

4.1 INTRODUCTION

This chapter is built from the previous chapters and relates to the third objective for this study, which was to explore the services rendered by social workers to families affected by a stroke. This chapter presents the empirical analysis of the social work services to families caring for a family member who suffered a stroke. Empirical data were collected through interviews with social workers rendering services to families caring for a family member who suffered a stroke.

From these sections, six main themes could be identified, namely the application of policy and legislation guiding the care of stroke patients; the needs of family caregivers; challenges in taking care of a stroke patient; social work services rendered to family caregivers; social work services still needed; challenges in social work service delivery to family caregivers; and improvement of services to lessen the caregiving burden. These six themes are discussed in this chapter, based on the analysis of the data.

4.2 RESEARCH METHODOLOGY

The research methodology introduces the research question on which the study was based, the goals and objectives of the study, research design, research approach, research instrument, research sample and the data collection and analysis procedure.

4.2.1 Research question

The research question was: What social work services are rendered to families caring for a family member who suffered a stroke? The empirical study was thus based on this research question.

4.2.2 Goal and objectives

The goal of the study was to gain a better understanding of the social work services rendered to families caring for a family member who suffered a stroke and had become disabled and dependent on family members. This goal was achieved by means of the following objectives:

- To describe policy and legislation with regard to patients of a stroke and the challenges families experience in caring for them;
- To identify the social work services that should be rendered to families caring for a family member affected by a stroke from an ecological perspective;
- To explore the services rendered by social workers to families affected by a stroke;
- To present conclusions and recommendations on social work services for organisations and rehabilitation centres that render services to family caregivers of stroke patients' post-acute rehabilitation.

4.2.3 Research approach

A qualitative research approach was applied in this study. De Vos et al (2011) state that qualitative studies are concerned with small samples and non-statistical techniques, and are frequently purposefully selected. Cropley (2015) moreover adds that the duty of qualitative research is to gain insight into the structure of the world, i.e., to hear how it is interpreted by people in the course of their daily lives.

This research approach by De Vos et al (2011), provided the researcher with the opportunity to listen to the participants' experiences and gain insight into the social work services rendered to family caregivers of stroke patients. The narratives of participants, in turn, provided more depth to the literature and allowed deeper discussions for analysis of the empirical study. This was extremely helpful since not much previous research has been done on this topic, thus, with more detail provided by participants, the discussion on the topic could be more comprehensive.

4.2.4 Research design

An exploratory and descriptive research design was used. Exploratory studies assist the researcher to develop methods that are used cautiously in later studies and develop insight into and unknown area (Creswell 2007; De Vos et al., 2011). By applying an exploratory design, the

researcher was able to investigate social work services to family caregivers who were caring for a family member who suffered a stroke in an open, supple, inductive and orderly approach in search of new insight into the phenomenon (Terre Blanche & Durrheim, 2002; Rubin & Babbie, 2005).

4.2.5 Research instrument

Data collection was done by means of a semi-structured interviewer schedule (Annexure 2). Semi-structured interviews were used to gain a detailed picture of the participant's account of social work services rendered to family caregivers of stroke patients who had become dependent on family members (Greeff, 2005). The researcher used a voice recorder to audiotape the interviews, after consent from the participants had been obtained (Annexure 1). The study was conducted in either Afrikaans or English, depending on the chosen language of the participant. The interview schedule consisted of four sections, namely identifying particulars; policy and legislation guiding the care of stroke patients; service rendering to families caring for a stroke patient; and services rendered by social workers from an ecological perspective.

However, it is imperative to mention that the researcher tested the data collection method by conducting a pilot interview with Participant 1, who formed part of this study. The pilot interview was undertaken to test and evaluate whether the research instrument as well as the voice recorder were effective. The interview schedule remained unchanged after the pilot interview was conducted as it covered all the information the researcher sought. The only change which was necessary concerned moving the voice recorder closer to the participant. This was implemented going forward and made interviews much more effective.

4.2.6 Population, sample and sampling method

Arkava and Lane (in Strydom, 2010) declares that population pertains to individuals that hold specific characteristics in the universe. For the purpose of this study, the population consisted of social workers rendering services to families caring for a family member who suffered a stroke in the Western Cape Metropolitan area. Non-probability, purposive sampling was chosen as the most appropriate method for this study, as purposive sampling provides a clear definition of the population and intended sample (Munhall, 2008). Interviews were conducted with 18 participants.

The method used for sample selection firstly was to get permission to conduct interviews with social workers from institutions and the Department of Health in the Western Cape that deliver social work services to families caring for a family member who suffered a stroke. According to Creswell (2007) and Fouché and Schurink, in De Vos et al. (2011), this method is called gatekeeping.

The research proposal was submitted to the National Health Research Database for ethical clearance. Access to the participants was only gained once the study had been approved (see Annexure 5). As aforementioned, potential participants in private practice wanted to be remunerated since they were working for remuneration per hour. The researcher managed the situation by explaining to the social work managers of this private practice that participation in the study was voluntary, that participants would remain anonymous and that the data collected would be used to advance social work services to families caring for a family member who suffered a stroke. Even though the researcher explained that the study included no form of remuneration; that participation was voluntary; that participants would remain anonymous; and that the data collected would be used to advance social work services to families caring for a family member who suffered a stroke, the decision of these managers remained unchanged. Hence, alternative participants had to be found.

This study aimed to include social workers rendering services to families caring for a family member who suffered a stroke in the Western Cape Metropolitan area. The social workers were fluent in Afrikaans or English, irrespective of their race, gender, culture, religion or age, and formed part of the research sample. As previously stated, the researcher had to seek alternative participants due to one proposed rehabilitation centre denying access to their facility as potential participants in private practice wanted to be remunerated because they were working for remuneration per hour and the other one had too few social workers with whom to conduct the study. Consequently, the researcher sent her proposal to the provincial Department of Health, which granted approval for her research at seven government institutions. In addition, NGOs and private rehabilitation centres were also approached to obtain enough participants for the study.

Tertiary hospitals, NGOs and both private and government rehabilitation centres in the Western Cape Metropolitan area were therefore included in the study. Telephonic and email contact was made with the directors who serve as the gatekeepers of both government facilities, NGOs and private rehabilitation centres in the Western Cape, in order to obtain consent and gain entry into the facilities to conduct the study. The researcher explained the purpose of the research telephonically and via email. In addition, she sent her proposal and letters requesting to conduct the research to the managers at the identified government facilities, NGOs and the private rehabilitation centres in order to gain permission to conduct the research. The managers then approached the participants and informed them about the research interviews. Once permission was received, the identified social workers were approached by the social work managers in order to schedule appointments to conduct the research interview. The managers of the facilities scheduled a date and different time slots for the interviews. The participants, who agreed to participate in the study, signed an informed consent form.

The number of years of experience of the social workers was not important in this study as the researcher focused on the social work scope of services that the selected rehabilitation centres and hospitals render to families caring for a family member who suffered a stroke. The sample size comprised 18 participants. Five participants were employed in tertiary hospitals, six at a government rehabilitation centre, five at NGOs and two at private rehabilitation centres.

During the interview process, the purpose of the study was explained face to face with the participant. The researcher explained the consent form to the participants in order to gain their written permission to participate in the study. The interviews only commenced after the consent forms were signed. Each participant kept a copy of the consent form. In-depth phenomenological interviews were conducted with 18 participants until data saturation was reached. De Vos et al., (2011) declare data saturation as occurring when the researcher begins to hear corresponding information from participants, and no new information is coming forth. Data saturation was reached after analysing the in-depth interview of the 18th participant. This also contributed to data verification checking, which is discussed in the next section.

The study used a denaturalism approach to transcribing. Afflerbach (2020) describes the denaturalism approach as the removal of elements such as stutters, pauses, non-verbal factors or involuntary vocalizations, which suggest that there are certain meanings and perceptions within speech. Additionally, the number of years of experience of the social workers was not important in this study as the researcher was focusing on the social work scope of the services the selected facilities render to families caring for a family member who suffered a stroke. The criteria for inclusion were that a participant:

- be employed and render social work services to family caregivers of stroke patients
- be a registered social worker,
- be conversant in Afrikaans or English.

4.2.7 Data quality verification

Credibility of the data was addressed by means of triangulation of information from different sources and through reaching consensus on themes (Mabuza, Govender, Ogunbanjo & Mash, 2014). De Vos et al. (2011) state that the objective of credibility is that the subject of the study is honestly identified and portrayed. According to Shenton (2004), tactics to help ensure honest sharing of information by participants further add to the credibility of the study. For the goal of this study, each participant was given the chance to withdraw or decline to participate and given the opportunity to refuse to answer any questions they did not wish to answer, with an assurance of their anonymity (Annexure 1). Should anyone wish to determine whether findings can be transferred to other settings, an audit trail and record-keeping system is available (Mabuza et al., 2014). Additionally, one of the transcripts were sent via email to the participant, to verify whether an honest reflection of the interviews was recorded. This participant verified the information via email and declared that the interview transcripts are honest reflections of the interview.

The researcher further ensured validity and reliability, by letting one participant from the study read through the empirical chapter, (Chapter 4), to state their view on whether the findings that the researcher outlined in the study, are agreed upon. The participant informed the researcher that they agree with the findings of this study. The researcher also made use of an independent coder that is currently busy with a post graduate degree in Social Work and that is also registered with the South African Council for Social Service Professions (SACSSP). This independent coder

read through the researcher's transcriptions and empirical chapter to confirm the themes, sub-themes and narratives (Annexure 3).

4.3 FINDINGS REGARDING SOCIAL WORK SERVICES TO FAMILIES CARING FOR A FAMILY MEMBER WHO SUFFERED A STROKE

This section aims to present the findings regarding social work services to families caring for a family member who suffered a stroke. A description of the profile of the participants is presented. The data obtained from the investigation are presented as typical of qualitative analysis – using themes, sub-themes, and categories, where relevant. Subsequently, the views of participants and their knowledge of policy and legislation will be discussed, along with an analysis of social work services as rendered by the various service providers.

4.3.1 Identifying particulars of participants

The identifying particulars of the 18 participants who participated in the study are indicated in Table 4.1. This table supplies a summary of the profile of the participants.

Table 4.1: Identifying particulars of participants

	Age of participant	Years of experience in social work	Highest qualification obtained in social work	Type service provider
Participant 1	32	10	B Social Work	Government
Participant 2	24	3	B Social Work	NPO
Participant 3	47	25	BA Social Work	NPO
Participant 4	49	19	BA Social Work	Government
Participant 5	37	14	B Diac Social Work	Government
Participant 6	51	29	Bachelor of Social Science	Government
Participant 7	40	4	B Social Work	NPO

Participant 8	54	4	Diploma in Social Work	NGO
Participant 9	36	3	B Social Work	NPO
Participant 10	63	42	Diploma in Social Work	Government
Participant 11	62	39	BA Social Work	Government
Participant 12	48	19	BA Social Work	Government
Participant 13	63	28	MPhil in Social Work	Government
Participant 14	55	32	Diploma in Social Work	Government
Participant 15	29	8	BA Social Work	Government
Participant 16	35	10	BA Social Work	Government
Participant 17	52	28	BA Social Work & Honours in Psychology	Private practice
Participant 18	35	14	B Social Work	Private practice

4.3.2 Age of participants

Most of the participants were aged between 30 to 59 years, but there was an even spread of participants amongst the different age groups. The advantage for the study was that most of the participants were experienced social workers, as only five participants had less than 10 years' work experience

4.3.3 Years of experience as social worker rendering services to family caregivers of stroke patients

Most of the participants had more than ten years' experience in rendering services to families caring for a family member who suffered a stroke. Four participants had less than one year of experience while another four had between two and three years' experience. Only two participants indicated that they had four to five years' experience as a social worker rendering services to families caring for a family member who suffered a stroke. In conclusion, participants had between 8 months and 39 years of work experience with family caregivers of stroke patients. The criteria for inclusion were that participants, as aforementioned:

- be employed and render social work services to family caregivers of stroke patients
- be a registered social worker,
- be conversant in Afrikaans or English.

4.3.4 Type of service provider

Eleven participants were employed within the government sector. Five participants indicated that they are employed within non-profit organisations (NPO), while only two participants specified being employed in the private sector. These findings indicate that government, the private sector and NPOs render social worker services to family caregivers of stroke patients.

This finding links to the 2015 White Paper on the Rights of Persons with Disabilities (WPRPD) which calls for civil society, government and the private sector to work in collaboration to guarantee the socioeconomic inclusion of persons with disabilities (“Official Guide to South Africa 2018/19,” n.d.)

4.3.5 Highest qualification obtained in social work

Seven participants indicated that they had obtained a BA degree in social work. A BA in social work is a three-year undergraduate course divided into six semesters. Five participants indicated that they had obtained a bachelor’s degree in social work. Bachelor of social work or B social work degree is a four-year undergraduate degree (normally this degree includes honours as the fourth year). Three participants indicated that they had a Diploma in social work.

One participant indicated having a Bachelor of social science degree, whereas one participant also indicated to have a B Diac social work degree. B Diac social work means diaconal services within social work. The one participant obtained this degree from Huguenote College in Wellington, Cape Town. Another participant obtained a master’s degree in social work. None of the participants had obtained a doctorate degree in social work.

The finding indicates that the majority of participants did not pursue postgraduate studies. Social workers wanting to continue their studies may need funding, whether from their own finances or from other resources. Historically, social work has been a low-paid career (Sheafor, Horejsi and Horejsi, 2000; Patel, 2007; Sithole, 2010; Dlamini & Sewpaul, 2015). In the absence of funds, pursuing postgraduate studies therefore may be completely ignored or overlooked. Moreover, the

Department of Social Development as well as NGOs offer almost no incentive for improving qualifications (Sithole, 2010). The one participant who held a master's degree explained that she pursued her further studies out of personal interest.

4.4 THEMES, SUB-THEMES AND CATEGORIES DERIVED FROM DATA ANALYSIS

The data gathered from participants during the empirical study were grouped into different themes, sub-themes and categories, as can be seen in Table 4.2 below. These data are discussed below the table.

Table 4.2: Themes, sub-themes and categories derived from data analysis

THEMES	SUB-THEMES	CATEGORIES
Theme 1: Policy and legislation guiding the care of stroke patients	Policy and legislation utilised in service rendering	The Constitution of Republic of South Africa (Act 108 of 1996) Older Person's Act (Act 13 of 2006) White paper on Social Welfare (RSA, 1997)
	Lack of awareness of policy and legislation	
Theme 2: Challenges and needs of family caregivers of stroke patients	Challenge to adapt to the new role of caregiver	Accepting changes in the stroke patient Lack of formal support Lack of facilities in the household for effective care Lack of suitable housing Lack of physical aids Inaccessibility of houses
	Needs of family caregivers of stroke patients	Financial assistance Psychosocial support Need for different forms of information on stroke Training on providing physical care
Theme 3: Services rendered by social workers from an Ecological perspective	Micro-level services to family caregivers of stroke patients	Counselling services to family caregivers of stroke patients Medical information sharing on stroke
	Meso-level services to family caregivers of stroke patients	Family meetings Sexuality groups
	Macro-level services to family caregivers of stroke patients	Home-based care services Respite services

		Day care services Rehabilitation services Stroke awareness programmes Obtaining social security for stroke patient
Theme 4: Challenges in social work service delivery to family caregivers of stroke patients	Unrealistic expectations of social workers from family caregivers	
	Lack of transport to attend social work services at organisation	
	High caseloads and insufficient time of social workers to engage with family caregivers	
	Shortage of social workers rendering services to family caregivers of stroke family members	
Theme 5: Suggested improvements for service delivery to family caregivers of stroke patients	Employment of more social workers	
	Continuous support, training and education to family caregivers	

4.5 DISCUSSION OF RESULTS

The results as depicted in Table 4.2 are discussed.

4.5.1 Theme 1: Policy and legislation guiding the care of stroke patients

Policy and legislation play a significant role in direct social work service provision to vulnerable groups such as people with disability and their caregivers. The execution of policy and legislation that advance social justice and equity is often challenging as it benefits vulnerable groups (Duncan et al.,2005). As mentioned in Chapter 2, South African policy and legislation guiding service provision for people with disabilities is contained in the Constitution of Republic of South Africa (Act No. 108 of 1996), the INDS (1997), the White Paper on Social Welfare (RSA, 1997), the NRP of South Africa (DoH, 2000) and the Policy on Disability (DSD, 2013).

These policies stipulate objectives for effective rehabilitation services, which include the full participation of persons with disabilities in the preparation, supervising and assessment of services rendered. It is therefore important that social workers are aware of the various policy and legislative documents which guide their service provision. In this study, participants were asked to identify the policies and legislation they utilise in everyday practice that guides the care of stroke patients, thus policies and legislation utilised in service rendering emerged as a sub-theme and is discussed next.

4.5.1.1 Sub theme: Policies and legislation utilised in service rendering

Despite the array of both national and international policies and national legislation guiding the implementation of services to persons with disabilities, only a few participants were able to identify specific documents. These documents are identified and discussed as categories.

4.5.1.1.1 Category: The Constitution of the Republic of South Africa (Act No. 108 of 1996)

A few participants pointed out that they work with the family as well as the stroke patient's rights and therefore the Constitution of the RSA (Act No.108 of 1996) is important and applied when they are rendering services to families of stroke patients. Participants mentioned:

“So obviously, the White Paper on Social Welfare and then the Constitution is very important.” (Participant 3)

“Definitely, you know, the human rights. The -- ja, that will be the Constitution.” (Participant 12)

It is evident from the narratives above that participants are aware that stroke patients and those who care for them have particular rights in terms of the country's constitution. The Bill of Rights, as enclosed in the Constitution of the RSA (Act No. 108 of 1996), places emphasis on equality and non-discrimination for people with disabilities. Thus, participants indicated that they are aware of these rights to ensure that they in service provision to stroke patients and their family caregivers are not denied their right to equality, dignity and freedom.

Moreover, the Constitution of the RSA (Act No. 108 of 1996) embraces both socio-economic and social protection rights as human rights. This is helpful for family caregivers as the GIA

provides support to an individual who is in need of full-time care due to a physical or mental disability. The role of social worker is to be a mediator, in order to provide the benefits of the GIA to the family caregivers who are entitled to gain the benefits. The social work services in this respect assure justice and equality. Participants however did not mention this aspect as a reason why they are utilising the Constitution.

4.5.1.1.2 Category: Older Person's Act (Act 13 of 2006)

The Older Person's Act (Act 13 of 2006) emerged as a category as participants identified it as a legislative document used to guide their service provision to stroke patients over the age of 60. These participants stated that the Older Person's Act (Act 13 of 2006) is utilised together with the Policy on Disability (DSD, 2013), with a focus on the care and protection of the patient as can be seen in the narratives below:

“Ya and then the one you don't have here, is the Older Person's Act. Ja, we use that one as well but that one goes together with the Policy on Disability. So, if we do have an older person that suffers from a disability, we work together with those two.” (Participant 2)

“Well, the Older Person's Act is used with elderly people and very important. Uhm, with the Older Person's Act, need for care and protection-that is crucial. We need to assess whether this person is going into, when they are discharged, into an environment where their needs are being met whether they are safe.” (Participant 5)

The finding that the Older Persons Act and the Policy on Disability are utilised together is confirmed in legislation (Act 13 of 2006; DSD, 2013), as it is indicated in Chapter 5, section 25 in the Older Person's Act (Act 13 of 2006) that it is important for determining whether an older person is in need of care and protection, particularly if they have, for example, suffered a stroke. Moreover, this Act also serves as a framework for empowering and protecting older persons and promoting and maintaining their status, rights, wellbeing, safety and security. The participants highlighted this section as crucial to service provision.

4.5.1.1.3 Category: White paper on Social Welfare (RSA, 1997)

The White Paper for Social Welfare (RSA, 1997), emerged as another category. Several

participants pointed to the White Paper on Social Welfare as a policy document that is implemented to guide service provision to stroke patients and their family caregivers. However, the narratives merely indicate that participants are aware of the White Paper on Social Welfare (RSA, 1997), but did not illustrate the extent to which the policy is applied in service provision to stroke patients or family caregivers. This is indicated in the following narratives:

“For us it must be the White Paper because we refer so much into the White Paper.”
(Participant 7)

“So, it would be the White Paper on Social Welfare, the Constitution of the Republic of South Africa, the World Health Organisation.” (Participant 16)

One participant elaborated on how The White Paper on Social Welfare is being implemented and said:

“The White Paper on Social Welfare....uhm, we do sometimes make use of it, if it’s a charity case. Like we had this one guy that lived on the streets and then we took him in and we went according to the White Paper of Social Welfare but then also we worked in conjunction with the disability policy because he has a stroke, while he was in the street.”(Participant 2)

These findings, as depicted in the narratives above, provide evidence that social workers are aware of the White Paper on Social Welfare but do not show how it is specifically relevant to guide the care of stroke patients. The fact that one participant however pointed out that they use the White Paper in conjunction with the Policy on Disability (DSD, 2013) when dealing with a homeless person who has had a stroke, is confirmed in literature. The Policy on Disability (DSD, 2013) can be related to section 3 of The White Paper for Social Welfare (RSA, Ministry for Social Welfare and Population Development, 1997) where focus is placed on people with disabilities as well homeless persons. This section outlines that community-based support services can provide persons and their families with a variety of options to advance independent living, as well as reintegration into society.

Most participants identified only these three legislative documents, which guide their service provision. It seems that there is a lack of tangible knowledge of the various documents which are

applicable to guide the care of stroke patients, despite the array of national and international policies that serve to guide social work services. These documents include: The United Nations Rules on the Equalisation of Opportunities for Persons with Disabilities (UN, 1993), the United Nations Conventions on the Rights of People with Disabilities (UNCRPD, 2006), The World Health Organization (2010) and the Global Stroke Bill of Rights (2014). National policies and legislation include the Integrated National Disability Strategy (1997) and National Rehabilitation Policy (DoH, 2000). The lack of awareness of policy and legislation thus emerged as a sub-theme and is discussed next.

4.5.1.2 Sub-theme: Lack of awareness of policy and legislation

Participants were asked to explain the policies and legislation that they use in everyday practice, which guide their service provision. Some participants clearly stated their ignorance regarding policy and legislation, as is evident in the narratives below:

“Wow. You asking me which policies do we use”!?!? Oh my word, I don’t know all these policies.” (Participant 3)

“I have no idea.” (Participant 6)

These narratives are indicative of how most participants responded when asked about the policies and legislation they used in every practice.

Policies and legislative documents are all aimed at guiding service provision, particularly to the most vulnerable population, which includes those with disabilities, as indicated by Zhou (2015). Ignorance regarding the policy and legislation as displayed by the participants is detrimental to service provision, as indicated by Graham et al. (2010).

4.5.2 Theme 2: Challenges and needs of family caregivers of stroke patients

Participants were asked to describe the challenges family caregivers experience when caring for a family member who suffered a stroke. The sub-themes and categories derived from the data are discussed.

4.5.2.1 Sub-theme: Challenge to adapt to the new role of caregiver

The first sub-theme identified concerned that family members must adapt to the new role as caregiver once a stroke patient returns home after the hospital stay. Cameron et al. (2006) and The National Academics Press (2016) stated that the unexpected and rapid adjustment of becoming a family caregiver for a stroke patient can be physically challenging, thus a very distressing experience. The first category that was identified related to accepting the changes in the stroke patient.

4.5.2.1.1 Category: Accepting changes in the stroke patient

Participants indicated that family members have to accept that the stroke patient has changed. As a result, families need to accept changes in the person, which is a challenge for families. This is evident from the following narratives:

“With any disability comes change, you know, so especially in a case where the patient had a stroke for the first time, it’s new for the patient it’s new for the family how the patient’s premorbid functioning was at this level but now after the stroke it has completely changed. So, and sometimes they don’t know, families doesn’t know how to deal with that.” (Participant 12).

Another participant mentioned that the personality of the person could change and that family members have to come to terms with the fact that it is not the same person as before the stroke.

“I think the biggest one [challenge] is coming to terms with the fact that ‘who I knew before is not the same as the person I know now’. Personalities change. Some patients are nonverbal. So, you would have had a very chatty person who now cannot say a word. So, I think it’s coming to terms with the change in that person, it’s not the husband you knew.” (Participant 18)

These narratives indicate that accepting changes in the stroke patient is a challenge that family caregivers are facing. The finding that accepting the changes in the stroke patient is a challenge that a family is facing is also confirmed in literature. Rombough, Howse and Bartfay (2006) indicate that changes such as speech difficulties are disheartening for the family caregiver and

result in misery. Kon (2011) further stipulates that, post the stroke, families mourned the changes that occurred in their family member, as it resulted in the loss of equality, balance and a shared burden. It is thus evident that accepting the changes of the stroke patient is a challenge which families are facing when adapting to the caregiver role. Therefore, families could require formal support, which is also indicated by participants to be lacking. This lack of formal support is elaborated on in the category that follows.

4.5.2.1.2 Category: Lack of formal support

The lack of formal support for family caregivers upon discharge of their family member could lead to uncertainties about how they should manage the situation, according to the participants. The following narratives from participants reveal that family caregivers do not receive the necessary formal support services.

“There are no formal resources.” (Participant 5)

“Little or no formal support, leaving them [family caregivers] overwhelmed, exhausted and lost. A kind of uncertainty because they don’t know what to do with the patients.”
(Participant 9)

The finding that families do not receive formal support in order to guide them regarding the process involved when the stroke patient returns home corroborates with the views of Rittman and Van Puymbroeck (2005) who declare that little is known about what emerges after the patient has been discharged from hospital, which links to the lack of formal support or resources received upon discharge. Pindus et al. (2018) similarly found that stroke patients and family caregivers felt that health services neglected them. These feelings of neglect arose due to marginalisation by services and a lack of skills and knowledge to re-engage with the needed services and healthcare providers.

4.5.2.1.3 Category: Lack of facilities in household for effective care

Participants indicated that caregivers and other family members, such as the children, often struggle to care for the stroke patient because of a lack of facilities in the household for such as

transferring the patient between the bath and the bed or a chair. Participants shared the following in relation to a lack of facilities for effective care in a household:

“Uhm, most of them struggles to transfer the person. So, if it happens that the person did have a stroke and they are now paralyzed or they lost movement in some places of their body. The family normally struggles to transfer them from the bed to the chair or from the chair to the bed. It is also very challenging if it is the person’s wife because then she struggles to bath him or to feed him because it’s too emotional for her but we also find that children struggle to adapt to that environment when it’s a parent of one of them.”(Participant 2)

Another participant indicated that the lack of accessibility in the household, for example the lack of toilet railings, makes it difficult for family members to cope.

At times, you need to get in carers and that’s expensive and it's not only that, also simple aids - toilet railings, a toilet seat that make it safer for the patient to use the toilet...uhm.. urine bottles just simple stuff. Tools uhm...an assessment of the person's home environment to say ok we have to remove the stuff or you have to remove these rugs, things like that. Families don’t get that input. I know when I used to work in England, we used to do a home visit, the physio, the OT and me would go. We used to take the patient from the hospital, go to the house, we would ask them to show us how they operate, we would assess, see if the patient can operate in the kitchen, see if they can do the stairs, then we decide - these rugs need to go, these furniture needs to be moved, and things like that. That services are not here at all. You need to take it to the house and do an assessment in that person's environment.” (Participant 5)

This finding, namely that the lack of facilities in the household hampers effective caregiving, corroborates the views of Strydom (2015) who found that the lack of physical resources hampers effective caregiving in South Africa. Thus, families need facilities within their homes for effective caregiving. First-world countries like the United States make assessments about the home environment of the person with a physical disability (National Research Council, 2010). These assessments determine what needs to be modified and how.

Organisations in South Africa do not have the necessary means to support families financially and families often do not have the finances available to use resources (Strydom, 2015). Consequently, families do not possess the necessary means to adapt their homes. As a result, the lack of suitable housing emerged as a category.

4.5.2.1.4 Category: Lack of suitable housing.

Participants indicated the lack of suitable housing, as some families reside in informal settlements. The narratives below declare the realities of families that live under poor socio-economic circumstances.

“I think the biggest challenges for me is that the family lives in a shack or in someone’s yard” (Participant 8)

“At the end of the day I end up like stuck with the patients here because they ask you: so what do you want me to do with my mom, I stay in a shack.” (Participant 9)

The finding that there is greater strain on resources if a family lives under poor socio-economic circumstances because there is less money links to findings by Vergunst (2016) who found that persons with disabilities who live under such socio-economic circumstances face a greater probability of hardship. These families do not have the funds to remodel their homes and make it suitable for the stroke patient, in order to provide the stroke patient with effective care facilities. The lack of funds also means that households are unable to afford the required material resources, such as wheelchairs, as it is out of reach due to its financial implications.

4.5.2.1.5 Category: Lack of physical aids

A few participants pointed out that physical aids to family caregivers of stroke patients are either lacking or are limited and this is evident from the narratives below:

“In some cases, you’ll find out that some people don’t get everything that might assist them in to assisting them into moving from point A to point B. That will be then your wheelchair, your crutches.” (Participant 7)

“we have all those things available such as wheelchairs, we have those walkers. Ya we have all those things. But but, I want to say that we have it available but what we do here actually is we rent it out at a very phenomenal fee.” (Participant 3)

Despite the above findings which indicate that there is a lack of physical aids, in particular wheelchairs, some participants explained that physical aids are provided to families upon discharge. This can be seen in the narratives below:

“Physical aids I can say they do get from the Department of Health, which is the your wheelchairs, you can say...although in some cases you’ll find out that some people don’t get everything that might assist them in to assisting them into moving from point A to point B. That will be then your wheelchair, your crutches.” (Participant 7)

“as part and parcel of our rehab programme here all assistive devices are provided within... we don’t give you hoisted stuff but your basic needs you will get your, proper wheelchair, proper seating; that’s one of our areas that we actually specialise in. Any walking assistive devices because of our OT department.” (Participant 14)

The views of participants contrast with each other, indicating that service delivery is not consistent and varies from one organisation to the other. It seems that some families have out-of-pocket expenses concerning physical aids such as wheelchairs and some families receive assistive devices from rehabilitation centres or hospitals. These findings support the views of Strydom (2015) who indicated that resources like wheelchairs were not affordable for those families caring for persons with a physical disability who live in informal settlements. Strydom (2015) moreover argues that there is no government assistance in the form of wheelchairs and that it is often impossible to utilise a wheelchair in informal settlements due to structural issues, e.g. sand.

Similarly, Visagie et al. (2013) also found that the lack of wheelchairs due to insufficient financial resources was one of the greatest obstacles. The Western Cape government stipulates that they intend to prescribe, supply, maintain and recycle assistive devices such as walkers and wheelchairs to persons who are in need thereof. However, they do state that they are in short supply throughout the Western Cape and that services are often dependent on donations for second-hand items and buying of new equipment (Visagie et al, 2013).

Even though Article 20 of the UNCRPD (2006) emphasises that state parties and the international community must commit to assisting access to quality assistive technology, for example by making this accessible at a low cost, the narratives are indicative that assistive technology is not accessible to everyone and this could be due to being dependent on donations for second-hand items and buying of new assistive devices. Assistive devices play a significant role in enabling persons with disabilities to function and participate in society; hence lessening the caregiving burden (WHO, 2015). In order to achieve this for every person with a disability, state parties and the international community must commit to access to assistive technology.

4.5.2.1.6 Category: Inaccessibility of houses

A few participants indicated that houses were not accessible, in particular to wheelchair users. This is demonstrated by the narratives below:

“If you want to look for example most of our patients, they are coming from poor backgrounds, they’re living in like informal dwellings where there is gravel roads, there is no tar road that even if you’re going to be issued a wheelchair how are you going to propel it? You look at the bathroom toilet; it’s all in the communities meters away from your little shack where you live. So, you find out they don’t have proper resources to care for a patient and it’s a huge challenge. There’s no space in it to propel a wheelchair, there’s no toilet, there’s no running water in the house. So, you find out those things are the ones that kind of affecting my discharge and it’s a huge challenge that the caregivers are facing and pushing the burden to the social worker.” (Participant 9)

“Families are struggling with so many issues out there and we can’t change, we can’t change situations. If that person must go back to the second floor or the third floor of a flat, that’s where they must go back to, we can’t - we don’t have magic wands to make a house more accessible. If patient is going to be discharged into a one-room apartment that isn’t totally wheelchair accessible - that’s what we have. All we must do is ensure that the patient understands diagnosis and prognosis.” (Participant 14)

The finding that houses are inaccessible, especially for families who are living in informal dwellings or in an apartment building without an elevator, corroborate the view of Dingana (2012) who reported that persons with physical disabilities in Bika Township in the Eastern Cape needed more accessible homes, as they felt that passages in their homes were too small for wheelchairs to turn around in them. She further recommended that, when it came to allocating housing, municipalities should give preference to people with physical disabilities who live in informal settlements.

According to Article 9 of the UNCRPD (2006), member countries must ensure that physical barriers to entering buildings, transport, roads, workplaces and housing are eliminated, for people with physical disabilities to have the same access as those without physical disabilities. However, the narratives in this study point out that Article 9 of the UNCRPD (2006) is not achieved, as participants expressed that physical barriers prohibit stroke patients from entering their homes while using wheelchairs. In South Africa and other parts of Africa there are ample examples of hindrances due to inadequate infrastructure, including stairs and inaccessible pathways to grant equal access to amenities for people with disabilities (Coulson et al., 2006; Algurén, Lundgren-Nilsson & Sunnerhagen, 2009; Urimubenshi & Rhoda, 2011).

4.5.2.2 Sub-theme: Needs of family caregivers of stroke patients

The second sub-theme that was identified concerned the needs of family caregivers of stroke patients. In a research study, family caregivers reported emotions of isolation due to 24-hour caregiving duties (Qayyum et al., 2013). This burden of care needs to be recognised. Different categories emerged from the data analysis, such as the need for financial assistance, psychosocial support, information on stroke and need for training in providing physical care, which are discussed as categories below.

4.5.2.2.1 Category: Financial assistance

Participants indicated that caregivers often have a need for financial assistance. Even though the disability grant plays a crucial role in at least improving the situation somewhat, it is evident that it is not enough to replace a salary or see to the needs of the stroke patient. This is demonstrated in the following narratives:

“Uhm, uhhhh if you the only one looking after this person and the rest of the people is working then you definitely going to find it hard. Especially if it’s a really frail person. So, Financially the Grant-In-Aid that SASSA offers is R400 if I’m correct, a month. It’s obviously nowhere close to replacing a salary that you might have said goodbye to cause you have to care for this person now. And it doesn't really go to and it doesn't really go to the carer, it’s added to the patient’s grant if they are a SASSA pensioner. So, it’s not really something that goes directly to the carer, it goes to the patient and it’s used for the needs. Uhm but, I think if it’s someone that’s quitting their job, and act as a carer then financially there is huge adjustments to the household circumstances.” (Participant 5)

One participant indicated that some families are left destitute due to leaving their full-time job or losing an income due to the stroke patient’s incapability to return to work.

“Support, financial support. Yes, emotional, financial and also support from your communities. The care burden like a loss of income and changes in your day-to day-living. Some families have to stop working to care for their loved one.” (Participant 13)

The finding that caregivers are in need of financial assistance is supported in the literature. Authors remark that family caregivers of stroke patients experience financial stress, particularly under conditions where the stroke patient had been the breadwinner or if they have to make changes in their working hours by either shortening it or terminating employment in order to take on the caregiving role. Furthermore, out-of-pocket expenses are related to caregiving due to the needs of the stroke patient (Anderson et al., 1995; White et al., 2004; Hassan, 2009; Maleka et al., 2012; Rhoda et al., 2015).

Financial difficulties place a lot of stress on the family caregiver and even greater stress if the caregiver has to terminate work as well (Olaoye, 2013). Consequently, psychosocial support is needed to help the family caregiver to be psychologically sound and to work through their stress, which is discussed next.

4.5.2.2.2 Category: Psychosocial support

Participants indicated that family caregivers need psychosocial support in the form of education, as illustrated in the narratives below:

“Also for the family, they also need emotional support, the family also needs guidance, educational programmes about it because what we find is that most of the families don’t know what the patient has been through and it goes the same for the patient as well. Also, it is difficult for the families to really care for someone if they don’t have the knowledge of what the person has been through.” (Participant 2)

We provide both psychosocial support to the patient because it could be counselling to the patient and individual or it would be counselling to the family because we work with life threatening illnesses whereby the family is kind of like—find it difficult to accept the condition of the patient.” (Participant 9)

The finding that family caregivers are in need of psychosocial support is in line with the study by Collins, Swartz, College and Jefferson (2011) and Gardner and Werner-Lin (2012) that states that caregiving is associated with a psychological burden for the family, hence the need for psychosocial support. Hankey (2004) likewise found that family caregivers had to adjust emotionally to the caregiving role while meeting the needs of the family member who suffered a stroke. Families therefore require psychosocial support in order to cope with the difficulties they face in caring for the stroke patient.

4.5.2.2.3 Category: Need for different forms of medical information on stroke

Participants indicated that family caregivers often need medical information on what will happen to the stroke patient in hospital, as they often lack knowledge of the processes involved. This can be seen in the following narratives:

“Explaining what the processes involved for the patient to be in the hospital. Explaining sometimes what the scans are for, why we are doing scans, why we are looking at the heart if there are problems in the brain, why the patient is still so sleepy...uhm...why they can’t talk, why they have a chip in their nose. You know, a lot of explaining after you’ve contained, after you have reassured and explained actually this is what is going to happen.” (Participant 6)

Another participant indicated that there is a need to give information about the changes in the emotions and the behaviour of the stroke patient to enhance the understanding of the caregiver.

“Yes, they are not prepared and there is also a lack of information about the patient’s emotions and behaviours because now that they have a disability. Definitely like stroke, it affects part of the brain of the patient so now there is this kind of behaviours that the patient presents of which the caregivers is not prepared; they don’t know how to deal with such a patient.” (Participant 9)

The narratives above are indicative of caregivers requiring information about rehabilitation for stroke patients. This supports the findings of Pindus et al. (2018) which indicate that family caregivers and stroke patients experienced frustration and dissatisfaction with the lack of information to assist with the care and recovery of the stroke patient. Similarly, Stroebele et al. (2011) indicated that lack of information is generally prevalent in developing countries, which is the case in South Africa.

This is despite SA being a signatory of the Global Stroke Bill of Rights (2014), which clearly states that stroke patients should be well informed and prepared for the impact of the stroke. This implies also keeping the caregiver informed, so as to best care for the patient. Rule 5 of the United Nations Rules on the Equalisation of Opportunities for Persons with Disabilities additionally states that patients should have access to communication and information (UN, 1993).

Bråndal et al. (2016) declare that, in having access to the relevant information, the burden of the family caregiver is lessened. Therefore, access to communication and information on stroke is crucial to the family caregiver, alongside the need for training in how to physically care for the patient, which emerged as the next category.

4.5.2.2.4 Category: Training on providing physical care

Several participants indicated that education and training regarding the physical care of the stroke patient are required by family caregivers. These participants stated that the family caregivers would require training in mobilizing the patient and in providing specific tasks such as

bathing, toileting and feeding. A few participants reported that it is even more difficult if the patient is discharged from the hospital or the rehabilitation facility with a nasogastric tube. Families are not trained to deal with this type of equipment as can be seen in the narratives below:

“Normally the carers just need a bit of education and training on how to provide that care. Uhm, physical care to the patient, if patient is bedbound, then how to turn them, how to turn them to bed, bath, toileting, nappies, feeding, if they've got a nasogastric tube, that type of thing.” (Participant 1)

“There are some patients when the prognosis is very bad and there's nothing the medical team can do to better their health condition and you will be forced, it would be discharged on an NG (nasogastric tube). The families will be a bit reluctant to deal with that. They would tell you that we are not equipped to care for such a patient.” (Participant 9)

“One would say: ‘we live on a third floor, now we can't have someone who's in a wheelchair or who can't walk up the stairs, we are all employed, there's no one to look after her during the day’ or ‘we're not trained to do physio, we don't know what to do with her when she gets home.’” (Participant 16)

It is clear from the above narratives that family caregivers require training to provide physical care to the patient. This was also found by Khondonwe and Mpofo (2007) and White, Cantu & Trevino (2015) who indicated that family caregivers of stroke patients need skills training, in order to provide physical care to stroke patients. A lack of training could lead to family caregivers feeling overwhelmed with caregiving duties (Cameron et al., 2013; King & Semik, 2006). The Global Bill of Rights for Stroke Patients (2014) places emphasis on the right of patients to receive the best care. In order to do achieve this, caregivers require adequate training. The narratives in this study indicate that this right is not achieved as participants highlight that family caregivers are not equipped with necessary information or skills to provide the best care for stroke patients. Khondonwe and Mpofo (2007) similarly confirmed that informal caregivers of stroke patients reported a lack of information and the requirement for skills training.

Therefore, the need for training in providing physical care is crucial to the family caregiver to ease the burden of care and provide support to the caregiver. Participants were therefore asked about the services they render to stroke patients and their family caregivers on a micro, meso and macro level. The services rendered on these levels are discussed next.

4.5.3 Theme 3: Services rendered by social workers from an Ecological Perspective

Social workers provide various services to the family caregivers in order to enable the caregivers to provide proper care to the stroke patients as well as to effectively and holistically address the needs of the family caregiver (Kokorelias, Gignac, Naglie & Cameron, 2019). These services are provided at different levels, namely the micro, meso and macro level of the ecological perspective, as seen in Chapter 3.

4.5.3.1 Sub theme: Micro-level services to family caregivers of stroke patients

As previously stated, the micro level is concerned with the individual, and includes attitudes, knowledge, values, self-esteem, self-concept, skills and behaviour (Miley & DuBois, 2010). Two categories emerged under this sub-theme, namely counselling services and medical information sharing, which are discussed below.

4.5.3.1.1 Category: Counselling services to family caregivers of stroke patients

A few participants stated that they render counselling services to both the patient and their families. This counselling includes family and couple counselling. Both types of counselling are often rendered because of the changes that the stroke has on the individual, their partner and the family. A stroke frequently leaves individuals with a physical disability, which may affect sexual relationships and roles within the family, especially if the stroke patient had been the breadwinner. Thus, the families need counselling to adjust to the new role as caregivers. This is evident from the following narratives:

“Family counselling, couple counselling because it’s sometimes a spouse or the partner who’s had a stroke.” (Participant 13)

“If a couple wants to come talk about how they’re going to have sex now that the person is disabled, we can make an appointment... so it’s -- all the services we give to the patient

can be extended to the family if the family asks for it. We give education, the social workers give education on sexuality.” (Participant 15)

Another participant mentioned that individual counselling is also utilised to assist family members with the adjustment.

“One-on-one it’s the individual, it’s the social work services, you know, the therapeutic counselling, individual counselling.” (Participant 14)

Participants also referred to the fact that, besides counselling for making adjustments to their changed circumstances, there is strong emphasis on educating family members about the available resources and how to access these resources.

“So, the social worker’s role is to now counsel with regards to this adjustment, this what has happened now, how the person is and how do they plan for the future in terms of getting an old age home application because they have waiting lists everywhere. Disability grants, we educate them on what’s the process, if the doctors needs to complete one, they do that and we make families aware of the resources out there for the respite care, maybe sometime in their life they need a break they might just apply for the person to be there for a week or two.” (Participant 16)

The narratives presented above reflect that social workers are rendering different types of counselling services on a micro level to stroke patients and their families, in order to help the family adjust to the disability and to assist with any changes. According to the third right in the Global Bill of Rights of Stroke Patients (2014), all patients should be supported in their recovery. The counselling offered by social workers thus serves to fulfil this right, as social workers enable the patients and family caregivers to adjust to the disability, to understand the disability and to enhance the capabilities of the caregivers (Strydom, 2015; Chitereka, 2014).

4.5.3.1.2 Category: Medical information sharing on stroke

Participants indicated that family caregivers need medical information on stroke, as they often do not have knowledge of the medical processes involved in caring for the patients once they return

home. Some participants stated that they share information on stroke with the family caregivers, as seen from the following narratives:

“So, if the patient is cognitively okay, I will explain everything to the patient and then usually the telephonic phone call to the family, just to give them a breakdown of what is going to happen and what the process is.” (Participant 1)

“Explaining what the processes involved is for the patient to be in hospital. Explaining sometimes what the scans are for, why we are doing scans, why we are looking at the heart if there are problems in the brain, why the patient still so sleepy...uhm... why can't they talk, why they have a chip in the nose.” (Participant 6)

These narratives indicate that social workers share information on stroke with family caregivers. This finding is supported by other studies. The combined delivery of counselling and information by social workers to stroke patients and family caregivers in the out-patient phase has been described as crucial for patient adjustment (Padberg et al., 2016). Thus, sharing medical information on the effects of a stroke with the family caregivers can be considered a crucial intervention. Stein et al. (2003) have also proposed that caregivers with a greater understanding of the functional ability of the stroke patient may have increased potential to make specific predictions of recovery. This may also alleviate the feelings of stress experienced by caregivers.

In addition, Rule 5 of the UN (1993) stipulates that measures need to be implemented to supply access to communication and information to persons with disabilities. The narratives are indicative that social workers are once again unknowingly fulfilling Rule 5 of the UN (1993), which addresses access to communication and information for persons with disabilities. The social worker's role within the MDT, is to enable family caregivers to access the needed resources through interventions such as advocacy, guidance and referrals that assist the family (Dorset, 2010)

4.5.3.2 Sub theme: Meso-level services to families of stroke patients

Meso-level services can be defined as a set of micro systems which link with one another; one such example of social work intervention is group work. Intervention on the meso level intends to address issues that affect interaction and family relationships (Hepworth et al., 2017); these

include addressing the mental wellbeing of family caregivers and the patients themselves (Engstrom, 2012).

Participants pointed out family meetings, peer support groups and sexuality groups as meso-levels services offered to family caregivers of stroke patients, which are discussed as categories in the following:

4.5.3.2.1 Category: Family meetings

A few participants stated that family meetings are conducted in order to discuss the medical prognosis of the stroke patient, objectives of care and the discharge plan. Participants expressed the following regarding family meetings:

“Depending on the complexities of the case I mean there will sometimes be at the family meeting where the doctor will be involved or the doctor and the therapists or sometimes the therapist will call the family in so that they can have like a training session with everyone so speech will be there to show them and OT will be there to show them. So, if for example the doctor decides to call the family meeting. It’s usually just to give the family a breakdown of the medical condition of the patient what has happened, what is expected, what is the prognosis. Uhm...what services have been provided by the patient has been here. Sometimes they discuss tests or scans or procedures that need to take place because sometimes the patient is not able to give consent, so the family has to do that. Uhm...But also, it gives the doctor an idea about the family structure, family support, family insight.” (Participant 1)

“We do with all of our stroke patients what we call a family meeting where we discuss what has happened up until now, what are our goals and what do we need in place for discharge. And that’s when we will then talk about the care, that level of care that’s needed and that’s when I’ll then say okay, you need 24 hour care, I’ll get you three quotes so you can start comparing. You need respite, these are the options, and these are the financial brackets and we discussed that within the meeting and then take it from there.” (Participant 18)

The narratives indicate that family meetings are arranged to discuss the way forward, provide the family with information, as well as addressing the abilities of the family, are supported in other studies. Metze, Abma and Kwekkeboom (2016) confirm that family meetings are organized to address strengths and abilities of the family. Huson and Aranda (2014) reported that family meetings provide a chance to discuss the nature of care to patients with advance diseases and their family caregivers. These authors add that the main purpose of the family meeting is to explain the objectives of care, talk about the patient's condition and any progression of the condition. Consequently, family meetings are crucial as these can help the family caregivers to understand the nature of the stroke and prepare them for the caregiving role, thus reducing the burden of care, as collective participation becomes relevant. Social workers engage families in family meetings in order to provide the best care for patients, as stipulated in the Global Bill of Rights of Stroke Patients (2014). The narratives are further indicative of social workers unknowingly applying Rule 9 of the UN rules on the equalisation of opportunities for persons with disabilities (UN, 1993), which speaks to families needing to be involved in the recovery and care of patients.

4.5.3.2.2 Category: Sexuality groups

A few participants indicated that sexuality groups are facilitated with stroke patients who experience a sexual dysfunction. The narratives, however, did not state that the spouse of the stroke patient who became the caregiver is included in these groups. However, the family caregiver who is the spouse can indirectly benefit from the sexuality group if the stroke patient attends such a sexuality group.

We have sexuality groups as well...it affects their sexuality...with any stroke, ja, so any stroke it affects your sexuality, male or serv.” (Participant 12)

“The sexuality group is a therapeutic group and then we have the services of peer supporters also. Sexuality groups is more for spinal cord injured but if it's also a stroke patient where there's a sexual dysfunction, we can also organise that.” (Participant 14)

The finding from the narratives above, that sexuality groups are facilitated with stroke patients who experience a sexual dysfunction, indicates that stroke patients are included in sexuality

groups in order to help them overcome sexual difficulties and is supported in the third right of the Global Bill of Rights of Stroke Patients (2014). According to the third right in the Global Bill of Rights of Stroke Patients (2014), all patients should be supported in their recovery. The narratives are indicative that Rule 9 of the UN (1993) is applied, which applies to the patient's right to personal integrity and to not experience discrimination on grounds of such a patient's sexual relationship.

4.5.3.3 Sub theme: Macro-level services to family caregivers of stroke patients

Macro-level social work practice refers to the capability to intervene in the big picture with larger systems in the socioeconomic environment. This may entail that social workers collaborate with consumers of various services to maximise and strengthen opportunities for people at community, organisational and global levels (Cox, Carolyn & Long2019). Home-based care, respite and day care services assisting with referrals to rehabilitation facilities and assisting the families with grant applications emerged as categories under this sub-theme and are discussed below.

4.5.3.3.1 Category: Home-based care services

Home-based care services are an integral component of community-based care (Department of Health, 2001). A few participants expressed that families are referred to home-based care services as part of the service rendered by the social worker at the hospital or rehabilitation centre. This is evident from the narratives cited below:

“There'll be a lot of referrals out whether it's for step down or it's for home-based care or uhm...that type of thing.” (Participant 1)

“For people not requiring intense rehab on those levels we will just refer to the local community-based services, a home-based carer.” (Participant 5)

Uhm, we refer patients to home-based [care services] almost all the time, whether they need it or not, so that's like part of our discharge plan.” (Participant 6)

The above narratives speak to the third right of the Stroke Global Bill of Rights (2014), which indicates that patients should be supported in recovery. Home-based care services thus serve to

fulfil this right, as patients and families are referred to home-based care services and these services are co-ordinated from the primary level of care, in order to assist the family caregiver to help them with caregiving duties and addresses respite care (De Wet, 2012; Hassan, 2009). Respite care is discussed later.

One participant also indicated that home-based care services are not sufficient in some cases, because family members work, and the patient is alone at home:

“A lot of time there's nobody available, there's nobody available at home, they are all working the patient is just going to be home alone. So, it's when the patient needs more than just the home-based care popping in the morning and then you're gone again, that's when it becomes a challenge.” (Participant 5)

The finding that home-based care is not always adequate to support the needs of the caregiver who cares for the patient is confirmed by Uys (2005) who indicated that families sometimes need a more comprehensive service but that home-based care is not designed to replace the family caregiver. It therefore is not a 24-hour service, which families may need. Home-based care only serves as a supportive and complementary function.

Some participants also mentioned that there are insufficient home-based care services in communities, which means that the patient may be referred to the home-based care system, but not gain access to the needed service as seen below:

“Home-based care system can't meet all the needs, so very often the client won't be attended to even though they are referred.” (Participant 11)

Home based care... Access to that, it doesn't work as efficiently as it's supposed to because sometimes, you know, caregivers, they wait for a long period until a home based carer rocks up at, you know, at night.” (Participant 12)

It is evident from the above remarks by participants that home-based care services are inadequate in some communities. Home-based care is an invaluable service to family caregivers, but it seems that there are not enough carers for home-based services. Furthermore, they only render services for a few hours on alternative days and some home-based carers lacked the knowledge to provide adequate care to the stroke patient. A scarcity of home-based care services in the

Western Province is confirmed by Maart & Jelsma (2013) and Hassan, Visagie & Mji (2011). As a result, family caregivers perform caregiving duties most of the time and this leads to the need for respite services.

4.5.3.3.2 Category: Respite services

Respite care services offer inpatient care by a facility to the patient for a period of at least a month at a time in order to relieve the family caregiver from the caregiving duties (Hassan, 2009). A few participants stated that they refer family caregivers to respite services, as is evident in the narratives below:

“At our facility they can either come into respite. We have a 24h nursing care services available to them and then we also have the day care facility and they are working adults and they would still like to look after the person when the person go home. They can then bring the person in in the morning, then the person is here and get 24h care and then they can go home with the person. Or when they are in respite, they are here for 2 weeks.” (Participant 2)

“We make families aware of the resources for respite care, maybe sometime in their life they need a break they might just apply for the person to be there for a week or two.” (Participant 16)

The finding that respite care services offer inpatient care by the facility is confirmed in literature. Respite care provides caregiver support in a way that enables caregivers to retain employment as well as allowing the caregiver to take a break from caregiving (Hassan, 2009; Qayyum et al., 2013). The availability of respite care services serves as an example of how community resources can be made available to support family caregivers in caring for stroke patients, as indicated in Article 9 of the UNCRDP (UN, 2006), despite perhaps not being readily available, as only some participants made reference to respite care. Respite care also comes in the form of a day care service and it is discussed in the next category.

4.5.3.3.3 Category: Day care services

Day care centres provide care to persons who are in need of care throughout the day while the family caregiver sees to daily duties (Hassan, 2009). A few participants indicated that family caregivers need time for themselves and some family caregivers cannot afford to resign from their daytime jobs. Hence, day care centres offer a day programme for a stroke patient who requires full-time care. Families can bring their family members in for the day and have to collect their family members at four or five o'clock the afternoon. Throughout the day, patients are cared for by a variety of trained caregivers and professionals. The following statements highlight that day care services are being offered to stroke patients:

“We have a 24h nursing care services available to them and then we also have the day care facility and they are working adults and they would still like to look after the person when the person go home. They can then bring the person in in the morning, then the person is here and get 24h care and then they can go home with the person.” (Participant 2)

“So, we have a day programme here, like where people can come in for the day. The residents. Not residents, day visitors.” (Participant 3)

The finding that day programmes are available to stroke patients, which allows the family caregivers to remain employed as well as allowing stroke patients to remain living within their homes, is supported in Article 19 of the UNCRPD (UN, 2006). According to this Article, persons with disabilities should have access to a range of community resources that support them and should not be obliged to live in a specific living arrangement. Day care services achieve this, as these services enable the stroke patient to remain living in their homes and to access the day care services on a day-to-day basis. Day care centres offer an organised day programme in order to rejuvenate the self-care of the patient, as well as counselling to both the patient and family (Olaoye, 2013; Choi, 2013). This benefit both the family caregiver and the stroke patient, as both will be receiving psychosocial support and it will lessen the caregiving strain.

4.5.3.3.4 Category: Rehabilitation services

The aim of rehabilitation services is to provide patients whose functioning is impaired with services that improve and maintain their social functioning (WHO, 2015). A number of participants indicated that stroke patients receive rehabilitation services, but they did not elaborate on the services being extended to the family caregivers. Participants had the following to say regarding rehabilitation services:

“We refer those who have the potential to rehabilitation facilities. There’s people at the district health, they reach out to that organisation. So, the physio and OT would go there once or twice a week I think.” (Participant 5)

“As a rehabilitation centre we have a set philosophy which we work on outcome-based, goal orientated, client centred model. We believe in rehabilitation. That is what it is and that’s why for strokes here, their average length of stay is about six to seven weeks.” (Participant 10)

“We have an average of five to seven weeks of inpatient rehab for a stroke patient.” (Participant 18)

The finding that rehabilitation services are provided to stroke patients is confirmed in literature. The above narratives reflect that stroke patients are referred to rehabilitation services, which is a goal orientated programme. The availability of rehabilitation services serves as an example of how community resources can be made available to support family caregivers in caring for stroke patients, as indicated in Article 9 of the UNCRDP (UN, 2006). According to Article 26 of the UNCRPD (UN, 2006), suitable and effective measures should be taken to empower persons with disabilities to achieve and maintain maximum independence, full mental, physical, vocational and social capability, and full involvement and participation in all aspects of life through rehabilitation services. It remains questionable whether this article is achieved, as social workers were not asked whether these services are implemented.

In addition, Article 25 of the UNCRDP (UN, 2006) stipulates that persons with disabilities deserve the privilege of a supreme achievable standard of health without discrimination. To provide the highest achievable standard of health to people with disabilities, early recognition

and provision of services intended to lessen and counteract further disability should be taken into consideration (UN, 2006). The narratives are thus indicative that rehabilitation services aim to lessen and counteract further disabilities.

4.5.3.3.5 Category: Stroke awareness programmes

Stroke awareness implies realising how to recognise when someone is having a stroke, as well as knowing the relevant signs to recognise when stroke might be occurring (“FortHealthCare”, 2017). Very few of the participants stated that they create awareness around strokes. Such awareness was created through sport days, projects, a stroke awareness week and National Stroke Day. That stroke awareness is receiving attention is confirmed in the following narratives:

“We had last year, a stroke awareness day, which we do every year.” (Participant 6)

“We do our awareness of the caregivers. We do have sport days for fun days, for the clients as well. That is something we do to make sure that they go out because most of them, because of the disability, they feel that they lock themselves indoors and they don’t want to go out.” (Participant 7)

“I think there can’t be too much awareness and I think awareness especially around chronic conditions, lifestyle, life conditions of living, you know. Like hypertension, cholesterol, diabetes, which are primary causes of strokes.” (Participant 11)

The finding expressed in the narratives above indicates that efforts to increase stroke awareness take the form of awareness programmes. These awareness programmes include family caregivers, providing them with information on lifestyle and living conditions. These narratives link to Rule 9 of the UN rules on equality (UN, 1993), which refers to families needing to be involved in the recovery and care of patients. Additionally, it links to Rule 5 (UN, 1993), which stipulates that programmes of action need to be established and information needs to be accessible to persons with disabilities. The availability of stroke awareness programmes serves as an example of how awareness programmes can be made accessible to support family caregivers as well as stroke patients, as outlined in Rule 9 and Rule 5 (UN, 1993), regardless of

perhaps not being readily accessible, as only a few participants made reference to stroke programmes.

Moreover, Article 25 of the UNCRPD (UN, 2006) states that persons with disabilities deserve the privilege of a supreme achievable standard of health without discrimination. This Article further says that, in order to provide the highest achievable standard of health to people with disabilities, early recognition and provision of services intended to lessen and counteract further disability should be taken into consideration (UN, 2006). This is thus achieved, as stroke programmes intend to create awareness of the early recognition of strokes.

4.5.3.3.6 Category: Social Security as a form of support for the family caregiver of the stroke patient

Social grants offer a financial buffer to family caregivers in terms of the Disability Grant, the Care Dependency Grant and the Grant-In-Aid (RSA, 2004) to ease the burden of those with disabilities and their caregivers. The Grant-In-Aid (GIA) provides support to an individual who is in need of full-time care due to physical or mental disability; the Disability Grant (DG) provides funding to adults with disabilities; and the Care Dependency Grant (CDG) offers funding to families with a disabled child who is below the age of 18.

A few participants stated that they apply on behalf of the families for the DGs and the GIA.

“If you’re under 60 then we apply for the Disability Grant and a Grant-In-Aid, if he qualifies. And then when the person reaches the age of 60, then it automatically will switch over to an Old Aged Pension.” (Participant 11)

“We will at all cost try to complete the DG applications as an inpatient but for whatever reason we couldn’t, then we just transfer, or we refer the client to their local SASSA office for example.” (Participant 12)

Some participants stated that they only assist and guide the family through the grant application. This is evident from the following narratives:

Then, obviously if the family represents themselves and says ‘I am going to look after this person now’, then the doctor will help with the medical assessment form for the

Grant-In-Aid. Then, we would refer that family member or patient to SASSA to complete the necessary application.” (Participant 5)

“We do not do the applications for the grants but we always give them guidance on how to go about it and most of them... because they going to...because remember most of our our referrals from the [name of rehabilitation centre taken out] before they are discharged from the hospital. They do the application for them, but for those that have hiccups, they get discharged before the application is done.” (Participant 7)

Even though family caregivers as well as stroke patients can be in receipt of a DG and GIA, participants stated that the grants are very small and do not cover all the expenses the family might have.

“So financially, the Grant-In-Aid that SASSA offers is R400, if I’m correct, a month. It’s obviously nowhere close to replacing a salary that you might say goodbye to cause you have to care for this person now and it doesn’t really go to the carer. It’s added to the patient’s grant if they are a SASSA pensioner.” (Participant 5)

“So, we do the SASSA disability grant. We look at what we call Grant-In-Aid, which is the caregiver’s grant because you find out in some families, they have to leave their work to come and take the responsibility. So, we also assist them with a little bit of R400 that is put on top of the normal Disability Grant just to assist because some of them, they are using nappies, it’s costly for them to buy so it’s a way of assisting them.” (Participant 9)

The finding is that the DG and the GIA provided to family caregivers are too little to support and meet all the out-of-pocket expenses that family caregivers might encounter while caring for the stroke patients. Not having financial means could be a barrier to accessing health care services and obtaining the necessities for the stroke patient, which will place stress on family caregivers. The above narratives support the finding by Strydom (2015) that indicate that families do not have the financial means to care for their disabled family member and therefore cannot afford to pay for out-of-pocket expenses such as nappies and wheelchairs. Equipment such as wheelchairs and nappies are expensive, and the DG and GIA funding is too little to cover these expenses monthly.

Rule 8 of the UN rules (1993) acknowledges that states are responsible for the provision of social security and income maintenance for persons with disabilities and that such support should point out the special needs of the person, for example, and other expenses related to the disability. Further, the support offered should as much as possible additionally provide cover for family caregivers (UN, 1993). The finding is thus indicative that this rule is not achieved, as participants highlight that family caregivers are often in need of financial support due to the caregiving role and experience out of pocket expenses related to the disability.

In addition, Graham et al. (2010) discovered that the grant money is frequently used to cover basic needs, such as food, and is not used to purchase the aids the person might require or used towards providing care. This moreover links to what was previously discussed under the need for financial assistance. Participants stated that caregivers often have a need for financial assistance, even though the disability grant plays a crucial role in at least improving the situation somewhat. However, it does not replace a salary or cover the needs of the stroke patient.

4.5.4 Theme 4: Challenges in social work service delivery to family caregivers of stroke patients

Challenges in social work service delivery to family caregivers of stroke patients emerged as the fourth theme as participants were asked to name the challenges they experience in social work service delivery to family caregivers of stroke patients. Various challenges that hamper the delivery of social work services to family caregivers of stroke patients were elaborated upon by participants. These challenges occurred at micro-, meso- and macro-level service provision. In addition, these challenges place constraint on social workers. These challenges are discussed next.

4.5.4.1 Sub-theme: Unrealistic expectations of family caregivers from social workers

Several participants stated that families have unrealistic expectations when it comes to social work service delivery. They expect the social worker to assist them with all the decision making. Participants indicated:

"This is going to sound wrong, but a lot of families has the wrong expectations of what the social work services are supposed to provide. So like for example, like I said earlier, when I call a family now to discuss the application for short-term placement or whatever

the case is...uhm, you'll hear that there's this expectation cause there this, whatever question I am asking, will come back to me. Uhm, so if I say: Has there been a family meeting to discuss the care of the patient when the patient should be coming home? Uhm, then it will be: "No but isn't the social worker going to sort that out"? (Participant 1)

'Some have unrealistic expectations... They expect the hospital needs to find a place for this person. And we often have to explain to them, I cannot identify a facility. There is financial implications. That's why you as a family need to consider. I always tell family "here's the list of rehabilitation centres." (Participant 5)

This finding that family caregivers have high expectations of social workers as expressed in the narratives above support the views of Graham and Shier (2013), who also found that communities have high expectations of social workers, especially when it comes to decision making. Social workers furthermore are also expected to deliver high quality services and care in order to improve society (Malley & Fernandez, 2010; Braye & Preston-Shoot, 2006). According to Article 25 of the UNCRPD (UN, 2006), persons with disabilities deserve the privilege of a supreme achievable standard of health without discrimination. Additionally, the Global Bill of Rights for Stroke Patients (2014) places emphasis on the right of patients to receive the best care. Thus, social workers should deliver the best service possible to the stroke patient as well as the family.

4.5.4.2 Sub-theme: A lack of transport to attend social work services at organisation

A lack of transport to attend social work services was reported as a challenge to rendering effective services to family caregivers. Participants shared the view that the provision of transport to family caregivers will ease their burden of care. These views are shared in the narratives below:

"Transport for them...There are wheelchair users, there is crutches and taxi service is like fast fast fast. If there can be transport available...I don't know who God can send from wherever, whether it's heaven or wherever. So, this is the transport now for persons with like and their carers. If there can be that, I believe many other things will fall into place." (Participant 7)

“And you can’t also, you know, it’s not easy for them to access this facility. Do you know that for somebody to travel from say Gansbaai area to go out for a weekend, it sometimes cost R1000 – because it’s coming to fetch, going back home, bringing back and going back home again. So, it’s like a double trip. It’s not easy.” (Participant 11)

The finding demonstrates that families experience transport difficulties such as high transport fares and the unavailability of transport, which prevents them from receiving social work services. Hence, participants stated that the provision for transport to family caregivers will ease the caregiving burden so that the family will be able to attend social work sessions and not rely on telephonic contact. These findings validate findings by Olaoye (2013) who found that transportation fares to the rehabilitation facilities were not affordable and that in some cases poor travel routes from the family’s home to the facilities are a hindrance to accessing services. Additionally, Johansson and Wild (2011) believe that difficulties in access to rehabilitation services may occur due to geographical barriers and inadequate resources.

This is despite the fact that Article 9 of the UNCRDP (UN, 2006) stipulates that member countries, including South Africa, must ensure that physical barriers to entering buildings, transport, roads, workplaces and housing are eliminated for people with physical disabilities to have the same access as those without such disabilities. Article 19 further states that people with disabilities should have access to a range of community resources that support them and should not be required to live in a specific living arrangement. Nevertheless, it is evident from the finding above that institutional barriers such as the lack of transport for accessing services, including social work services, are experienced by family caregivers.

4.5.4.3 Sub theme: High caseloads and a lack of time on the part of social workers to engage with family caregivers

The participants cited high caseloads and a lack of time to engage with family caregivers as a hindrance to the provision of social work services. Different reasons were identified, such as the fact that it is not possible to see families after hours. Participants responded by saying the following:

“And just in terms of time. You know...we don’t always have the time to fully engage with the family. And it can be for lots of reasons. If you are working and the family is

working. I mean I only work until 4 o'clock. If they can't get off work to come and see you...you know, there's all these constraints of how we engage each other or how we find time to engage with each other." (Participant 3)

"Time. A lot of our patients come in; we average five to seven weeks of inpatient rehab for a stroke patient so. We work with a six to eight-week backlog before first contact. You cannot be here that long." (Interview 18)

The finding, as revealed in the narratives above, is consistent with former studies, which indicates that social workers have a backlog and high case load, which makes it challenging to render social work services to families (Dlangamandla, 2010; Strydom, 2010). Moreover, Pinzon, Asanti, Sugianto & Widyo (2009) also found that a lack of time because of increased caseloads on the part of health professionals is an issue in engaging with all families. This finding can be indicative of a shortage of social workers rendering services to family caregivers of stroke patients, which is discussed next.

4.5.4.4 Sub theme: Shortage of social workers rendering services to family caregivers of stroke patients

The shortage of social workers rendering services to family caregivers of stroke patients emerged as a sub-theme. It became apparent from the narratives of some participants that social workers are too few in numbers to render extensive services to family caregivers. The participants noted the shortage of social workers in the following way:

"So, the areas are far apart. You can only maybe see 5 clients. We also have other activities we have to fit in. Everything during those 2 times. That is the only big challenge for me. Where you might have wanted to see a client and maybe say 2 times a term but you cannot." (Participant 8)

"I mean if you're looking within the community settings we are few and far between at the Community Health Centres and your service delivery and inputs are going to be a more crisis intervention driven which means you're only going to see the guy whose head is falling off. The others won't even get to you. If we can have more social workers at that level who can actually take hands with the Occupational Therapist and run more supportive programmes, I think we can achieve a lot." (Participant 10)

The finding that there is a lack of human resources noted in the narratives above, particularly the shortage of social workers rendering services, has been noted in various studies (Strydom, 2010; Schmid, 2012; Sibanda, 2013; Loffell, Allsopp, Atmore & Monson, 2008; Lombard & Kleijn, 2006; Skhosana, Schenck & Botha, 2014). The lack of human resources could result in fewer support programmes being implemented by social workers at community level. Having fewer social workers to implement support programmes has a further negative impact on the ability of organisations to adhere to Rule 4 of the UN rules (1993), which calls for support services to stroke patients and their caregivers.

4.5.5 Theme 5: Suggested improvements for service delivery to family caregivers of stroke patients

This theme represents the participants' description of suggested improvements for delivery of services to family caregivers of stroke patients in order to ease the burden of care. The suggested improvements that emerged as sub-themes involve the employment of more social workers and specialised social work teams and ongoing support, training and education of family caregivers. These sub-themes are discussed below.

4.5.5.1 Sub-theme: Employment of more social workers and specialised teams

Participants expressed the need for more social workers in order to improve services to family caregivers, as indicated by the following narratives:

"I think more can be done in terms of support to the families. And again, that takes manpower, it takes time, it's not always possible and you got one social worker like we have for 700 residents and it makes it very very difficult. We haven't extended that services to the family yet, it's actually only for the residents at this point, where the counsellor could go in and spend one on one time with the residents." (Participant 3)

"How can you implement all these policies and all these legislation and you have this little manpower to do it with? Resources and manpower is too little and I said earlier, you get one social worker that maybe covers sometimes at a facility 600 patients." (Participant 5)

Another participant mentioned that there is a need for specialised services to stroke patients as there are a large number of patients requiring these services.

“Stroke has now become--it has become big; it’s no longer limited to a certain group of people; it’s out there. And it happens to the poor and the rich and who offers specialised services to them?” (Participant 16)

The finding that there is a need for social worker services to family caregivers of stroke patients and that employing more social workers as well as specialised services to family caregivers would contribute to effective services being rendered is confirmed in the literature. These suggestions link to what has been discussed earlier in the chapter. A lack of human resources, particularly the shortage of social workers rendering services, has been noted in various studies (Strydom, 2010; Schmid, 2012; Sibanda, 2013; Loffell, Allsopp, Atmore & Monson, 2008; Lombard & Kleijn, 2006; Skhosana, Schenck & Botha, 2014). This view, however, is contrary to the view held by Capa (2019), who stipulated that, at that stage, a backlog of 3 969 social workers who had been given scholarships by the DSD had not been assigned social work positions. Nonetheless, organisations do not have money to appoint social workers, hence positions have not been assigned (Goliath, 2018).

The shortage of social workers rendering services to family caregivers of stroke patients poses challenges to the realisation of policy and legislative objectives guiding the care of stroke patients. For effective service delivery to be guaranteed, policies and legislation need to be executed effectively. For this to materialise, human resources are needed. Social workers employed in the particular sector should thus be trained in the necessary knowledge of the specific policies and legislation for effective implementation and ultimately render effective services in line with the set guidelines of policies. Consequently, employing more social workers as well as specialised teams in this regard will improve services to family caregivers of stroke patients.

4.5.5.2 Sub-theme: Ongoing support, training and education of family caregivers

The participants highlighted the need for the provision of ongoing support services, training and education for family caregivers. Several participants stated that support services, training and caregiver education stops when the stroke patient is discharged. Participants therefore expressed the need for ongoing services post-discharge, as seen from the narratives below:

“Uhm but but like I said previously about the group work, uh support groups or even just awareness campaigns and things like that. Just the fact that the caregivers would know where to go if they need help. Uhm and where to go for specific help. Cause a lot of times they are so lost, they are very new, they don’t know what they are doing uhm...and they get so anxious. We can ease those concerns by providing the training here but at home if something happens then (laugh) are they going to remember the training that they got or are they just going to freak out and have a meltdown and then call the ambulance so that the patient can come back to hospital. ” (Participant 1)

“So, education. Like I said...First education about your health. How to take good care and then obviously if something happens – what to do. Uhm, I think it’s pretty important. And then I think people need. Because you know uhm...most people just want to return to the way they were before. People want things just to settle down. The other thing that people also tend to forget is when you had a stroke, your chances of having another stroke is very high. And so, proper care after you had your stroke is just as important.” Participant 6)

“I think we need support for family, professional support either by doing group sessions, educating them.” (Participant 16)

The finding that ongoing support, training and education is a great need that may ease the burden of care is in line with the guideline set in UNCRDP as well as the Global Bill of Rights for Stroke Patients (2014). White et al. (2015) further reiterated this finding by indicating that training family caregivers to provide physical care, as well as education on active coping- and problem-solving skills, may result in positive caregiving outcomes, and thus benefit the patient and family caregiver. Training family caregivers may also decrease personal expenses and advance their quality of life (Rhaman & Salek, 2016) and assist in mitigating potential caregiver burnout (Kessler, Dubouloz & Egan, 2009).

4.6 CONCLUSION

An empirical investigation into the perceptions of social workers regarding services to families affected by a stroke was conducted and the analyses of the empirical findings as gathered by means of a semi-structured interview schedule are presented in this chapter. The third objective for this study which was to explore the services rendered by social workers to families affected by a stroke has thus been achieved.

This chapter reports that social workers are not well versed in international or national policies and legislation guiding social work services to family caregivers of stroke patients. The objectives for accountable and effective rehabilitation services regarding full participation of persons with disabilities in the planning, assessment and monitoring of services, which social workers were not well versed in, are outlined in the above-mentioned policies and legislation.

Despite the array of national and international policies, it is evident that there is a lack of tangible knowledge of the various documents that relate to the care of stroke patients and their family caregivers and serve to guide social work services. The ignorance concerning these policy documents has a negative impact on family caregivers of stroke patients, as they are excluded from services and barriers to including family caregivers in services are not eliminated.

However, it is acknowledged that social workers face a variety of challenges, which prevents family caregivers from accessing social work services. This includes a lack of follow-up services in the community and a shortage of social workers. To enable social workers to render effective services to family caregivers of stroke patients, the researcher suggests the employment of more social workers and specialised teams and the provision of ongoing support, training and education to family caregivers, which will ease their burden of care. The findings of the empirical investigation were confirmed and controlled against findings in the literature chapter. In the next chapter, the focus is on the conclusion and recommendations arising from this study.

CHAPTER 5

SUMMARY OF FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

This study aimed to gain an understanding of social work services rendered to families caring for a relative who suffered a stroke. This aim was attained through the implementation of four research objectives. The first objective of this study was met in Chapter 2, in which policy and legislation with regard to patients of a stroke and the challenges families experience in caring for them were discussed. The second objective of this study was addressed in Chapter 3, which identified the social work services rendered to families caring for a relative affected by a stroke from an ecological perspective. Chapter 4 aimed to attain the third objective by presenting the empirical investigation on the perceptual experiences of social workers in respect of the social work services rendered to families caring for a relative who suffered a stroke. The aim of this final chapter is to present the conclusions drawn from the study and to make suitable recommendations.

5.2 CONCLUSIONS AND RECOMMENDATIONS

The conclusions and recommendations discussed in this chapter are based on the findings of the empirical investigation and are presented following the structured themes and sub-themes to that of Chapter 4, hence, following the order of the semi-structured interview schedule.

5.2.1 Profile of participants

The criteria for inclusion in this study expressed that participants had to be registered social workers, proficient in English or Afrikaans and working with family caregivers of stroke patients. Participants were from the different sectors such as the government, the private sector and NPOs. Most of the participants were between the ages of 30 to 59 years, thus there was an even spread of participants amongst the different age groups. The advantage for the study is that most of the participants were experienced social workers, thus providing insightful responses adding much value to the study, from a diversity of services sectors, including the government, non-profit and private sectors.

The majority of the participants' highest qualification obtained in social work was a BA social work degree. None proceeded to doctorate level. Therefore, it can be concluded that the majority of the participants did not pursue further academic qualifications. This could be in view of postgraduate qualifications not being a prerequisite to practice with families and stroke patients.

Recommendations:

- Social workers rendering services to family caregivers of stroke patients should consider pursuing postgraduate qualifications in social work in order to improve their experience and skills with regard to policy and legislation guiding the care of stroke patients.
- The DSD must provide incentives within the social work profession so that social workers can enrol in postgraduate training in the form of a Master's or Doctorate degree with the aim of contributing to social workers' career trajectories and to increase their income. This will assist social work interventions to remain evidence-based and pertinent in social work service delivery to family caregivers of stroke patients.
- Training in understanding and being knowledgeable about policy and legislative frameworks which guide social work services to family caregivers of stroke patients, are required by the DSD.

5.3 POLICY AND LEGISLATION GUIDING THE CARE OF STROKE PATIENTS

The policy and legislation documents guiding the care of stroke patients are overarching documents from a macro level that guide service provision on a micro as well as meso level.

5.3.1 Familiarity with policies and legislation guiding the care of stroke patients

The findings indicate that social workers lack knowledge and familiarity with these legislative documents and policies, both internationally and nationally. Participants were only able to identify two legislative documents and one policy document related to rendering services to stroke patients and their caregivers that they were aware of. These included The Constitution of Republic of South Africa (Act 108 of 1996), Older Person's Act (Act 13 of 2006) and the White Paper on Social Welfare (1997). If social workers have limited knowledge about policy and legislative documents, this limitation could influence the delivery of social work services.

Recommendations:

- Social workers should be knowledgeable about policy and legislation pertaining to service delivery to stroke patients and their families.
- In-service training should be available to ensure that service delivery is tailored to policy and legislation guiding the care of stroke patients and family caregivers.

5.4 CHALLENGES AND NEEDS EXPERIENCED BY FAMILY CAREGIVERS OF A STROKE PATIENT

The challenges that participants faced in rendering services to family caregivers of stroke patients were investigated.

5.4.1 Challenges of family caregivers of stroke patients

The findings of this study indicate that family caregivers experience challenges on physical, emotional and economic levels. Challenges on a physical level included the lack of physical aids for stroke patients and the inaccessibility of houses. The identified challenges on an emotional level included accepting changes in the behaviour of stroke patients and the lack of formal support in communities. On an economic level, it included the lack of facilities for effective caregiving and the lack of suitable housing.

Another challenge which arose was the lack of resources in organisations, such as the financial means to assist families and that families lack funds to obtain resources such as physical aids. These challenges repressed family caregivers from effectively caring for stroke patients once the stroke patient returned home from the hospital or rehabilitation centre.

It can thus be concluded that challenges on a physical, emotional and economic level, hamper effective caregiving of stroke patients.

Recommendations:

- Social workers should equip or link family caregivers to resources that provide them with knowledge about providing care and regarding the nature and effects of stroke. This can be done by means of training programmes to enhance skills and to enable family members to care for stroke patients at home.

5.4.2 Needs of family caregivers of stroke patients

The needs which were identified by service providers include micro-, meso- and macro-level interventions, such as the need for financial assistance, psychosocial support, information on stroke and need for training on providing physical care.

Financial difficulties place a lot of stress on family caregivers due to the fact that some family caregivers may have to terminate their employment if the stroke patient cannot return to work. Furthermore, providing care can be a psychological burden; hence caregivers are in need of psychosocial support. In addition, without information on stroke, caregivers may lack the basic knowledge for caring for stroke patients and this sometimes results in feelings of frustration. Lastly, a lack of training on providing physical care may render caregivers to feel overwhelmed and unprepared for caregiving duties, according to the findings of this study.

Therefore, it can be concluded that the fulfilment needs of family caregivers of stroke patients or the lack thereof directly affects the care of stroke patients. If these needs are not fulfilled, family caregivers may continue to feel overwhelmed with caregiving duties and experience caregiver burnout.

Recommendations:

- Social workers should render psychosocial support services to family caregivers of stroke patients. These services should include access to communication and information on stroke.
- Social workers should link family caregivers to access training on how to physically care for the patient, such as community-based services.

5.5 SERVICES RENDERED BY SOCIAL WORKERS FROM AN ECOLOGICAL PERSPECTIVE

In order to gain an understanding of social work services to family caregivers of stroke patients, participants were asked to describe the services rendered on a micro, meso and macro level. All participants indicated the services that were rendered in terms of case work, group work and community work.

5.5.1 Services to family caregivers of stroke patients

From the findings of this study, it can be concluded that social work services to family caregivers of stroke patients are rendered on micro, meso and macro level in the form of case work, group work and community work. With regard to service delivery, the majority of the participants stated that they find it difficult to render services to the family caregivers as focus is placed on the stroke patient and, once medically stable, the stroke patient is discharged. The reasons that were given for the difficulties experienced by service providers in rendering services to family caregivers concerned the lack of transport to organisations that render social work services to family caregivers caring for stroke patients, high caseloads, a lack of time on the part of social workers to engage with family caregivers and a shortage of social workers to render services to family caregivers of stroke patients.

Micro-level services are intended to help family caregivers to adjust to the disability and understand the nature of the disability, as well as to provide the family with medical information regarding stroke. The findings of this study indicate that some social workers render micro level services in terms of counselling services and share medical information at micro level. Meso-level services are directed at families with regard to understanding the objectives of care and aim to lessen the burden of care, as collective participation becomes relevant. Service providers mentioned family meetings and sexuality groups on a meso level. Nonetheless, the minority of social workers pointed out that they are doing group work with family caregivers of stroke patients.

Macro-level services are directed at stroke patients, family caregivers and the community at large. Macro-level services aim to create awareness regarding stroke, provide SASSA grants to the community, and offer community services such as day care centres, respite services and rehabilitation services. The majority of participants indicated that they link the families to home-

based care services, respite services, day care service and rehabilitation services, whilst the minority pointed out that they are facilitating stroke awareness programmes and obtaining social security for the stroke patients. Not much macro-level service is rendered by way of stroke awareness programmes.

This study found a general lack of available and accessible services to stroke patients and family caregivers on a micro, meso and macro level. The conclusion can be drawn that the participants were not rendering sufficient service in terms of supporting family caregivers. They were more focused on linking and referring families instead of indicating that they provide social work services, for instance at day care centres, or completing the grant applications. The lack of these services increases the burden of caregiving.

Recommendations

- Organisations should be aware of the needs of family caregivers so that Social work services could be directed at family caregivers to equip them with the needed support to take care of stroke patients post discharge.
- Follow-up social work services should be provided by the organisations to support and ensure that the family caregivers have the necessary support resources, in relation to the identified needs – emotional, physical and financial – or how to fulfil these needs.
- Group work in the form of support groups which are accessible to family caregivers in the communities in which they reside, should be included in services to family caregivers in order to integrate the insights and viewpoints of others into their own pool of resources.
- Social workers should collaborate with NPOs within the community to maximize and strengthen opportunities for family caregivers at the community and organisational, as well as the global level.
- Social workers rendering services to family caregivers of stroke patients should seek to build their knowledge regarding community programmes that are developmental in

nature. This can be done through continuous research on community work models to better address the different needs of family caregivers.

5.5.2 Challenges in social work service delivery to family caregivers of stroke patients

This study found that social workers experienced various challenges in order to effectively deliver services in accordance with national and international policy and legislative frameworks. Most participants recognised the following common challenges that they encountered in social work service delivery to family caregivers of stroke patients: unrealistic expectations from social workers by family caregivers; a lack of transport to attend social work services at organisations; high caseloads and a lack of time on the part of social workers to engage with family caregivers; and a shortage of social work to render services to family caregivers of stroke patients.

Challenges such as the lack of transport to attend social work services at organisations are due to social workers not rendering services to family caregivers post discharge and family caregivers not having the necessary funds to use public transport to travel to organisations. Additionally, in some cases, poor travel routes from family homes to the organisations or hospitals serve as a hindrance to accessing social work services. Social workers also have high caseloads, which makes it challenging to render social work services to families. The lack of social workers rendering services to family caregivers could also result in family caregivers not receiving post discharge services from social workers.

It can thus be concluded that a shortage of accessible services, access to transport, a lack of vehicles for social workers to do home visits and a shortage of social workers hamper effective service delivery to family caregivers of stroke patients.

Recommendations:

- Employment of more social workers to render services to family caregivers of caregivers is needed.
- Funding from government should be made available for transport and resources to improve access to social work services.

- Community based support services, such as home-based care and training for family caregivers should be improved through government funding.

5.5.3 Suggested improvements for service delivery to family caregivers of stroke patients

The views of participants regarding the improvement of services required to ease the burden of care were investigated. The participants felt that employing more social workers and having specialised teams, ongoing support, training to provide physical care to stroke patients and education to family caregivers are needed to ease the burden of care for family caregivers.

Findings from this study indicate a need for more social workers rendering services to family caregivers of stroke patients and this is indicative of a lack of ongoing social work services rendered by government and NPOs to those affected by a stroke. It can evidently be concluded that there is an apparent lack of resources to effectively render social work services that are accessible to family caregivers. The findings of this study are thus indicative of the need for more human resources and accessible community resources for the improvement of service delivery to family caregivers of stroke patients.

Recommendations:

- The Government should make more funding available in the welfare budget to appoint more social workers.
- Hospitals and rehabilitation centres should provide on-going training, support and education to family caregivers to keep them abreast with the changes of the stroke patient, to enhance their knowledge on strokes and to provide them with necessary skills to physically care for the patient.
- Increasing education and public awareness about caregiving is required to help caregivers and communities to understand the connection among respite and services for care receivers.

5.6 FURTHER RESEARCH

- It is suggested that further research regarding the nature of community-based social work services required for easing the burden of care of caregivers caring for a family member who has suffered a stroke, is conducted.
- Further research is also needed on how the understanding and awareness of policy and legislation can improve service provision to caregivers of stroke patients.

5.7 CONCLUSION

The research question for this study was: What social work services are rendered to families caring for a relative who suffered a stroke? This question has been answered through applying a qualitative research method utilising an exploratory and descriptive research design.

According to the findings of the study, family caregivers of stroke patients have various needs and challenges, which can be addressed by rendering adequate services at micro, meso and macro level (case work, group work and community work) specifically directed at caregivers of stroke patients. Nonetheless, a lack of community resources and financial constraints negatively impacts on families' access to services, which likewise challenges their caregiving duties.

It is clear from the study that there is a need for social workers working with family caregivers of stroke patients and that these social workers need to be empowered to apply policies and legislation which guide the care of stroke patients in their service provision. Additionally, there is a need for stroke awareness and education to the public. The need for direct service provision to family caregivers, post discharge, was repeatedly expressed by participants, thus emphasizing the lack of adequate available social work services.

There needs to be acknowledgment from government that improvement with regard to social work services to caregivers of stroke patients is needed and access to funding and resources should be facilitated. The researcher anticipates that the findings of this study and its recommendations will be well accepted by stakeholders and that it could aid in improving social work services to families caring for a relative who suffered a stroke.

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ANNEXURE 1: CONSENT FORM



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jou kennisvennoot • your knowledge partner

STELLENBOSCH UNIVERSITY CONSENT TO PARTICIPATE IN RESEARCH

SOCIAL WORK SERVICES TO FAMILIES CARING FOR A FAMILY MEMBER WHO SUFFERED FROM A STROKE

You are asked to participate in a research study conducted by Clarice Ruby Cairncross, Master in Social Work, from the Department of Social Work at Stellenbosch University. The results of this study will become part of a research report. You were selected as a possible participant in this study because you are a service provider to stroke patients and their families.

1. PURPOSE OF THE STUDY

The goal of the study is to gain an understanding of the social work services rendered to families caring for a family member who suffered a stroke and has become disabled and dependent on family members. The objectives of the study are:

- To describe policy and legislation with regards to patients of a stroke and the challenges families experience in caring for them.
- To identify the social work services that should be rendered to families caring for a family member affected by a stroke from an ecological perspective.
- To explore the services rendered by social workers to families affected by a stroke.
- To present conclusions and recommendations on social work services for organisations and rehabilitation centres, which intervenes with the family members of stroke patients' post-acute rehabilitation.

2. PROCEDURES

If you volunteer to participate in this study, we would ask you to do the following things:

A semi-structured interview will be utilized to gather information confidentially. You need not indicate your name or any particulars on the interview schedule. The schedule will be completed during an interview conducted by the researcher. The interview will be recorded.

3. POTENTIAL RISKS AND DISCOMFORTS

There are no known potential risks or discomfort to be gained from participating in this study, other than your time within your working hours. Participating in this research requires that you agree to be interviewed for maximum 45 minutes by the researcher.

4. POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

The results of this study will inform service providers' perspectives are regarding social work services available to families caring for a family member who has suffered from a stroke and has become disabled and dependent on family members. This information could be used by services providers for further planning of service delivery.

5. PAYMENT FOR PARTICIPATION

No payment in any form will be received for participating in this study.

6. CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality will be maintained by means of coding where each interview schedule is numbered. All interview schedules and recordings will be managed, analysed and processed by the researcher and will be locked in a cabinet in the office of the researcher. Transcripts will be saved on the laptop of the researcher, protected by a password known only to the researcher.

7. PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw from this research if circumstances arise which warrant doing so.

8. IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact: Mrs T Cornelissen-Nordien (Supervisor), Department of Social Work, University of Stellenbosch, telephone 021 - 808 2070, E-Mail: nordien@sun.ac.za

9. RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development.

SIGNATURE OF RESEARCH SUBJECT OR LEGAL
--

The information above was described to me the participant by _____ in English and the participant is in command of this language or it was satisfactorily translated to him / her. The participant was given the opportunity to ask questions and these questions were answered to his / her satisfaction.

I hereby consent voluntarily to participate in this study.

Name of Participant

Signature of Participant

Date

SIGNATURE OF INVESTIGATOR

I declare that I explained the information given in this document to _____ [name of subject/participant]. [He / She] was encouraged and given ample time to ask me any questions. This conversation was conducted in English and no translator was used.

Signature of Investigator

Date

BYLAE 1: TOESTEMMINGS BRIEF



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY
jou kennisvenoot • your knowledge partner

UNIVERSITEIT STELLENBOSCH TOESTEMMING OM DEEL TE NEEM AAN NAVORSING

MAATSKAPLIKE DIENSTE AAN GESINNE WAT VIR 'N GESINSLID SORG WAT 'N BEROERTE GEHAD HET

U word versoek om deel te neem aan 'n navorsingstudie wat deur Clarice Ruby Cairncross van die Departement Maatskaplike Werk aan die Universiteit Stellenbosch uitgevoer sal word. Die resultate van die studie sal deel word van 'n navorsingsverslag. U is as moontlike deelnemer aan die studie gekies omdat u 'n diensverskaffer is aan beroertepasiënte en hulle gesinne.

1. DOEL VAN DIE STUDIE

Die doel van die studie is om begrip op te doen van maatskaplike dienste wat aan gesinne gelewer word wat 'n gesinslid versorg wat 'n beroerte gehad het en daarna gestremd en van gesinslede afhanklik is. Die doelstellings van die studie is:

- om beleid en wetgewing te beskryf met betrekking tot diegene wat 'n beroerte oorleef het en die uitdagings wat gesinslede moet trotseer om vir hulle te sorg;
- om vanuit 'n ekologiese perspektief die maatskaplikewerkdienste te identifiseer wat aan gesinne gelewer moet word wat vir 'n gesinslid sorg wat deur beroerte geraak is;
- om die dienste wat deur maatskaplike werkers aan gesinne gelewer word wat deur beroerte geraak is, te ondersoek; en
- om gevolgtrekkings en aanbevelings te bied aan organisasies en rehabilitasiesentrums wat saam met gesinslede tydens die beroertepasiënt se post-akute rehabilitasie tussenbeide tree oor maatskaplike dienste.

2. PROSEDURES

Indien u inwillig om aan die studie deel te neem, sal ons die volgende van u vra:

'n Semi-gestruktureerde onderhoud sal gevoer word om inligting vertroulik in te samel. U hoef nie u naam of enige besonderhede op die onderhoudskedule aan te dui nie. Die skedule sal tydens 'n onderhoud wat deur die navorser gevoer word, voltooi word. Die onderhoud sal op band opgeneem word.

3. MOONTLIKE RISIKO'S EN ONGEMAK

Daar is geen potensiële risiko's of ongemak identifiseer om aan hierdie navorsing deel te neem nie, behalwe u tyd binne u werksure. Deelname aan hierdie navorsing vereis dat u ingestem om vir maksimum 45 minute 'n onderhoud te voer met die navorser.

4. MOONTLIKE VOORDELE VIR DEELNEMERS EN/OF VIR DIE SAMELEWING

Die resultate van die studie sal diensteverskaffers se perspektiewe inlig oor maatskaplikewerkdienste beskikbaar aan gesinne wat omsien na 'n gesinslid wat 'n beroerte gehad het en wat gestremd en afhanklik is van gesinslede. Hierdie resultate kan benut word deur diensverskaffers vir verdere beplanning van dienslewering.

5. VERGOEDING VIR DEELNAME

Geen vergoeding van enige aard sal vir deelname aan hierdie studie ontvang word nie.

6. VERTROULIKHEID

Enige inligting wat deur middel van die navorsing verkry word en wat met u in verband gebring kan word, sal vertroulik bly en slegs met u toestemming of soos deur die wet vereis bekend gemaak word. Vertroulikheid sal gehandhaaf word deur middel van kodering waarvolgens elke onderhoudskedule genommer word. Alle onderhoudskedules en opnames sal bestuur, ontleed en verwerk word deur die navorser en in 'n kabinet in die kantoor van die navorser toegesluit word. Transkripsies sal op die rekenaar van die navorser geberg word en deur 'n wagwoord wat slegs aan die navorser bekend is, beskerm word.

7. DEELNAME EN ONTTREKKING

U kan self besluit of u aan die studie wil deelneem of nie. Indien u inwillig om aan die studie deel te neem, kan u te eniger tyd aan die studie onttrek sonder enige nadelige gevolge. U kan ook weier om enige van die vrae te beantwoord wat u nie wil beantwoord nie en steeds aan die studie deelneem. Die ondersoeker kan aan hierdie studie onttrek indien omstandighede dit noodsaaklik maak.

8. IDENTIFIKASIE VAN ONDERSOEKERS

Indien u enige vrae of besorgdheid omtrent die navorsing het, kontak gerus mev. T Cornelissen-Nordien (Toesighouer), Departement Maatskaplike Werk, Universiteit Stellenbosch, by telefoonnommer 021 808 2070 of e-pos: nordien@sun.ac.za.

9. REGTE VAN NAVORSINGSDEELNEMERS

U kan te eniger tyd u toestemming terugtrek en u deelname beëindig, sonder enige nadelige gevolge vir u. Deur deel te neem aan die navorsing doen u geensins afstand van enige wetlike regte, eise of regsmiddel nie. Indien u vrae het oor u regte as navorsingsdeelnemer, kontak me Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] van die Afdeling vir Navorsingsontwikkeling, Universiteit Stellenbosch.

VERKLARING DEUR NAVORSINGSDEELNEMER OF SY/HAAR GSVERTEENWOORDIGER
--

Die bostaande inligting is aan my, die deelnemer, _____, deur Clarice Ruby Cairncross in Afrikaans gegee en verduidelik en ek is die taal magtig of dit is bevredigend vir my vertaal. Ek is die geleentheid gebied om vrae te stel en die vrae is tot my bevrediging beantwoord.

Ek stem hiermee vrywillig in om deel te neem aan die studie. 'n Afskrif van hierdie vorm sal aan my gegee word.

Naam van navorsingsdeelnemer

Naam van regsverteenwoordiger (indien van toepassing)

Handtekening van navorsingsdeelnemer

Datum

VERKLARING DEUR ONDERSOEKER

Ek verklaar dat ek die inligting in hierdie dokument vervat verduidelik het aan _____
en/of sy/haar regsverteenwoordiger _____. Hy/sy is aangemoedig en
voldoende tyd gegee om vrae aan my te stel. Dié gesprek is in [*Afrikaans/Engels*] gevoer en geen
vertaler is gebruik nie.

Handtekening van onderzoeker

Datum

ANNEXURE 2: ENGLISH SEMI-STRUCTURED INTERVIEW

SCHEDULE UNIVERSITY OF STELLENBOSCH

DEPARTMENT OF SOCIAL WORK

SEMI-STRUCTURED INTERVIEW SCHEDULE

**SOCIAL WORK SERVICES TO FAMILIES CARING FOR A FAMILY
MEMBER WHO SUFFERED FROM A STROKE**

Interviewer: Clarice Ruby Cairncross

Dissertation for M in Social Work

All the information recorded in this questionnaire will be regarded as confidential.

PARTICIPANT NUMBER: _____

INTERVIEW DATE: _____

SECTION A: IDENTIFYING PARTICULARS OF PARTICIPANTS

1.1 How old are you?

1.2 For how many years have you been practicing social work?

1.3 How long have you been rendering services to families caring for a relative who suffered a stroke?

1.4 What is your qualification?

1.5 What type of organisation do you work for? E.g. NPO, government, private practice

SECTION B: POLICY AND LEGISLATION GUIDING THE CARE OF STROKE PATIENTS

1.1 Explain the policies/legislation that you utilize in practice?

1.2 How does the policies and legislation guide your service provision?

SECTION C: THE CHALLENGES OF SERVICE RENDERING TO FAMILIES CARING FOR A STROKE SURVIVOR.

1.1 What are the needs of family caregivers caring for a stroke patient?

1.2 What resources are available for families caring for a stroke survivor?

1.3 What are the challenges experienced by family caregivers caring for a stroke patient?

1.4 How do the patients and families get referred to your services?

SECTION D: SERVICES RENDERED BY SOCIAL WORKERS: ECOLOGICAL PERSPECTIVE

1.1 What services do you offer to family caregivers of stroke patients on:

Micro level: _____

Meso level: _____

Macro level: _____

1.2 Identify other social work services which in your view should be available to family caregivers on:

Micro level: _____

Meso level: _____

Macro level: _____

1.7 Do you have any recommendations for improved social work service delivery on micro, meso and macro levels?

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS INTERVIEW!

BYLAE2: AFRIKAANS SEMI-GESTRUKTUREERDE VRAELYS

**STELLENBOSCH UNIVERSITEIT
DEPARTEMENT MAATSKAPLIKE WERK
SEMI-GESTRUKTUREERDE VRAELYS**

**MAATSKAPLIKE DIENSTE AAN GESINNE WAT VIR 'N GESINSLID
SORG WAT 'N BEROERTE GEHAD HET**

Onderhoudvoerder: Clarice Ruby Cairncross

Tesis vir M in Maatskaplike Werk

Al die inligting opgeneem in hierdie vraelys sal vertroulik hanteer word.

DEELNEMER NOMMER: _____

ONDERHOUD DATUM: _____

AFDELING A: IDENTIFISERENDE BESONDERHEDE VAN DIE DEELNEMER

1.1 Hoe oud is u?

1.2 Hoeveel jaar praktiseer u as 'n maatskaplike werker?

1.3 Hoeveel jare lewer u maatskaplike dienste aan families wat sorg vir 'n familielid met 'n beroerte?

1.4 Wat is u kwalifikasie?

1.5 Watter tipe organisasie werk u voor? Byvoorbeeld NGO, staat, privaat?

AFDELING B: BELEID EN WETGEWING BEGELEIDING VAN DIE SORG VAN BEROERTE PASIËNTE

1.1 Watter beleide/wetgewing gebruik u as u praktiseer of dienste lewer aan familie versorgers?

1.2 Die wetgewing waarmee u bekend is, hoe lei dit u dienste aan familie versorgers wat omsien aan 'n familie lid wat 'n beroerte gehad het?

AFDELING C: DIE UITDAGINGS VAN FAMILIE LEDE WAT SORG VIR 'N FAMILIELID MET 'N BEROERTE.

1.1 Wat is die behoeftes van die familie versorgers wat omsien na 'n familie lid 'n beroerte ervaar het? Gee voorbeelde.

1.2 Watter hulpbronne is beskikbaar vir familie versorgers wat omsien na 'n familie lid 'n beroerte ervaar het?

1.3 Wat is die uitdagings van familie versorgers wat omsien na 'n familie lid 'n bereted revere het?

1.4 Hoe word patiente en families verwys na u dienste?

**AFDELING D: DIENSTE GELEWER DEUR MAATSKAPLIKE WERKERS:
EKOLOGIESE PERSPEKTIEF**

1.1 Watter maatskaplike dienste bied u aan familie versorgers op 'n:

Mikro vlak: _____

Meso vlak: _____

Makro vlak: _____

1.2 Watter ander dienste moet na u mening beskikbaar wees vir familie versorgers op 'n?

Mikro vlak: _____

Meso vlak: _____

Makro vlak: _____

1.3 Het u enige aanbevelings om maatskaplike dienste aan familie versorgers te bevorder on 'n mikro,meso en makro vlak?

DANKIE VIR U TYD OM DIE ONDERHOUD TE VOLTOOI!

ANNEXURE 3: INDEPENDENT CODER DECLARATION

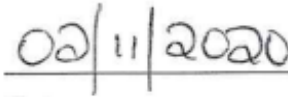
ANNEXURE 3

INDEPENDANT CODER DECLARATION

I, PHUMEZA EMENIKE, hereby declare that I read through the semi-structured interviews and empirical research chapter of Clarice Cairncross (the researcher) and that my findings correspond with the themes, sub-themes and categories as suggested in the empirical study.



Signature



Date

ANNEXURE 4: PERMISSION LETTERS FROM THE DEPARTMENT OF HEALTH



Health Impact Assessment
Health Research sub-directorate
 Health.Research@westerncape.gov.za
 Tel: +27 21 483 0666; fax: +27 21 483 8895
 5th Floor, Norton Rose House, 8 Bebeek Street, Cape Town, 8001
www.westerncape.gov.za

REFERENCE: WC_201905_042
 ENQUIRIES: Dr Sabela Petros

Stellenbosch University
 Faculty of Health Sciences
 Francie Van Zijl Drive
 Tygerberg
 Cape Town
 7505

For attention: Ms Claire Cairncross

Re: Social Work Services To Families Caring For A Family Member Who Suffered From A Stroke.

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research.

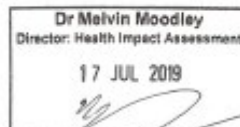
Please contact the following people to assist you with any further enquiries in accessing the following sites:

Paarl Hospital	Winnie Nicholas	021 860 2500
Western Cape Rehab Centre	Janine White	021 370 2300
Mitchells Plain Hospital	Hans Human	021 377 4305

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. By being granted access to provincial health facilities, you are expressing consent to provide the department with an electronic copy of the final feedback (**annexure 9**) within six months of completion of your project. This can be submitted to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).
3. In the event where the research project goes beyond the estimated completion date which was submitted, researchers are expected to complete and submit a progress report (**Annexure 8**) to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).
4. The reference number above should be quoted in all future correspondence.

Yours sincerely



DR M MOODLEY
 DIRECTOR: HEALTH IMPACT ASSESSMENT



Health Impact Assessment
Health Research sub-directorate
Health.Research@westerncape.gov.za
tel: +27 21 483 0864; fax: +27 21 483 9895
5th Floor, Norton Rose House, 8 Riebeeck Street, Cape Town, 8001
www.westerncape.gov.za

REFERENCE: WC_201905_042
ENQUIRIES: Dr Sabela Petras

Stellenbosch University
Faculty of Health Sciences
Francie Van Zijl Drive
Tygerberg
Cape Town
7805

For attention: Ms Claire Cairncross

Re: **Social Work Services To Families Caring For A Family Member Who Suffered From A Stroke.**

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research.

Please contact the following people to assist you with any further enquiries in accessing the following sites:

New Somerset Hospital	Dr Donna Stokes	021 402 2448
Karl Bremer Hospital	Dr Linda Naudé	021 918 1222

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. By being granted access to provincial health facilities, you are expressing consent to provide the department with an electronic copy of the final feedback (**annexure 9**) within six months of completion of your project. This can be submitted to the provincial Research Co-ordinator [Health.Research@westerncape.gov.za].
3. In the event where the research project goes beyond the estimated completion date which was submitted, researchers are expected to complete and submit a progress report

(**Annexure B**) to the provincial Research Co-ordinator
[\[Health.Research@westerncape.gov.za\]](mailto:Health.Research@westerncape.gov.za).

4. The reference number above should be quoted in all future correspondence.

Yours sincerely

Dr Melvin Moodley
Director: Health Impact Assessment
13 AUG 2019

DR M. MOODLEY

DIRECTOR: HEALTH IMPACT ASSESSMENT



GROOTE SCHUUR HOSPITAL

Enquiries: Dr Bernadette Eick
E-mail : Bernadette.Eick@westerncape.gov.za

Ms. C. Calmcross
STELLENBOSCH UNIVERSITY

E-mail: nubwclarice@gmail.com

Dear Ms. Calmcross,

RESEARCH PROJECT: Social Work Services To Families Caring For A Family Member Who Suffered From A Stroke

Your recent letter to the hospital refers.

You are granted permission to proceed with your research, which is valid until **23 May 2022**.

Please note the following:

- a) Your research may not interfere with normal patient care.
- b) Hospital staff may not be asked to assist with the research.
- c) No additional costs to the hospital should be incurred i.e. Lab, consumables or stationary.
- d) **No patient folders may be removed from the premises or be inaccessible.**
- e) Please provide the research assistant/field worker with a copy of this letter as verification of approval.
- f) Confidentiality must always be maintained .
- g) **Should you at any time require photographs of your subjects, please obtain the necessary Indemnity forms from our Public Relations Office (E45 OMB or ext. 2187/2188).**
- h) Should you require additional research time beyond the stipulated expiry date, please apply for an extension.
- i) Please discuss the study with the HOD before commencing.
- j) Please introduce yourself to the person in charge of an area before commencing.
- k) On completion of your research, please forward any recommendations/findings that can be beneficial to use to take further action that may inform redevelopment of future policy / review guidelines.
- l) **Kindly submit a copy of the publication or report to this office on completion of the research.**

I would like to wish you every success with the project.

Yours sincerely

DR BERNADETTE EICK
CHIEF OPERATIONAL OFFICER
Date: 20 June 2019

C.C. Mr. L. Naidoo
Mr A. de Vos

G46 Management Suite, Old Main Building,
Observatory 7925
Tel: +27 21 404 6288 fax: +27 21 404 6125

Private Bag X,
Observatory, 7935
www.capegateway.gov.za

ANNEXURE 5: REC ETHICAL CLEARANCE LETTER



NOTICE OF APPROVAL

REC: Social, Behavioural and Education Research (SBER) - Initial Application Form

24 May 2019

Project number: 9149

Project Title: SOCIAL WORK SERVICES TO FAMILIES CARING FOR A FAMILY MEMBER WHO SUFFERED FROM A STROKE

Dear Miss Clarice Cairncross

Your REC: Social, Behavioural and Education Research (SBER) - Initial Application Form submitted on 24 May 2019 was reviewed and approved by the REC: Humanities.

Please note the following for your approved submission:

Ethics approval period:

Protocol approval date (Humanities)	Protocol expiration date (Humanities)
24 May 2019	23 May 2022

GENERAL COMMENTS:

The researcher is reminded to submit to the REC proof of permission as soon as these are obtained from participating organisations. [ACTION REQUIRED]

Please take note of the General Investigator Responsibilities attached to this letter. You may commence with your research after complying fully with these guidelines.

If the researcher deviates in any way from the proposal approved by the REC: Humanities, the researcher must notify the REC of these changes.

Please use your SU project number (9149) on any documents or correspondence with the REC concerning your project.

Please note that the REC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

FOR CONTINUATION OF PROJECTS AFTER REC APPROVAL PERIOD

Please note that a progress report should be submitted to the Research Ethics Committee: Humanities before the approval period has expired if a continuation of ethics approval is required. The Committee will then consider the continuation of the project for a further year (if necessary)

Included Documents:

Document Type	File Name	Date	Version
Research Protocol/Proposal	Cairncross-Proposal_-_30 November Final (1)	05/02/2019	1
Request for permission	Request for permission letter- WRC (1)	05/02/2019	1
Informed Consent Form	Informed consent form(Afrikaans & English)	25/04/2019	2
Data collection tool	CLARICE - ANNEXURE 3	26/04/2019	3
Default	Changes letter(1)	26/04/2019	
Budget	Budget	22/05/2019	1
Request for permission	Letter- Mrs Alitha Watkins	22/05/2019	1
Request for permission	Spescare- request letter	22/05/2019	1

If you have any questions or need further help, please contact the REC office at cgraham@sun.ac.za.

Sincerely,

Clarissa Graham

REC Coordinator: Research Ethics Committee: Human Research (Humanities)

*National Health Research Ethics Committee (NHREC) registration number: REC-050411-032.
The Research Ethics Committee: Humanities complies with the SA National Health Act No.61 2003 as it pertains to health research. In addition, this committee abides by the ethical norms and principles for research established by the Declaration of Helsinki (2013) and the Department of Health Guidelines for Ethical Research: Principles Structures and Processes (2nd Ed.) 2015. Annually a number of projects may be selected randomly for an external audit.*